

# Care Housing for People with Dementia:

## Towards an Evaluation

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## **Abstract**

This study set out to evaluate a small scale model of care for people with dementia that aimed to support residents within a daily household routine (termed household care). Stemming from a pluralistic evaluation, this thesis examines issues identified as important to residents' experience, namely the ability of the care houses to provide a home for life, the process and effectiveness of recreating a homely environment and the implications of group-living. Three case studies were investigated with multiple methods, including semi-structured interviews with staff, relatives and representatives of managing agencies, structured observation and assessment of dependency.

Respondents believed care housing was superior to its alternatives and attributed perceived improvements in residents' well-being to the nature of staff support and the 'homely' setting. Agency representatives were preoccupied with their relationships with each other and how to sustain and expand this model of care. Staff focused on the nature and conditions of the work. Kin were keen that residents should settle and stay in the care houses. Residents' support needs at least matched entry criteria but over half had to move out to hospital because of physical illness and behavioural problems. This study suggests that it was very difficult for residents to accept the houses as 'home'. Residents' and their relatives' participation was, in practice, limited but one house was particularly successful in implementing household care; reasons are suggested for this. Residents' interactions with each other seemed to be increased by household care but their relationships were influenced by a number of factors, including the presence of dementia. The latter exacerbated the tensions of group-living. The challenge for care houses was to sustain care as dementia progressed and extend good quality care to those with more substantial behavioural and physical support needs.

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## CHAPTER ONE

### INTRODUCTION

This study arose from contemporary interest in developing high quality and affordable long stay care for people with dementia. This chapter explains why an evaluation of care housing for people with dementia was considered important. The care houses' origins and aims are noted and the research questions introduced. The points raised are covered in greater depth in the literature review (Chapter Two) where references are given. The terminology used in this thesis is explained at the end of the chapter.

Housing Associations, in collaboration with health and social services, have developed a small number of care houses since 1990. Care housing provides accommodation for people with a diagnosis of dementia, on the basis of assessed need, and offers 24 hour support. Residents live together in groups of between eight and twelve people and support staff strive to maintain patterns of daily life within a domestic environment. This model of care developed from the contemporary assumption, now embodied in policy, that 'home' and 'community' provide the best locus of care-giving, and that any substitute for this should be as domestic as possible. This assumption challenges the role institutions have played in providing long stay care. A wider policy concern is whether care housing can act as a substitute for institutional care in the context of considerable shortage of support provision for people with dementia and a predicted increase in the incidence of dementia. Dementia is a syndrome that is irreversible, progressive and has an unpredictable course.

By October 1994, there were seven specialist care houses in Scotland, with plans to open perhaps as many again. All were within the Central Belt of Scotland, the most densely populated area of the country, and either in towns or cities. Numerically, the contribution of care housing in Scotland was very small, by October 1994 having accommodated a total of 127 people, when altogether up to 20 000 people with dementia may be in long stay care in Scotland. Although not developed explicitly as such, the case studies used in this research acted as pilot schemes, directly for the agencies involved and indirectly for an audience of policy makers and practitioners.

Proponents of care housing assert that not only is it possible to combine specialist care for people with dementia with the preservation of a normal, or ordinary, lifestyle, but that this is beneficial in helping people with dementia remain oriented and engaged. This social model, emphasising environment, may be contrasted with a medical model, where the focus is on impairment, aetiology and biomedical treatment. The ideals of care housing stand in opposition to the institutionalisation of people with dementia and medicalised approaches to their care. Each unit aimed to help residents be as independent as possible and stressed the individuality of people with dementia,



and their rights to choice and autonomy. The houses intended to offer a home for the remainder of the residents' lives. These aims applied the principles of ordinary living that have become current in the support of other client groups to the care of people with dementia.

This a multi-method case study of the three longest established Scottish care houses specialising in the care of people with dementia. In order to consider the effectiveness of care housing in its own terms, this study sought initially to identify the plural perspectives of the success of care housing in the case studies. This helped elucidate what participants (staff, kin and representatives of the agencies involved) thought were the important inputs to the care houses and how these were linked to outcomes. Given that several agencies had collaborated in developing care housing, a pluralistic approach was helpful. Furthermore, the perspective of people with dementia is particularly hard to obtain, and they frequently depend on others to interpret their needs. The three major foci of the study were determined once a pluralistic view was gained, and are set out below.

Firstly, a concern shared by managing agencies, staff and kin was identified: how could and should care houses deal with the progression of dementia and accompanying physical frailty? Each case study found it could not provide a home for life for all residents, despite aiming to do so. Investigation of what in practice happened when residents' support needs increased was accompanied by an assessment of whether dependency characteristics matched entry criteria, and what changes were perceived by kin and staff in physical and mental health following the move.

Secondly, the aim of providing a homely environment was a central tenet of the support offered by the care houses. A sense of homeliness - like quality of life - depends upon subjective appraisal: in what ways were these units homely, according to participants? It appeared that 'home' could be compared both to an ideal as well as a supposed polar opposite, an institution. Taking part in the life of the household was thought to enhance independence, and a small-scale setting was considered essential to nurture individuality. Providing this kind of support - here termed household care - for people with dementia was a new venture for the agencies who developed the houses, and staff groups were learning how to implement these aims. The literature was uninformative about the influence dementia might have on the way older people live at home. Whilst it is widely assumed that it is beneficial to live in a domestic setting and be involved in day to day activity, there has been little discussion of what these benefits are, how they might be perceived by people with dementia, and if there is variation between residents. This study has therefore investigated the process and success of the implementation of a model of household care, as reflected in residents' activities and well-being.

The case studies claimed the status of housing, but this is misleading since they were developed as an alternative to residential care and were in line with reforms



to this sector rather than being ventures in Community Care. By their design, the care houses required that residents shared living areas, and were therefore a form of communal rather than private living. Shared living was justified therapeutically, in that company and stimulation were thought helpful to residents, but there also appeared to be pragmatic reasons for providing care to a group rather than individual residents. The term 'pragmatic group' is adopted in this thesis to describe those settings where people are brought together to receive care. Therefore, as a third focus, this thesis argues that considering the success of group-living is an essential part of an evaluation of the quality of care offered by care housing, and that far too little attention has been paid to the way that people with dementia interact in pragmatic groups.

Methods adopted included semi-structured interviews with staff, relatives, and representatives of managing agencies, and structured observation combined with qualitative note-taking. Dependency assessments and supplementary questionnaires and checklists were used to ensure that data collection was systematic between case studies. Lastly, a postal questionnaire was used for all care houses in Scotland, including the three case studies, about moves in and out of care housing, placing the case studies in a national context.

The study, arising from the concerns of policy-makers and practitioners, had the attendant difficulties of applied research. The diversity of the relevant fields has demanded an eclectic approach, characteristic of social policy. The first theoretical problem was to identify an approach to evaluation which could overcome the lack of previous work in the field and uncertainty about what positive outcomes would be. Identifying good quality dementia care demands a model of the dementing process and the ways in which interventions may be therapeutic. This study aimed to contribute to an undeveloped field where conventional quasi-experimental evaluative designs had prevailed and where little account has been taken of subjective appraisal and the process of care.

The evaluative literature on comparable projects is sparse, mainly consisting of small studies drawing comparisons between care housing and institutional care, generally recognised to be in need of reform. Other approaches to evaluation include discrepancy between practice and established principles of good quality care, and a normative approach which takes into account values current in wider society. Little theoretical attention has been directed to the ways that benefits can be achieved for residents. There has been no investigation of the extent to which different individuals benefit. This study has assumed that aims relating to care housing are diverse, that they may not be explicit, that they may change over time, and that there may be different degrees of success for residents. This position justified a qualitative, exploratory approach with attention to the process by which aims were implemented as well as outcomes achieved.



In summary, this study set out to evaluate a small scale model of care for people with dementia that aimed to provide household care. The title of this thesis acknowledges the particular difficulties of researching services for people with dementia who find it difficult to express their satisfaction and to validate and discuss research findings. This study, which has tended towards practice rather than policy concerns, has not considered the costs of the case studies in relation to their effectiveness. It has instead achieved a pluralistic overview of participants' hopes and expectations and the perceived success, which meant that further research questions could be identified that seemed particularly important to the residents' experience of care housing. The first concern was the possibility that the case studies could not offer a 'home for life' for all residents, despite aiming to do so. The second concern was to identify participants' perceptions of the homeliness of the case studies, and the process by which household care was implemented. Evidence of success was sought in residents' activities and well-being. The final concern of this study was the nature of group-living for people with dementia, and influences on the way that residents interacted with each other.

### **A note on terminology**

Care housing has been variously called 'augmented housing', 'specialist housing' and 'accommodation with support'. The term 'care housing' is preferred as it distinguishes the case studies from both mainstream housing or other kinds of supported accommodation such as hostels. Care houses for older people who are physically frail are not discussed in this thesis. In one case study the term 'tenant' was preferred to the term 'resident' in order to reinforce the ideal that people with dementia who live there were in their own home, unlike the staff. According to Payton and Reed (1995), researchers should consider carefully what terms they use, given the prevailing institutional metaphor in research into care homes for elderly people. Continuing to use the term 'resident' may imply a passivity that neither accurately describes their situation, nor facilitates a changing paradigm of care. However, any other term would be misleading since residents of care houses did not have tenancy agreements. The term 'community housing' is used to refer to living in owned or rented housing, relative's home, and sheltered housing. The term 'care home' is used for any form of long stay care except hospital. Conventionally, the terms 'admission' and 'discharge' are used with reference to care homes. The phrases 'moving in' and 'moving out' are used instead so that the passivity of residents in this process is not assumed, though it may well have been the case.

Proper names of individuals and organisations who provided data have not been used, with the exception of Scottish Homes who funded this studentship. Codes have been used which permit readers to cross-refer between quotes and vignettes.



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The literature review opens by considering the nature of dementia (section 2.1), a clinical diagnosis required for residents of the case studies investigated in this thesis. The wider context of Scottish care housing is then discussed (section 2.2), leading to consideration of quality of life and the concept of home (2.3). Innovations, comparable to the case studies, that have been the subject of evaluative research are covered in 2.4. The last three sections deal with literature on the effects on residents of moves into long stay care (2.5), activity as a dimension of quality of care (2.6), and interactions between people living communally in pragmatic groups such as care housing (2.7). This chapter considers some implications of this work for evaluative research, noted in section 2.8.

## **2.1 Dementia: biomedical causes and environmental influences**

This section identifies views of dementia from the disciplines of medicine and social science, and consequent approaches to care, especially those depending upon the manipulation of the physical or social environment.

### **2.1.1 Dementia: the clinical picture**

The term 'dementia' describes a medically recognised syndrome, defined by Burns *et al.* (1995:35) as 'an acquired generalised (or global) impairment of intellect, memory and personality without disturbance of consciousness.' Although the prevalence of dementia increases with age, it is not a normal part of ageing. For those affected, the impairment is progressive, and accompanied by a differential deterioration in the function of a number of domains, including self care, physical functioning, and emotional well-being. Clinical work has suggested patterns of losses with dementia (Jacques, 1992) but these are unpredictable in any one individual, who may perform better in some domains than others. The concept of dementia as a disease that can be staged (see Reisberg *et al.*, 1982) and classified as 'mild', 'moderate', or 'severe' may therefore be misleading. Carr and Marshall (1993) rejected the idea that clinical performance in cognitive tests, or any uni-dimensional hierarchical scale, can indicate severity.

Different causes have been identified for sub-types of dementia, which have different implications for the course of dementia. Recent research has demonstrated 'new' forms of dementia that make previous classifications appear crude (Holden, 1995). The most common sub-types are Alzheimer's disease and vascular dementia (Burns *et al.*, 1995). The neurological cause of Alzheimer's disease is poorly understood; Tobiansky (1993) concluded that its aetiology is multi-factorial, and that environmental factors (such as trauma, toxins, and infections) may lead to the death of neuronal cells.



The characteristic development of plaques and neurofibrillary tangles may be a response to this, and in some cases may be influenced genetically. Describing Alzheimer's disease, Burns *et al.* (1995) referred to an initial phase, lasting up to 4 years, where judgement becomes impaired and there is a likelihood of negative personality changes. Dementia is characterised by the presence of amnesia, apraxia, and agnosia. Disturbance of memory, particularly short term, is universal, and the ability to communicate deteriorates. Voluntary motor tasks, such as dressing, or using knife and fork, are likely to be disrupted progressively. People also have difficulties with identification and recognition which may be associated with psychiatric and behavioural problems. Burns *et al.* (1995) concluded that while depressive symptoms are common in dementia, true depressive syndromes are unusual. Some people may have hallucinations or delusions. People may become incontinent of urine and faeces. Behavioural disturbances were reported to be most common as dementia advanced, and included nocturnal wandering, aggressive behaviour, eating disturbances, and sexual disinhibition.

Vascular dementia is most commonly caused by a series of infarcts, that is, blood vessel blockages which cause localised damage. The greater the brain damage, the worse the impairment (Jacques, 1992). The overall picture is of a progressive step-wise decline. Temporary acute confusion can occur after a stroke, which may persist for weeks, or clear within a few hours. Unlike Alzheimer's disease, parts of the brain may remain unimpaired.

Although occasionally people who appear to have dementia actually have a treatable condition, no cure for dementia has, to date, been identified. Clinicians may distinguish symptoms of dementia that are 'primary', meaning those which arise directly as result of brain damage, or 'secondary', encompassing those which arise through interaction with the physical and social environment, and reflect adaptation to the disorder (Annerstedt 1995:12).

Dementia is likely to be accompanied by other health problems (Moak, 1990). Most people die within four to twelve years after the onset of dementia (Tobiansky, 1993). Over the last four decades, people with Alzheimer's disease have been surviving longer, and particularly in the later stages of the illness: older females have consistently been found to survive longer than men (Christie, 1994).

### *Aggressive behaviour*

Aggressive behaviour, which may be unpredictable, illustrates the interplay of neurological impairment and environment that makes caring for people with dementia so challenging. A review by Patel and Hope (1993) indicates that it is one of the most serious behavioural disturbances, being the most common cause of referral to psychiatric services, and possibly leading to a move to nursing home or hospital, where



aggressive behaviour constitutes a serious management problem needing a high ratio of staff to residents. Different nurses understood different things by the term 'aggressive behaviour', but included both verbal and physical acts and saw it as an overt, non-accidental, act against an object or person. Many, if not most, people with dementia were reported to be at least verbally aggressive, and a third or more were physically aggressive (Patel and Hope, 1993). Aggressive behaviour may be a direct result of brain damage, resulting in neurotransmitter abnormality and also a response to environmental factors. Psychological reasons can include a response to becoming aware of being increasingly forgetful, or finding oneself with an impaired ability to communicate, with one's actions misinterpreted by the carer. Aggressive behaviour may be a response to moving to a new environment, for example one which is noisy and has inadequate lighting, or as a result of irritability and aggression on the part of carers. Aggressive behaviour may be exacerbated by adversarial management styles. Research has established no clear relationship between aggressive behaviour and sex, age, or degree of dependency (Patel and Hope, 1993).

Managing aggressive behaviour requires careful review of the antecedents of the behaviour, and removal, if possible, of the underlying cause (Patel and Hope, 1993). Both drug and psychosocial treatments may be adopted; for example, Stokes (1987) provided a handbook to train carers to minimise the risk of depression. Increased personal space may help to reduce the risk. People with dementia with aggressive behaviour are more likely to be given drugs, and also to fall over. Major tranquillisers do not necessarily act specifically on aggressive behaviour, but may instead act as general sedatives, perhaps even worsening behaviour (Patel and Hope, 1993).

### **2.1.2 A developing picture from social science**

Contributions to sociological perspectives on dementia are set out in this section, leading to a review of how social and physical environment has been acknowledged by therapeutic approaches. Lyman (1989:597) asserted that in the absence of a cure, social scientists should be concerned with the social settings and relationships that may contribute to dementia. The literature about dementia and environment is poorly developed, but the theoretical stances taken are recognisable from other work on mental health (see Dworkin, 1992) and reviewed in relation to dementia by Bond *et al.* (1990). The social environment has received more attention (e.g. Kitwood, 1990) than the physical environment, though the latter has been examined for its influence on behaviour (see Netten, 1993). Least attention has been given to psychological influences, although the finding of a pilot study, which indicated that those people most able to deny intellectual impairment may escape depressive signs, suggests that psychological factors may account for some of the variability in the progression of dementia (Cottrell and Lein, 1993).



The legacy of the study of institutions (Goffman, 1968; Barton, 1959) is strongly evident in the sociological work reviewed here. The influential work by Wing and Brown (1970), demonstrating that the effects of institutionalisation could be modified by improving the environment, initiated a critique of the institutional care for psychiatric patients (see Pilgrim and Rogers, 1993). The work on dementia has, in the main, rejected the social constructivist position that societal reaction is the primary cause of dementia, and has accepted that a biomedical process is the primary cause. However, labelling theory has been employed to suggest that a process may be superimposed on the disease with negative effects (Dworkin, 1992) but these can be countered by a shift in the values of care-givers and wider society, following the arguments of normalisation (see Brown and Smith, 1992).

Lyman (1988), from a symbolic interactionist perspective, described the way in which staff of an American day care centre for people with dementia infantilised their patients on the basis of medical labelling with a prognosis of degeneration to a child-like level of functioning, and noted that 'premature dependency' could result. The resulting pattern of interaction was, according to Lyman, maintained by a philosophy of care that made it hard for staff to respond to what their patients were actually trying to communicate to them, and also that contradictions and inconsistencies within the philosophy made it difficult to perform their role. An additional point was made that, if patients were involved in the exchange, 'humour accomplishes therapeutic goals with greater equality and mutual empathy than other therapies allow' (1988:97).

Lubinski applied the concept of 'learned helplessness' to the experience of people with dementia, said to occur 'when individuals perceived that events and outcomes are independent of their responses and that any further action is fruitless' (1991:144). The assumption that the person with dementia cannot be expected to participate competently or meaningfully may be shared by the person with dementia and their carers, with a consequent restriction of opportunities to participate. Fear, frustration and depression naturally ensue. Helplessness could be minimised by accurate diagnosis, training of staff and support for families, and normalisation. Normalisation meant, to Lubinski (1991), to live in mainstream society insofar as possible, in personal and home-like settings; to dress appropriately according to personal taste; to participate in age-appropriate activities, complementing previous experience and interest; and to have the opportunity to take part in activities outwith the institution with life-long family and friends.

In this review, particular attention is given to the work of Kitwood, and colleagues from the Bradford Dementia Research Group, since this informed the choice of observational method in this study. Kitwood has challenged the perceived dominance of the biomedical model and championed a person-centred approach to care (Kitwood and Bredin, 1992a). This is explicitly derived from person-centred counselling, and borrows from the sociological approaches outlined above. A 'dialectical interplay' is



proposed between physiological and psychosocial factors that influence the experience and symptoms of dementia (Kitwood 1990, Kitwood and Bredin 1992a). A distinction is made between the 'personal psychology' accrued by an individual, including personality and biography, and 'social psychology', the latter defined vaguely but referring to the interaction between person and environment, and perceived as a powerful influence in enhancing or diminishing an individual's 'sense of safety, value, and personal being' (Kitwood, 1993:542). Dementia is cast as attracting a malignant social psychology, which may have a devastating effect on self-esteem by undermining the personhood of people with dementia through treachery, disempowerment, infantilisation, intimidation, labelling, stigmatisation, outpacing, invalidation, banishment and objectification (Kitwood, 1990).

Kitwood and Bredin (1992a) assert that persons exist in relationship with one another and that successful interactions with people with dementia require intersubjectivity, defined as deep and mutually satisfying empathetic interactions that enable the respondent to hold together the fragments of 'the self that is shattered in dementia' (1992a:285). A system of evaluating dementia care (Kitwood and Bredin, 1992b) depends upon a distinction between interactions that contribute to relative 'well-being' and 'ill-being' of people with dementia. Well-being in dementia was argued to be related to four global states that the indicators could describe, namely a sense of personal worth; a sense of agency; a sense of social confidence; and hope. Twelve indicators of well-being were operationalised by Dementia Care Mapping (DCM), namely the assertion of desire or will; the ability to experience and express a range of emotions; initiation of social contact; affectional warmth; social sensitivity; self-respect; acceptance of other dementia sufferers; humour; creativity and self-expression; showing evident pleasure; helpfulness and relaxation.

DCM seeks to indicate quality of care (or the quality of *social* life, Kitwood, Buckland and Petre, 1995:148, my emphasis) by measuring the time spent in different states of well-being. Subsequent work examined the relationship between well-being and physical and social environment, dependency and personality of individual residents as recorded by DCM over ten hours with 132 people with dementia living in 26 care homes (Kitwood, Buckland, and Petre, 1995). Both the regime and support offered to staff, in providing flexible, creative care responding to emotional needs, were considered vital to residents' well-being. Discriminant analysis suggested that well-being was positively associated with the amount of time spent engaged during the day, the quality and quantity of contact with other residents and visitors, and specific personality dimensions of openness and conscientiousness. Conversely, ill-being appeared to be associated with being left unattended by staff for periods over half an hour; physical and emotional dependency and the traits of neuroticism and if residents were found to be disagreeable (that is, seeking to manage and implement one's own ideas); as well as with regimes which were segregated from the local community, had



less participation from residents, and left residents to their own devices. Increased cognitive impairment was found to be associated with diminished well-being, fitting uncomfortably with previous assertions that well-being is sustainable throughout dementia. The physical setting was not found important in determining well-being. Well-being was highest and most consistent when the staffing ratio was one direct care staff member to 8 or 9 residents. Above and below this there was greater variation in group well-being, some of the highest as well as the lowest scores found with higher staffing levels, and a generally lower level of well-being found with lower staff levels.

Kitwood's work did not attract critical review until Adams (1996) noted that the qualitative methods on which his theory about the process of dementia was built, for example psychobiographies, lacked rigour and that insufficient attention had been paid to validity and reliability. The DCM method is evaluated in Chapter Three.

Other British psychologists have investigated interactions with people with dementia. Sabat and Harré (1992) argued that selfhood need not be 'lost' with the dementing process as may be assumed. Discourse analysis with people with Alzheimer's disease demonstrated that one specific sense of self, that is a sense of identity and agency, is maintained throughout the illness. They argued that a second type of 'self', the social recognition of personae, need not be lost as the disease progresses, but rather is related to the behaviour of those who are regularly involved in the social life of the sufferer. To react positively to increasingly fragile clues requires persistence and dedication, but the listener should assume that someone with dementia has a coherent reason for behaving as they do (Sabat and Harré, 1992).

Another strand in the sociological study of dementia has examined carers' attempts to make sense of the experience of dementia (Gubrium, 1987; Askham 1995). Gubrium, having observed in communal settings, described the process of structuring and also destructuring the experience of dementia. Askham argued that the different interpretations of dementia developed by carers in the private world of the home should be respected, but she suggested differences included whether the dementing process was perceived as simple or complex, as orderly or unpredictable, as normal or abnormal, as an illness or not, and, lastly, as positive or negative.

Social scientists are habitually critical of a biomedical model (e.g. Kitwood 1989, Lyman, 1989) but as Reed and Watson (1994) suggest, the 'medical model', meaning a narrow concern with pathology, may be a caricature of actual clinical views, and a shorthand reference to a set of values and concerns popularly associated with the medical profession. The term may be used to distinguish alternative and rival models, for example an holistic nursing approach, which (citing Holden, 1991) may only replace physiological reductionism with psychological reductionism, and provide descriptive models limited in predictive or explanatory power. Within psychiatry, a biopsychosocial model has been proposed (Engel, 1977, cited by Dworkin, 1992) to indicate biological, psychological, behavioural and social components of psychiatric illness, and to assert



that clinicians should be alert to the influence of each dimension. In practice, there is a need to integrate the expertise of both clinicians and social scientists in developing explanations of behaviour and therapeutic approaches. As well as the organisational issues broached by Kitwood, Buckland and Petre (1995) and more fully discussed by Lyman (1989), social structural factors affect people with dementia as they do all older people (see 2.2.2).

A strong theme of this section is that the multiple factors relevant to the development and experience of dementia need recognition. The term 'rementia' (Kitwood and Bredin, 1992a; Sixsmith *et al.*, 1993a) has been coined to refer to positive changes, or at least stabilisation, that may result from a person with dementia moving to an improved environment. Establishing rementia and proving negative effects of institutions demands a rigorous research design (Dworkin, 1992:20) with understanding of the expected cause of the illness as well as organisational process. Those committed to psychosocial forms of care may be more optimistic in terms of expected outcome than those with a more narrow clinical concern with neurological impairment. The idea that positive changes may accompany a degenerative condition has been promoted by proponents such as Kitwood. He noted however a danger of 'romantic over-optimism' where dementia can be mistakenly cast as a 'happy journey or path of discovery' (Kitwood, 1993:133).

### **2.1.3 Therapeutic Interventions**

Understanding behaviour requires recognition of external factors, that is physical surroundings and the behaviour of others, as well as internal factors, including health status and personality (Garland, 1990). This section notes therapeutic interventions intended to improve the experience of dementia. The work of Lawton (1982) has been important in suggesting, with the concept of 'environmental docility', that external factors may become increasingly important to those most affected by ageing.

As an individual's competence decreases, the proportion of behaviour directly attributable to external influences appears to increase. (Garland, 1990:124)

#### *Psychological therapies*

Holden and Woods (1995:10) defined positive approaches eclectically as those affirming the 'worth, humanity and dignity' of people with dementia, and having the capacity to help communication, to maintain and develop skills, and to address difficulties. Benefits may be mediated in different ways, including a possibility of recovery from brain damage, the positive effects of increased attention and stimulation with improved cognitive effects and relearning, and overcoming depressive withdrawal.



People with dementia may avoid failure by not attempting tasks that have become difficult, and as a result function at lower level than that imposed by the degree of impairment: 'Increased self-esteem could be a powerful mediator of generalised improvement.' (Holden and Woods, 1995:568)

Generally the value of psychological therapies has been difficult to demonstrate in terms of observable clinical improvements and some claims are speculative. Bleathman and Morton (1994) included reality orientation, reminiscence therapy, behaviour modification, psychotherapy, validation therapy, resolution therapy and expressive therapy in a review of the principles and effectiveness of psychological intervention. All approaches demand specific professionalised patterns of interaction, but, are based on different principles. Reality orientation is perhaps the most developed, and a number of studies have shown its capacity to improve verbal orientation, at least temporarily. Behaviour modification, which reinforces desired behaviour, is advocated by Stokes and Goudie (1990). Such techniques may be contrasted with approaches from humanistic psychology, as exemplified by Kitwood and Bredin (1992a) and Feil (1992). Reminiscence therapy, which may seek to assist 'life-review' (see Bornat, 1993), has been facilitated by the availability of various packages that seek to evoke memories of the childhood and adult eras of people with dementia. Latterly more attention has been paid to individual histories and life story work (Mills and Chapman, 1992) with an assertion that good practice demands that staff members get to know the backgrounds, personalities, and preferences of people with dementia, since they will not communicate this in the normal way (Marshall, 1993).

### *Physical environment*

A supportive physical environment may prolong independence and provide both a sense of challenge as well as safety, while an environment that is too complex may lead to the behavioural problems associated with dementia (Downs *et al.*, 1994). In a helpful review of North American work, Regnier and Pynoos (1992) suggested twelve environmental and behavioural principles derived from research on design that affect the behaviour and quality of life of cognitively impaired older people. Space does not permit rehearsal of all these, but for example, Regnier and Pynoos (1992) asserted that the built environment should be stimulating environment, safe but challenging. Such an environment could be achieved by being able to look outside or to see one's possessions, while reducing visual disturbance such as shadows or reflections. Netten (1993) sought to distinguish between residential environments in terms of how orienting they were to residents; others have suggested what design features promote orientation, for example Cohen and Weisman (1991) and Marshall (1992). Garland (1990) noted that containment has been a priority in residential care for residents considered at risk if they leave through disorientation. This may be reflected in



restraining features of design and surveillance apparatus, as well as in regime. The potential of technology to facilitate independence is currently attracting attention but perhaps with undue attention to surveillance rather than the support of failing function (Downs *et al.*, 1994).

A familiar environment is believed to compensate for physical sensory loss (Willcocks *et al.* 1987:6). Marshall (1993) asserted that small-scale, domestic accommodation is important for people with dementia, 'small' meaning units of about eight people.

Small scale is an essential characteristic of accommodation for people with dementia if they are not to be over-loaded with stimuli in terms of too many other people (both other residents and staff), too much noise and too much incomprehensible activity. (1993:1)

Marshall also suggested that for someone with dementia who has lost their short term memory, a 'familiar' environment would be the kind of design style that was prevalent when they were young adults. A further advantage of domestic design is that it can provide scope for purposeful activity, which brings benefits to both residents and staff. Living in mainstream housing that is not distinct from neighbouring houses is a principle of normalisation that has been extended to people with dementia (Cohen and Weisman, 1991; Regnier *et al.*, 1995).

## **2.2 The context of care housing developments**

This section examines the wider context of care housing. Contemporary policy, directed towards community care, needs to provide for increasing numbers of people with dementia. Long stay care remains important for people with dementia but has been criticised for being deficient in quantity and quality and legislative reforms demand adjustment between sectors. While some argue that long stay care may be a positive choice, others assert that linking accommodation with support is undesirable.

### **2.2.1 The prevalence of dementia and balance of care**

A large international study confirmed that the prevalence of dementia increases exponentially with age. Three to five percent of people over 60 - 65 years are affected and the rate of those with dementing disorders doubles every five years (Hofman *et al.*, 1991; Jorm *et al.*, 1987). Ott *et al.* (1995) classified about a third of all those affected as having 'severe' dementia. The consequence of a wider demographic shift in Scotland is that despite a fall in the total population, the number of people over pensionable age (60 for women, 65 for men) is projected to increase from 912 000 to 1 347 000 by 2032, and this increase will be greatest for those over 75 (Scottish Homes, 1995). This shift



implies an increased incidence of dementia. There are currently between 60 000 and 90 000 people with dementia in Scotland (Scottish Home and Health Department, 1988) and there may be over 20% more by the end of the year 2010 (Age Concern Scotland *et al.*, 1992).

The 1991 census showed that 96% of people over 65 in Scotland lived in private households in the community, a third of these lived alone, while the remaining 4% lived in 'communal settings' and form a majority in long stay care (Titterton 1994). Dementia is the most frequent cause for old people to move to long stay care, and people with dementia may be more difficult to support at home since they find it hard to organise themselves and to recognise danger (Godber and Wilkinson, 1994). There may be as many as 20 000 people with dementia in all forms of long stay care in Scotland (Age Concern Scotland *et al.*, 1992). Schneider *et al.* (1993) estimated that there were almost 320 000 people with 'advanced' dementia in UK: 63% of these lived in private households and 13% were living alone; 19% lived in residential care, 11% lived in hospital, and 7% were in private or voluntary nursing homes.

Older people in local authority and NHS nursing homes in the 1980s were predominantly over 75, with a probable ratio of five females to one male, the vast majority being single (Higgins, 1989b). Consistently, living alone has been found to increase the likelihood of entering care (Higgs and Victor, 1993). People in higher social classes may be less likely than others to enter institutional care (Grundy, 1992, cited by Higgs and Victor, 1993) and may be more likely to live in nursing homes than move to local authority homes (Wade *et al.* 1983, cited Higgins, 1989b). However people move between sectors; for example up to 50% of people in residential care may come from hospital or other institutions (Darton and Wright, 1992, cited by Higgs and Victor, 1993).

### **2.2.2 Policy for older people**

A political economy perspective (Phillipson, 1982) suggests the 'structured dependency' of elderly and disabled people on the state, and describes the process of how they become dependent on state benefits and are allocated comparatively few resources compared to other sections of the population who have more economic potential. This creates a general imbalance of power between service providers and elderly people, which is best viewed as a structural constraint. The influence of ageism, and the fact that most older people are female, may negatively influence services for older people, and contribute to pessimism about what can be achieved for them (Means and Smith, 1994). The neglect and shortfall of services for all older people is a recurring theme of the literature reviewed here, as is the possibility that the picture is not improving despite recent changes in policy. For example, over the two decades preceding 1994, services had steadily fallen behind need as resource allocation had



been based on a 25% growth of the over 65 population while the numbers of those over 75 had grown by 55% (Godber and Wilkinson, 1994).

Contemporary policy in industrialised countries has to address a disproportionate increase of older people in relation to younger age groups, pressure on domiciliary and institutional provision, and escalating costs (Johansson and Thorslund, 1991). A policy shift towards community care is arguably a response to increasing demands made by people over 75, who are high consumers of expensive health and social care services (Means, 1991) during a period of lowered economic growth (Baldock and Evers, 1992). The attempt to integrate and co-ordinate public provision of services for people with dementia with commercial and voluntary sectors has been problematic across Europe, although the central role of long stay care for people most disabled by dementia is agreed (Bleeker, 1994). The British government's policy in recent years of 'rolling back the state' (Clarke and Langan, 1993) means that competition and quasi-markets have been introduced to welfare services, together with the aim of the new managerialism of ensuring services provide better 'value for money'. Public services have been subject to various strategies seeking to improve their quality but, as Pollitt (1993) suggests in relation to the National Health Service (NHS), the definition of quality may neglect patients' representation and instead exercise the established power relations between professionals. A pessimistic view is that British welfare is being residualised and that it is delivering stigmatised, means-tested services for those people who have no choice but to accept, while other commentators are uncertain of the consequences of the recent policy shift to welfare pluralism and social corporatism (Clarke and Langan, 1993).

In the provision for elderly and disabled people, there is a gap between stated policy objectives and practice, and services have proved resistant to reform. Service professionals and administrators at local level have the power to influence how new policies are implemented, which may impede progress (Means and Smith, 1994).

Generally, within the legislative framework of 'top-down' reforms, 'bottom-up' developments may appear which have the following features: they aim to provide for need which is otherwise not met, they probably pay little attention of opportunity costs or to overall efficiency; they can only fill gaps, and do not change the structure of a local care market (Baldock, 1991). Innovations may seek to provide better quality of care in accord with wider social values. Possibly, with higher standards of living, expectations and assumptions for care received in later life are higher (Baldock and Evers, 1992). The aspiration to improve care co-exists with governmental interest in limiting welfare costs (Bleeker, 1994; Keen, 1993).



### 2.2.3 The mixed economy

Several agencies provide services to people with dementia that provide a notional continuum of care for different levels of support needs. The public sector co-exists with private and voluntary services. While the NHS has the prime responsibility to care for people in poor health, 'social' care is the remit of local authorities. 'Housing' responsibility is also separately allocated, generating further potential boundary disputes (Arnold and Page, 1992). In practice there is overlap between the sectors and some people are 'misplaced' (Sinclair, 1988:256). Murphy (1996) identified three streams emerging in the twentieth century: private care for the wealthy; means tested funding for the majority from central government or local authority sources; and for the most disabled and disadvantaged people, NHS care which they did not pay for. Since the mid 1970s there has been considerable growth in the private and voluntary sector (Corden, 1990). Part of this was due to an incentive to move to long stay care because it was easier to obtain financial subsidy for institutional care than to provide care at home (Higgs and Victor, 1993).

There are many potential overlaps both within and between sectors, an example within the health service being between geriatric medicine and psychiatry. Where people are treated may depend on what resources are available locally and the overall situation is 'a complex patchwork of services, working to different agendas, financial rules, and varying widely in their quality and provision from one district to another' (Godber and Wilkinson, 1994:569). Bebbington and Tong (1986) found poor co-ordination between sectors, with inadequate transfer of resources to assist a policy shift towards community care which has been emphasised in policy since the 1950s.

#### *Informal care in the community*

Most older people are not dependent nor disabled and live in private households; those who do need support are mostly cared for at home by relatives, and even the majority of the most disabled people live in private households (Victor, 1991; Sinclair, 1988). The stressful nature of caring for people with dementia has been well documented (see Gilleard, 1984). Levin *et al.* (1989) established that most relatives are keen to continue caring, but for many a crisis point is reached, and institutional care is sought (see 2.5.1). There has been a bias towards the question of how a move to institution may be delayed or prevented, rather than consideration of the best ways of supporting informal carers (Zarit and Teri, 1991). Informal carers' generally are poorly supported. Counselling and advice, particularly about benefits and day care may be in demand (Wenger, 1994). Informal carers may be seen as 'second victims' and undoubtedly have a difficult task; the accumulated research however has the effect of



focusing attention on the well-being of carers rather than that of the people with dementia (Lyman, 1988).

### *The ascendancy of community care*

The National Health Service and Community Care Act (1990, see Department of Health, 1989) was phased in from April, 1991, and finally implemented in April, 1993. The main events and the terms of this legislation are well documented (e.g. Means and Smith, 1994; Victor, 1991). The organisational change required was substantial, and was combined with uncertainty about how the reforms would be funded (Davidson and Hunter, 1994). According to Ritchie (1994), this legislation has been implemented in a context where overall strategy is lacking, and with a huge task of overcoming the barriers to collaboration between agencies. Innovative projects may have a small share of resources compared to 'traditional' services which resist change and whose philosophies are in conflict with the new services; new services have high start-up costs and this makes it hard for them to compete with existing services which have low marginal costs (Ritchie, 1994).

### *Adjustment and reform*

The abundance of research (see Sinclair, 1988) into the care of elderly people in institutional and residential care is paradoxical given the history of neglect of people with long term care needs, in terms of priority of resource allocation and the quality of care delivered (see Means and Smith, 1994). Historically, residential care has been persistently unpopular, being imbued with the workhouse stigma (Parker, 1988). Especially where mental illness is concerned, there is a stigma of association, with a lay belief that only mad or bad people go to institutions, and it can be very hard to get out. Social control can be exerted by offering people a stark choice between discomfort in the community, and discomfort and stigma in the institution. According to Parker, this popular consciousness contributes to a widespread support for community care.

### *Hospital provision*

Bleeker (1994) noted a trend towards demedicalisation of long stay care for people with dementia across Europe, being more developed in some countries than others, and in which dementia is re-cast as a chronic disabling condition amenable to psycho-social intervention, rather than as a disease that should be treated. However, in the UK the development of alternative homes is likely to be constrained by financial and registration requirements (Woods, 1995).



The Scottish Home and Health Department (SHHD) in 1988 referred to the large and increasing proportion of long-stay patients with dementia in psychiatric hospitals judged to be unsuitable, these hospitals being regarded as old, excessively large, isolated and inappropriately designed. This report estimated that half of all people with dementia had no need for formal care and support, but that there was considerable unmet need for others worse affected, especially very old women who were likely to be living alone. The theme of a previous report (SHHD, 1979) was developed, calling for new attitudes and approaches to care:

Hospital provision should be in small-scale units resembling as closely as possible domestic living conditions. They should be situated within the community from which patients are in the main drawn and should be integral to it. (SHHD, 1988:47)

This report specified the need for health services to work collaboratively in joint planning, and specifically encouraged Health Boards to work with housing agencies in the development of domestic-scale, local units. The *domus* units in London were used as a positive example (see Lindsay *et al.*, 1991, reviewed in section 2.4.1). There has subsequently been a failure to meet the targets set by the SHHD (Age Concern Scotland *et al.*, 1992). A recent attempt by the Royal College of Psychiatrists to achieve a consensus (Wattis and Fairbairn, 1996) indicated continued uncertainty about the role of the National Health Service (NHS): it was agreed that continuing care for those in need of health services should remain within the remit of the NHS and this should be in relatively small local units and integrated with other services. A critical voice (Murphy, 1996) demanded that psychiatrists should work to support other sectors and be prepared to surrender control of in-patient units.

### *Residential care*

The role of residential care has been reassessed in the light of Community Care. Changes in design of local authority residential care homes have historically reflected policy, moving away from the workhouse's institutional design towards, in the post war period, a 'hotel' or 'small home'. The introduction of group-living in homes meant that residents have more private space, and the various rooms they use are more integrated, that is, closer together (Peace, 1986). Since the Victorian era, 'we can see an increasing emphasis being placed on normality, client self-determination, and community integration' (Willcocks *et al.*, 1987:1). More recently, the Wagner Committee (1988) insisted that moving to residential care could become a positive choice if individual needs were responded to, and that residential care ideally encompasses a range of provision from long stay care to crisis shelters or shared care. Other arguments have been advanced for the continuation of residential care. Many older people have high levels of physical and intellectual impairment and support at



home round the clock would be prohibitively expensive (Higgs and Victor, 1993). Foster, P. (1991) noted the feminist critique of the implications of community care alternatives for carers.

Avebury (1984, 1996) set out eight principles of care for local authorities charged with inspecting residential care, being fulfilment, dignity, autonomy, individuality, self-esteem, emotional needs, responsible risk-taking, and quality of experience. Residential care has not always achieved these ideals; the advocacy of 'domestic' has been described as being illusory, and the National Consumer Study found that even in purpose-built group-living homes, the needs of the group still took precedence over those of individual residents (Peace, 1986:148, citing Willcocks *et al.* 1982). Bad practice in physical care was identified by Hughes and Wilkin (1987), giving the impression that institutionalisation is a process whereby dependence is generated and enforced.

The determinants of residents' experience (residents' experience being a concept analogous to those of 'regime' or 'social climate') are widely taken to be the staff, buildings, other residents, and inspection and other methods of control (Sinclair, 1988). This does not mean that these factors alone determine quality of life, nor that quality of life can be controlled by manipulation of the inputs of residential care. Kellaher (1986) suggested that determinants of quality of life include factors existing before the move, the characteristics of residents, as well as the residential environment. Baldwin *et al.* (1993) challenged major studies of the 1980s, stating that Goffman's (1968) influence may lead researchers to assume, mistakenly, that the process and outcome of institutionalisation is uniform, and that this assumption is unsupported by the relatively small amount of work comparing the experience of older people at home with their experience following a move. The co-existence of 'multiple regimes' that shape individuals' experience differently denies a uniform, 'steam-press', effect (Booth, 1985). Moreover, the structured dependency thesis suggests that it may be mistaken to consider that enforced dependency is a process that occurs only after a move to an institution.

Proposed reforms to residential care are particularly relevant to care housing developments. According to Willcocks *et al.* (1987), residential care needed considerable adaptation if attributes of home really were to be reconstructed, and the essential change was to enable people to live more privately. Single rooms had been in ministerial guidance since 1954, but a 'residential flatlet', would be a further improvement, providing territory where the resident could control what happened and lock the door. Moving to residential care could thus be akin to moving house rather than leaving home. There should be sufficient space to bring in large items of furniture, which could help to evoke 'significant memories and affirm individual status and identity' (Willcocks *et al.* 1987:151), and to entertain visitors and to eat meals in, perhaps with other residents. There would be equipment to make hot drinks, a vanity unit, shower



and WC, either contained or adjacent. Within the residential home, there should be capacity for residents to make snacks, and also communal areas where they would be able to meet other residents. Generally, the design of the whole unit should stress the separation of private and public domains, and facilitate orientation.

Foster, P. (1991) argued that good residential provision should be an integral part of care in the community and proposed a model that included professionals sharing care with unpaid relatives, both in practical caring tasks and policy making. A manifestation of such a policy would be a communal kitchen, which:

far from being off limits to most residents and certainly to all visitors as it is in most conventional homes today, would become a shared space for all staff, residents and caring relatives. (Foster, P. 1991:117)

Foster acknowledged that such a change required redefinition of tasks and re-training to change staff's attitude, and evidence existed that unskilled care staff resisted sharing practical care as this was an area of competence that they wanted to keep control of (Clough, 1981). In local authority care, specialised staff roles have been found to prevail; the officer in charge acting as manager, supervisory staff looking after medicines and paper work and resident's social lives, and care staff giving practical care, while domestic staff cook and clean (Imber, 1977, cited by Sinclair, 1988). The important role staff play in shaping residents' experience is generally agreed, especially the role of care assistants who generally are busy, doing dirty and exhausting work focused on practical tasks, undermining the possibility of getting to know residents and also persuading people to be more independent by doing things for themselves (Sinclair, 1988).

### *The housing sector: its contribution*

Housing Associations, as part of the voluntary sector, have an important role to play in the implementation of community care policies, not least because they have access to public subsidies to 'special needs' housing. Historically, the voluntary housing movement has sought alternative ways of housing people in need, and latterly has been favoured by government policy because it is capable of providing a flexible local response. Housing Associations have expanded their work considerably since the 1974 Housing Act, which created a generous framework for subsidies. In 1988, further legislation was passed in England and Scotland which changed and extended the priorities of Housing Associations. They were pushed towards the private sector by changing the basis of tenancies and the way in which funding was secured, now in part through private loans. There was an increased emphasis on value for money, and Housing Associations were expected to be sensitive to the market, and business-like in operation (Cope, 1990).



Arnold and Page (1992) found that housing authorities were marginalised in developing Community Care plans, and that their activities were characterised by inadequate funding and uneven relationships with Social Services and Health Departments. While partnerships and mixed funding schemes were evident, they proved costly in time and effort. If schemes developed and continued, it was thought to be a product of individual effort and persistence rather than due to facilitating policies and funding. Further, despite diversity in accommodation, individual users did not necessarily have choice.

Housing Associations are non-profit, voluntary organisations, with a common aim of providing housing and related services for people on low incomes and in housing need, which have to meet certain requirements to be registered with the government funding body, Scottish Homes, or the Housing Corporation in England and Wales. Housing Associations are diverse in their aims and organisation. Community based Housing Associations act in specified localities and may include 'special needs housing' amongst their 'general needs' programmes. Specialist Housing Associations exist to develop housing for specific groups. Housing Associations have had a long history of providing for elderly people (Cope, 1990), with the development of sheltered housing (Clapham and Munro, 1990) and very sheltered housing (Tinker, 1989) but have only recently expanded their remit to specialist provision for people with dementia. This expansion may be in part a response to problems encountered when elderly tenants in existing housing schemes develop dementia, and partly a response to projected increased need.

The focus of Housing Association activity has to some extent changed; support needs, rather than existing housing circumstances, can bring access to accommodation (Watson and Cooper, 1992). The demand for social rented housing and accommodation with support far outstrips supply: one estimate is that only 1% to 2% of the need for very sheltered housing for older people is met in Scotland (Titterton, 1994).

#### **2.2.4 The implications of linking support and accommodation**

Residential care can be defined as any care where the support is tied to specific accommodation, and people have to move to receive support (Spicker, 1991). In principle, it should not be necessary to forego quality of housing to receive care, yet with the notional continuum of care, where accommodation is prescribed hierarchically according to dependency, this may happen (Appleton, 1995). The development of special needs housing requires that client groups be identified and allocated differential priority by policy, and this process may have negative effects (Clapham and Smith, 1990). The rationale of targeting resources effectively is used to draw increasingly tight specifications around those whose needs are sufficiently 'special' (a phrase that is an euphemism for 'abnormal') which may stigmatise those with 'special needs' and exclude



them from the mainstream of society. Inflexible models of care are encouraged, where housing and support services are supplied according to predetermined agreement between agencies, and adapt by controlling who moves in rather than by tailoring care individually. Ideally accommodation and support should be separated, and appropriate support offered on an individual basis; instead an incremental reform of expansion in the number and categories of people entitled to accommodation with support occurs (Clapham and Smith, 1990). Sheltered housing schemes have tended to restrict the frailty of tenants coming to a scheme rather than provide more support, with a paradoxical consequence.

If only those people who most need and appreciate the unique features of sheltered housing were allocated places in schemes, the existing model ultimately could not provide sufficient support. (Clapham and Munro, 1990:27)

Spicker (1991) was pessimistic that the link between support and accommodation could be broken and believed that people moving into residential care would continue to have to move into territory that was not their own to define, and be constrained in what they could bring. However, a compensation of group-living was suggested, being access to facilities that individuals could not afford on their own.

How can specialised accommodation with support for people with dementia be justified? One proponent (Norman, 1987) has argued that informal carers can not be expected to sustain someone with dementia at home up to the point where they need 24 hour care, and pointed out that people with dementia are not always accepted in mainstream residential care. Segregation was argued to be unacceptable only if it means going to impoverished and stigmatising care; specialist residential care can be made more acceptable by recognising residents' rights and making their existence as normal as possible, while respecting the worth of staff. 'Special', according to Norman (1987), may be interpreted as 'excellent'.

### **2.3 Seeking quality: living at home with support**

Care housing seeks to improve the quality of life of its residents by providing good quality of care. This section identifies the complex nature and components of quality of life and examines the ideal of 'homeliness'. Considerable attention has been given to the evaluation and operation of residential care, but the attributes of 'home' and the assumed advantages of living there are much less well understood. Their environment may be particularly important to people with dementia. Work on principles of service provision is reviewed and some implications for evaluative research are noted.



### 2.3.1 Quality of life

Quality of life may be taken to refer to a 'sense of well-being and satisfaction experienced by people under their current life conditions' (Barry *et al.* 1993:43). The concept has been central to the development of social gerontology, but it has been variously conceptualised, defined and measured, reflecting its complexity (Hughes, 1990). Attention may be given to both subjective and objective appraisal, or the *experience* of life and the *conditions* of life (George and Bearon, 1980, cited by Hughes, 1990). A normative approach, where quality of life may be compared to explicit and positive values that reflect wider societal standards (see Evans *et al.*, 1988), differs from an alternative approach, where the relative importance of particular areas of life for each individual is assessed (Barry *et al.*, 1993).

The factors which shape quality of life have been given attention by a number of authors. Twining (1991) proposed that physical environment, social interactions, physical health, mental health, and personality and history each play a part in individual appraisal of quality of life. Hughes (1990) suggested quality of environment, socio-economic status, physical and mental well-being, expressed satisfaction, personal autonomy, cultural factors, social integration and purposeful activity as factors that social gerontological research should take into account. Twining's model emphasised subjective appraisal but omitted socio-economic status and purposeful activity which were included by Hughes. The contextuality of priorities was articulated by Maslow (1987) who argued that some factors rather than others are stressed according to circumstances. Needs were arranged in a hierarchy, in ascending order: physiological, security, social, self-esteem and self-actualisation (Maslow, 1987).

Critical approaches within social gerontology (e.g. Phillipson, 1982) insist that quality of life for people of all ages is shaped by the same factors and criteria, and also that social and economic factors are as influential in old age as biological characteristics. Sinclair and Williams (1990) implied agency within structured dependency:

.. the quality of life of old people depends on their ability to resolve the problems set by their increasing age in ways that are compatible with their chosen lifestyle. (1990:70)

There may be specific problems in later life. Sinclair and Williams (1990) suggested that these included the resolution of practical problems; involvement in social life, with loneliness as a possibility; and overall satisfaction with life, with a liability to become depressed. Illness and bereavement were recognised to have pervasive, and negative, effects on older people.

Proponents of normalisation are concerned by the way that some groups of people are segregated and isolated by society (see Emerson, 1992). The concepts



behind normalisation have been operationalised for people with learning difficulties to facilitate evaluative research. Leedham (1991, cited by Wright *et al.*, 1994) suggested a framework of accomplishments regarding them as experiences that everybody values (developing work by O'Brien, 1987, cited by Wright *et al.*, 1994). These accomplishments included community presence; choice; awareness of opportunities and constraints; competence; self-determination; respect; community participation; and personal continuity.

### **2.3.2 Being at home**

This section seeks to identify the idealised characteristics of home that accommodation with support may try to recreate, without wishing to imply necessarily that this is always possible nor that living at home is always better.

Community care policies assume that home is the best locus of care-giving, and any substitute for this should be as domestic as possible, even though this is not supported by robust housing and care policies to support those wishing to stay put (Harrison and Means, 1990). Institutional reform aims to create more domestic settings (see 2.2). The supposed character of institutions is well rehearsed and gives the impression that institutions and home are polar opposites (Baldwin *et al.*, 1993). The nature of the relationship between person and home in later life is poorly understood, despite a growing literature on the wider meaning of home (Sixsmith, 1990; Gurney and Means, 1993). Lack of knowledge about how people live at home may lead to false assumptions. For example, longitudinal research findings have indicated that the inactivity of old people in residential care was similar to levels before they moved (Spasoff *et al.*, 1978, cited by Baldwin *et al.*, 1993). Dependent people living at home might be institutionalised by services providing a rigid care programme and be isolated (Gavilan, 1992). Gurney (1990, cited by Means and Smith, 1994) recognised that domestic violence, child abuse and elder abuse occur at home, though supportive and loving relationships between kin and non-kin are more likely to take place at home than anywhere else.

Home, like quality of life, is a multi-faceted concept and a sense of being at home is a subjective experience. The characteristics of home vary historically, geographically and culturally (Watson and Austerberry, 1986). Various suggestions about the components of home have been made (Hayward, 1975; Somerville, 1992), but, at its simplest, home can be portrayed as having physical dimensions, being objects, space and boundaries; social dimensions, involving people, their relationships and interactions; and 'metaphysical' dimensions, the meaning and significance ascribed by individuals and communities to home (Downs and Stea, 1973, cited by Willcocks *et al.*, 1987). Inequality in housing conditions should be seen in the context of the wider social



structure (Morris and Winn, 1990) and the major social divisions of class, race, gender and age (Clapham *et al.*, 1990). Older people, especially in owner-occupied and private rented sectors, are likely to experience poor housing conditions; disrepair and the need for adaptations are significant problems in the implementation of community care (Leather and Rolfe, 1995).

Home has to be understood as an ideal place and seen within the context of contemporary dominant institutions and ideologies (Somerville, 1989:118). Facets of home may become relatively more important to people as they age and spend relatively more time at home, especially after retirement. This may be associated with restricted access to public spaces for older people, lack of money, increasing physical frailty, and positively preferring home to other places (Sixsmith, 1990). The implication is that quality of home-life becomes increasingly important in determining quality of life overall for older people.

Family life is widely seen as normal, natural and the only possible way of life, and in the last century became defined as a private sphere, maintained by women who belong at home. What happens in families is not easily amenable to researchers (Leonard and Speakman, 1986). Not everyone sees living at home with one's family as an ideal and alternatives need not be institutionalised (Dalley, 1988), though scepticism about the practicality of collectivist alternatives exists (Baldwin and Twigg, 1991, cited by Means and Smith, 1994). Higgins (1989b) suggested that residential care tests the idea of home and developed a framework to compare the characteristics of an institution with what happens in home-life. These were as follows: public or private living; strange or familiar cohabitants; intra-mural or extra-mural formal support; formality or intimacy; whether sexuality is accepted or discouraged; security of tenancy; being large or small scale; the experience of restriction or choice; the familiarity of people and place; and the presence of communal or individualised living arrangements. It is often assumed that at home people have some form of occupation that gives them a sense of purpose and constructive activity (Higgins, 1989b).

The allocation of space within accommodation is more than a functional arrangement, representing a 'spatial investment' which states, and then re-reinforces, the categories by which daily living is framed (Willcocks *et al.*, 1987:5). Given privacy and a measure of independence, people can adapt the space that they have to their own needs and preferences and to portray their identity and individuality, through for example the arrangement of personal possessions (Willcocks *et al.*, 1987; Steinfield, 1981; Sixsmith 1990). Having one's own things about you is considered desirable, compared to the minimal personal possessions accommodated in hospital wards (Mountain and Bowie, 1992).

Informality and formality at home may be analogous to Goffman's description of 'front' and 'back' space for 'actors', a dramaturgical model elaborated in *The Presentation of Self in Everyday Life* (1969). Behaviour in the parlour is analogous to



being 'on-stage' where people adopt formal or stylised roles. This behaviour may be very different from that in the kitchen, where 'backstage' behaviour may be informal, rougher, with 'kidding' and playful aggressivity, and other less restrained behaviour. The setting influences the view formed by others about the inhabitant's status. For example, visiting relatives may be forced, through lack of amenities, to sit by the bed in residential care, reinforcing the sense that the older person is in some sense 'sick' or 'abnormal' (Higgins, 1989b:168).

An assumed feature of home is being able to form social relationships voluntarily (Higgins, 1989b), as opposed to residential care where 'a group of erstwhile strangers live together in an artificial community, whose mores and social relations are ill-defined' (Willcocks *et al.*, 1987:2). The National Consumer Study found that elderly respondents preferred features of ordinary housing to group-living (Willcocks *et al.*, 1987). Plaisier *et al.* (1995b) suggested that older people with chronic physical diseases preferred a private apartment while people with mental health problems mostly preferred family-like settings. Wilkin and Hughes (1987:183) drew an analogy between the formal and polite relationships people have with each other in a lounge in a residential home where personal contact that could compromise privacy might be avoided, and the situation in a waiting room or public transport.

Neighbourhood is an aspect of home that also influences quality of life in that amenities can facilitate or restrict independence (Sinclair and Williams, 1990). Having lived in one place for a long time means that a social network may exist to offer support of various kinds and may be a practical reason to be attached to one's home and locality (Harrison and Means, 1990). However, changes in neighbourhood that are related to wider socio-economic trends may be hard to deal with as Wilson (1991) found with a sample of older people who received psychogeriatric services and lived in North London. Attachment to home and place derives from several sources, such as memories, familiarity, rootedness and an awareness of the end of life (Sixsmith, 1990:182). Respondents, referring to home as a final refuge, explained:

- Well it's that people have come to the end of their life and don't want to start a new one. When you get to that stage, you just sort of think that there is no point in moving.
- The trouble with moving is being sure of getting a good place and making friends in a new place. The trouble is though, that you haven't the time to make real friends properly, or settle down if you are already old. (Sixsmith, 1990:189)

The literature is consistent in suggesting that older people prefer to stay at home, and take pains to overcome practical difficulties (Wilson, 1991; Sinclair and Williams 1990; Sixsmith, 1990). Steinfield (1981) observed that for younger people, moving could be a positive status passage, but for older people it had negative connotations. This need not necessarily be the case but the deciding factor may be whether the move is to institutional care or not (Means and Smith, 1994). Higgins



(1989b) argued that the reasons older people experience loss included the problem that 'normal' relationships are not reproducible in residential care and people tend not to make friends; sexual relationships are absent; both staff and residents are predominantly female; and the tasks that people would usually do for themselves may become the preserve of staff.

Privacy may be centrally important to the quality of life for old people: without privacy, for example in residential care, the personal power of older people to conceal their frailty in certain areas and engage in real, social and material transactions with others are compromised (Willcocks *et al.*, 1987:9). Parmelee and Lawton (1990) noted that autonomy is emphasised in the literature, together with the need to maintain independence on moving from private home to special housing environments and defined autonomy as the perception of, and capacity for, effective independent action. For these authors, security was an equally important concept to bear in mind in the design of special environments for elderly people.

The concept of dependence is well rehearsed in the literature, at risk of being opposed to the idealised state of independence to the neglect of the more common, and preferable state, of interdependence (Johnson, 1990; Baldwin *et al.*, 1993). Sixsmith (1990:179) suggested that 'independence is a complex term that has a number of meanings: not being physically dependent; self-direction or control; and the absence of feelings of obligation'. The ideal of the absence of obligations, or the imposition of burden on others, can be substituted with an ideal of mutually satisfying reciprocity.

Can residential care offer a setting where the push and pull of independence and dependence, give way to a form of interdependence, where residents, relatives, and staff can share the responsibilities for exchanging care in a way that offers mutual satisfaction? (Willcocks *et al.* 1987:2)

Whilst interdependence may be a preferable state, the literature remains adamant that social and physical environment should enhance rather than compromise individuals' abilities.

In summary, quality of home life can be assumed to be a relatively large component of the quality of life for older people and, in supported accommodation, quality of care may become a very significant component. Ideals may be equally important both to people living at home and those who move to residential care. These ideals include satisfactory interdependence rather than independence; privacy with control over one's territory, including the ability to form social relationships of one's choice and to personalise it in a way reflecting one's identity; and autonomy balanced by security. What home means to people with dementia, and how they live there, is an undeveloped theme in the literature. According to Kellaheer (1986), creating a homely environment within an institution may be equivalent to attempting to square the circle, and, further, the creation of group-living within residential care is not comparable with



contemporary living arrangements, being neither wholly medical, institutional nor domestic.

### **2.3.3 Principles of service provision**

This section notes aspects of quality of care that may be particularly important for people with dementia and considers difficulties in its evaluation and the potential contribution of different methods.

Maxwell (1984) suggested there were six aspects relevant to the evaluation of quality of care, these being access to services, relevance to need for the whole community, equity, social acceptability, effectiveness, efficiency and economy. Criteria for improving and assessing the quality of residential care have been set out (Avebury, 1984; 1996) and specific aims have been proposed for people with dementia. Cohen and Weisman (1991) suggested important principles for people with dementia are to ensure safety and security; support functional ability through meaningful activity; maximise awareness and orientation; provide opportunities for stimulation and change; maximise autonomy and control; adapt to changing needs; establish links to the healthy and familiar; provide opportunities for socialisation; and protect the needs for privacy .

According to the King's Fund (1986), there has been misplaced attention to the components of services rather than how individuals experience the service as a whole, and also the evaluation of different service models may be hampered by the lack of a framework to compare community based models with institutional settings. A humanistic emphasis that the rights of people with dementia are equal to those of others led to an assertion of the need to counter stigmatisation. Whilst referring to universal rights and implying the values of normalisation, the capacity to respond to individual needs was also required from services. Specific points included the observation that occasionally the needs and wishes of service users may not be compatible with those of staff and service managers but also that quality of life depends on relationships that are reciprocal and voluntary and which respect each participant's rights and needs. For this reason, effective services were seen to be those which recognise and support the contribution of relatives and informal networks. The principle that every person with dementia is an individual can be particularly challenging to service providers.

Quality of life depends on maintaining personal continuity between the past, present and future, and on being recognised as a unique individual with a distinctive pattern of capabilities and needs. Effective services adapt themselves to match the previous life and circumstances of the person. They design and maintain individually tailored packages of care and have the flexibility to adapt the amount and form of help provided to match day-to-day and longer term changes in the individual. (King's Fund, 1986)



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### 2.3.4 Implications for evaluative research

The relevance of the points made above to evaluative research is explored here. Consideration of quality of life should seek to establish the subjective view of the individual, old or young, themselves and take into account their wants and aspirations (e.g. Sinclair and Williams, 1990) but this section suggests that attention should also be paid to external conditions that may be objectively assessed. The quality of life at home and the quality of care received is likely to be a particularly important component of the overall quality of life of people with dementia. Possibly, the higher the standards, or more ambitious the programmes are in terms of improving quality of life, the more difficult it is to demonstrate effectiveness of services (Twining, 1991).

Evans *et al.* (1988) argued that a preoccupation with institutional provision has misled researchers to evaluate the impact of residential establishments according to institutional standards, rather than in comparison with wider societal expectations and standards. At least in the field of mental handicap, behavioural psychology became increasingly influential in the selection of observational methods used in the smaller residential settings emerging in the 1970s. This has focused attention on the acquisition of skills by the resident instead of their interactions with environment or society (Evans *et al.*, 1988). Another point made by Evans *et al.* (1988) was that pre-post evaluative design of, for example, a community care programme for people with learning difficulties, having a narrow focus on the impact of de-institutionalisation on the individuals involved, misses the point that institutions are widely agreed to be detrimental.

The perspective of people with dementia is particularly difficult to establish and hence potentially easy to misrepresent. Services for people with mental illness are liable to greater variability in accepted standards than more technical health service interventions, such as surgery (Turner, 1989, cited by Harrison and Sheldon, 1994). This makes pluralistic evaluation attractive (Smith and Cantley, 1985) since it assumes that success is not a unitary concept but that plural interests should be acknowledged in establishing the research problem. This may counter other evaluative research that has neglected social process in the measurement of simplistic inputs and outcomes (Kellaher *et al.*, 1990). The possibility of potential differences in outcome for individuals should be explored by evaluative research (see Netten, 1991). Different attainment of success in residential care is not well understood and measures are conventionally presented in aggregated form.

It can be argued that the perspective of the intended recipient of any service should be central (e.g. Wallace and Rees, 1984). There are, unfortunately, problems with consumerist research. Shaw (1978) argued that from the researcher's point of view, it is difficult to know when consumers' opinions have been fully understood. Different clients, or groups of clients, may have different opinions and these opinions may



change. It is dangerous to treat present opinion as a prescription for the future. Clients may not necessarily be aware of the full potential range of alternatives, which may lead to conservatism on their part (Shaw, 1978). The advantages and disadvantages of a normative approach and subjective appraisal were noted by Barry *et al.* (1993:54) in relation to the evaluation of quality of life in long stay psychiatric services: subjective views may be limited by limited life experience, an idiosyncratic frame of reference, and particular life problems. These authors concluded that both normative standards and subjective appraisal should be taken into account.

Satisfaction is an important but problematic concept in studies that aim to represent the user perspective. Consistently, it is found that over a wide range of phenomena, a large majority of recipients are likely to express satisfaction, but, at least for forms of therapy, this may vary with characteristics such as age, occupational and educational attainment and income. Exploring satisfaction requires the researcher to disaggregate generalities, and to explore the context in which the experience is evaluated (Cheetham *et al.*, 1992). Older people in residential care, being in a position of dependency, may be obliged to comply to the norms of the institution and hence not express dissatisfaction (Willcocks *et al.*, 1987:123). True (1989) likewise noted that typically a high percentage of samples report positive satisfaction, regardless of other indicators, and commented:

This is such a pervasive pattern that some researchers feel you cannot place any reliance on inquiries about client satisfaction with services or benefits. If qualitative data can be quantified or regularised in some way, the patterns they show offer more reassurance to the evaluators. (True, 1989: 416)

Over and above the general problems of elucidating satisfaction, it has usually been considered inappropriate to interview people with dementia because of their memory problems and possible problems in abstract thinking, loss of interest, increased distractibility and delusions (Dworkin, 1992:60). In research with people with mental health problems, measures of function and cognitive impairment are often adopted as outcome measures (Dworkin, 1992) but these have their own problems of validity and reliability (Ramsay, 1995; Dworkin, 1992).

Observational methods may also be used as proxies for subjective assessment of outcome. In recent years, observational methods have been advocated in the evaluation of continuing care facilities for elderly people with mental and physical impairments since other means to explore residents' experiences, such as interviews and self-rating, are held to be seriously limited because of problems with respondent bias, reluctance to disclose sensitive or critical information, and unreliability due to the cognitive impairment of residents (Clark and Bowling, 1989).

Work published over the last few years asserts the possibility of a more active role for people with dementia in research and Cottrell and Schulz (1993) demanded



attention be paid to the perspective of people with dementia. Success with interview methods has been claimed, with reports that concerns were primarily with social aspects of care rather than physical (Sutton and Fincham, 1994; Lam and Beech, 1994, cited by Goldsmith, 1996). Plaisier *et al.* (1995b) developed a method of walking with residents of nursing homes with a tape-recorder, using the built environment to prompt its evaluation by the interviewee. Mclsaac (1995) reported success in applying therapeutic principles to interviewing confused older people, by not expecting a response, making physical contact, and acknowledging whatever form of interaction that developed. Interviews may, however, result in repetitive agreement with the researcher, indicating that the respondent successfully takes turns in conversation and anticipates a hoped-for answer (Shakespeare, 1996). If the goal is systematically to seek preferences and satisfaction, then interviews are likely, at best, to be a lengthy and difficult strategy.

## **2.4 Care housing developments, their origins, extent and evaluation**

This section introduces developments of care housing that are comparable to the Scottish case studies, and how they have been evaluated. The work is sparse and provides a limited and partial view. Findings about costs and staff satisfaction are reported here; those about residents' characteristics and their activity are covered in subsequent sections of the review.

### **2.4.1 Innovations and their evaluation**

Considerable attention has been paid to the evaluation of long stay care, for example Bland *et al.* (1992) investigated the quality of care and costs in private, voluntary and local authority residential care homes, and concluded that quality of care was higher in local authority homes that also had higher unit costs, but there was no direct relationship between cost and quality. The evaluation of innovative forms of supported accommodation is an established concern of applied social policy literature, since downward substitution towards enhanced home care is an international trend whose feasibility depends upon the assumption that some people can be more cost-effectively supported in a less intensive setting (Challis, 1992). Evaluative work has sought to compare quality of care. For example, nursing homes, developed within the NHS to substitute for hospital care, were found to offer higher quality of care to older people in random control trials with hospital patients (Bond *et al.*, 1989; Bowling *et al.*, 1991). Philp *et al.* (1991) however concluded from a study of the quality of care in nursing homes, geriatric and psychogeriatric hospitals that which sector provided care was less important than how this was shaped in each home or ward. Innovations in



residential care, such as group-living, have been less conclusively evaluated (e.g. Booth and Phillips, 1987). Specialist residential provision, which is larger in scale than care housing, gained the approval, if not rigorous evaluation, of Norman (1987). Prior to the implementation of Community Care, augmented home care and case management was implemented and evaluated piece-meal, with no clear findings that this influenced use of institutional care, though Community Care Demonstration projects in Gateshead and Darlington, which included people with dementia, were argued to be more efficient than existing services, with improved outcomes at lower cost (Challis, 1993). The evaluation of new developments may be made difficult by their heterogeneity, a point made by Ohta and Ohta (1988) about special units for people with dementia in North American nursing homes.

Care housing projects in London, France, Sweden and the Netherlands have been evaluated by independent researchers. In these examples, the innovative principle is that care housing should be home-like and stimulate residents to take part in everyday activities that they are used to doing. This social model of care is described here by the term 'household care'. Accommodation with 24 hour support is offered following an assessment of need for support, including a diagnosis of dementia. Co-residents live together in a small group. Firstly, the characteristics of these projects are noted, and secondly, the evaluative methods are reviewed.

#### *Domus units in London*

The *domus* developments were evaluated with the agreement of funding and management agencies from the point that they opened, enabling a cross-sectional and prospective evaluation. Two papers report outcomes for residents and staff (Lindesay *et al.*, 1991; Dean *et al.*, 1993) and the costs of the model are presented by Beecham *et al.* (1993). This is the most detailed British study. Two further *domus* projects in Scotland have to date not been rigorously evaluated.

The first *domus* unit was opened in London in 1987, with a further two following in 1989. *Domus* units were re-settlement projects, substituting for hospital and offering 'continuing care'. One was purpose built, including single bedrooms for twelve people, 4 shared toilets, 3 bathrooms, 2 living rooms, a dining room, and a kitchen. Another *domus* in converted hospital premises was unsatisfactory because, amongst other reasons, residents had to share rooms. *Domus* units have resident groups of between ten and 18 and staff have a nursing background. Like people in psychiatric hospital, residents are selected because they have disturbed and unmanageable behaviour. The *domus* units articulate a distinct philosophy.

Overall the emphasis is on maintaining residents' independence and residual capacities through active participation in the life of the *domus*. (Lindesay *et al.*, 1991:728)



Specific aims are that *domus* units should be a home for life, that the needs of the staff are as important as those of the residents and that residents' individual psychological and emotional needs may take precedence over physical aspects of care. The *domus* should seek to correct the avoidable consequences of dementia, averting deterioration where possible.

The first *domus* was managed and staffed by the NHS. There were 45.2 whole time equivalent staff for 32 patients. At the time of the first study, an occupational therapist aide assisted, and primary medical care was provided by a visiting general practitioner. A second *domus*, according to Beecham *et al.* (1993), had 18 full time care staff for 12 residents, at least one of whom was a registered mental nurse. Domestic and clerical staff were employed, and a volunteer worked part time. A general practitioner and psychiatrist both visited weekly and a psychologist supported staff.

### *French cantou*

*Cantou*, in local French dialect, means 'fireside' and the word is used to describe a form of non-medical communal care developed in France specifically for people with dementia which first appeared in 1968. *Cantou* were conceived as a cheaper alternative to hospital. Ritchie *et al.* (1992) were concerned not only to evaluate the contribution of *cantou*, but also to develop an appropriate methodology. Some developments that called themselves *cantou* were too dissimilar from the original model to be included in the evaluative study that used ten *cantou*, with a total of 110 residents. Unfortunately, little detailed information was given and neither the extent of this model in France nor the details of their design were noted. *Cantou*, ideally, should be self contained and administratively autonomous, with twelve to fifteen permanent residents and a stable staff group. Activities were revolved around tasks of daily living, with the aim that families should participate in *cantou* life and the autonomy and individuality of residents be respected. No information was given about how *cantou* were staffed, except that staff were generally less well trained professionally than their hospital counterparts.

### *Swedish gruppboenden*

The Swedish literature and experience are potentially particularly helpful in pointing to issues arising in practice but the research is sporadic and evaluation has been on a small scale. Wimo (1992); Malmberg and Zarit (1993) and Annerstedt (e.g. 1995) have reported on *gruppboenden* developed in different regions.

*Gruppboenden*, translated as 'group-dwellings', are small units of collective housing developed by local innovators in the 1980s as an alternative to institutional care for people with dementia (Johansson, 1990). Johansson and Thorslund (1991:126)



stated that the decision to establish new *gruppboenden* was taken virtually without any systematic or serious evaluation, but this model developed rapidly across the country, but developed more intensively in some areas than others. Sweden is the only country where care housing provides a substantial proportion of long-stay care. In 1987, an estimated 500 people lived in 50 *gruppboenden* (Johansson 1990:36); in 1989, Johansson and Thorslund (1991) reported that some 1500 people lived in 500 units. One prediction was that 25 000 of 90 000 people with dementia would live in *gruppboenden* by the year 2000 (Swedish National Board of Housing and Welfare, 1989, cited by Annerstedt *et al.*, 1993). *Gruppboenden* have been developed by both health and social services, but since reforms in 1990 all *gruppboenden* are administered by social services (Johansson, 1995).

*Gruppboenden* seek to offer high quality care to people with dementia, providing a 'home' with built in support services. These aims are consistent with Swedish policies of normalisation; in principle the units are specially designed and small-scale; staff are selectively recruited and given extensive training and support and are given authority and responsibility to organise the care. *Gruppboenden* have diverse designs and settings, ranging from mainstream housing, a part of sheltered housing, or a wing in a hospital. They may either be a cluster of apartments or a small group of dwellings with shared premises (Johansson, 1990). The residents always have their own bedrooms and frequently have their own bathroom and sitting area. The most generous amount of private space is described in Jönköping, where residents had their own kitchen, bathroom and patio besides a bed/living room (Malmberg and Zarit, 1993).

Malmberg and Zarit (1993) noted the emphasis on maintaining personal autonomy and competency and considered the following to be key features of *gruppboenden*:

a) creation of a familiar, home-like setting; (b) combining privacy of single apartments with the security of around-the-clock staff; (c) use of familiar household chores as activities for residents; and (d) staff serving as role models to engage residents in activities. (Malmberg and Zarit, 1993:683)

The ratio of staff to residents may vary from 0.5 per resident to 1.2, with an average of 0.9 (Johansson, 1990). Certainly before the 1992 reforms, care staff may have had either health or social care training (Johansson 1990). Malmberg and Zarit (1993) noted that staff were professionally qualified, usually having a basic nursing qualification.

### *CADE units in Australia*

Units for the Care of the Confused and Disturbed Elderly (CADE) were developed in New South Wales, Australia to supplement health service provision. CADE units are based on eight principles as follows. They are 'small', meaning a group of eight



residents; they are domestic; they are close to the community; there should be reduced extraneous stimulation; important stimuli should be emphasised; a simple environment is provided with 'total visual access' (meaning that you can see wherever you want to go from wherever you are); provision is made for planned wandering; and they should have familiar decor.

The need for economy of scale had meant that basic units of eight were doubled to provide 16 bed units, and latterly 32 bedded units (Fleming, 1991b). In Peppertree Lodge, designed by Fleming and Bowles (1987), the eight bedrooms were arranged around the sides, with a lounge and dining area in the middle and a fully equipped kitchen. The bedrooms were flexible so that couples could share if they wished, but were not built with en suite facilities. Staffing levels were based on those in psychiatric hospitals (Fleming, 1991b). The staff completed all duties in the unit except heavy laundry. In Peppertree Lodge, there were 18.5 staff for 16 residents. Two staff were on duty overnight.

CADE units were intended specifically for people with disturbed behaviour who presumably had not been successfully cared for elsewhere. If, however, residents of CADE units became physically frail, they were required to move into nursing homes.

### *The Anton Pieck Hofje in the Netherlands*

The Anton Pieck Hofje in Haarlem opened in 1989 and is an alternative to continuing care in nursing home consisting of six homes, each one for six people, arranged around a courtyard following a Dutch tradition of *hofjes*, which are equivalent to alms-houses (Schuijt-Lucassen and Leene, 1995). Front doors open on to a shared central courtyard where people can walk freely. There is a covered walkway around the courtyard passing by each front door and a single exit to the road outside. People are selected by clinical screening on the same basis as for psychogeriatric nursing homes, and according to the urgency of the case.

Anton Pieck Hofje was regarded as an experiment that could influence future substitution of care housing for nursing home care and has been evaluated from a sociological perspective as well as clinical and economic concerns (Plaisier *et al.* 1992; Plaisier *et al.*, 1995). Unfortunately, while this work is the most comparable to this thesis, the main report is in Dutch. The concept of 'warme zorg', literally translating as 'warm care', is central to this study.

The concept of 'warm care' for this group of people is meant to provide an environment in which people go on living much as they did in their own home before: in a small-scale setting which bears resemblance to the family setting. (Plaisier *et al.* 1992:xi)

Warm care consists of recognisable domestic surroundings, few rules and regulations, absence of means of coercion or restraint, and a non-medical attitude. This



concept depends on the argument that a disordered short memory explains anxiety and uncertainty in people with dementia, and in these circumstances, attachment behaviour is reactivated (see Miesen, 1992). A psychiatrist, Dr. Houweling, backing the project, proposed a 'safe protected haven' (translated term, Plaisier *et al.*, 1992:33) could reduce anxiety and uncertainty through the following characteristics. Contact should be maintained with a familiar neighbourhood that located the person in the present, and links them to the past. Surroundings should be recognisable and trusted, through being small scale, homely, with a stable staff-group and with residents taking an active part in keeping their own house, rather than having a structured activity programme. The importance of pets was asserted. Freedom of movement should be given through design. Finally, opportunity should be given for contact with families. De Boer, a psychologist involved in the project, contributed an insistence that residents are enabled to be themselves and that care staff offer support in this expression through observation and interpretation (1992:33, translated).

A full-time co-ordinator worked with a staff team of five (not all full time) in each of the 4 care houses, with leadership from a local nursing home. There was access to home-care services and district nursing, and to psychogeriatric and paramedical care from the local nursing home.

In summary, the aims of the care housing developments in the literature have been implied by the revival of archaic terms implying traditions of homeliness and share an ethos asserting household care. If 'home' is recreated, then diversity should be expected (see 2.3) and different designs reflect different traditions and climates. There are two main perceived benefits of household care: firstly, care houses are intended to retain residents' existing external links in keeping with normalisation goals and, secondly, residents live in an environment that can ameliorate symptoms of a condition that cannot otherwise be treated. Points of difference include location and design, some units being attached to larger administrative complex and others standing alone, even being part of mainstream housing. The amount and arrangement of private space varies. Except for Australian CADE units, care houses were planned at a local level by practitioners and service managers wishing to provide innovative care to meet a perceived need. Although this is not 'top-down' according to Baldock (1991), the aims have been professionally defined. Except for Swedish *gruppboenden*, care houses make a small contribution to long stay care; even in Sweden however, demand was unlikely to be met by the model's expansion (Johansson, 1995).

#### **2.4.2 Evaluative research into care housing**

The evaluative studies of care housing developments differ in methods used and outcomes investigated; comparison and generalisation of findings are additionally



difficult because the care houses varied in some respects in specific aims and design and also because the national contexts differed.

The basis of comparison should influence research design. Firstly, if reality is compared with ideals, a static, cross-sectional design at one point in time is reasonable; secondly, if changes over time are sought, for example by tracing an individual through a transition in services, longitudinal or retrospective designs are appropriate; thirdly a service may be compared with alternatives indicating a controlled study design (Wright *et al.*, 1994). The sparse evaluative studies of care housing developments have typically started at the opening date and been completed early on in the projects' history. Comparison with alternatives has been emphasised, rather than investigation of effectiveness or comparison of reality with ideals. Most studies have aspired to an experimental model of research, using, in the absence of control groups, matched samples of residents or at least cross-sectional comparison (Ritchie *et al.*, 1992; Lindesay *et al.*, 1991; Dean *et al.*; 1993; Wimo, 1992; Annerstedt, 1995). Malmberg and Zarit (1993) used a case study design, as did Plaisier *et al.* (1992), though the latter included cross-sectional comparison of dependency. The *cantou* study was most substantial, with a cross-sectional sample of 110 residents in 10 *cantou* and 242 hospital patients in 20 hospitals (Ritchie *et al.*, 1992). Otherwise studies have been small scale. Dean *et al.* (1993) had the broadest scope, measuring the social environment, activities and interactions, staff satisfaction, and cost effectiveness of two *domus* units. Plaisier *et al.* (1992) paid most attention to quality of care, investigating Anton Pieck Hofje as a place to live, as home, the relations between residents and relatives, the housekeeping, and care.

Outcomes investigated included clinical and functional tests, quality of care, satisfaction of staff and, sometimes, of relatives, and costs. The quasi-experimental designs required measurement of observable change in individual residents, with attention to clinical criteria, such as cognitive impairment, mental health, and ability to perform activities of daily living. These were used as outcome measures, with maintenance of function or improvement subsequent to the move being taken to indicate benefit. Socio-demographic factors, such as age, sex, and education, have been included for comparison with hospital populations and to find matched controls.

As section 2.5.5 will show, these studies have consistently found that the residents measurably have improved dependency characteristics, but the reason for this may be unclear and disputed. As the authors have pointed out, the findings need cautious interpretation. In a cross-sectional design, differences between the resident groups may be explained by diverse factors and explanation remains speculative. In longitudinal studies, the progression of dementia may mask improvements (Dean *et al.* 1993) and differences may exist between matched samples (Ritchie *et al.*, 1992). The evaluative studies have compared new care settings with psychogeriatric hospital care that is generally recognised to be impoverished and in need of reform, a strategy



rejected by Evans *et al.* (1988) and discussed in section 2.3.3. Consequently, any improvement noted may reflect the poverty of the previous setting as well the quality of the present one.

Little attention has been paid to whether care houses have effectively implemented their aims; none of the studies have sought directly to establish the residents' perspective and the extent to which individuals' needs and preferences have been met. Except for work by Plaisier *et al.* (1992), the process of care has been assumed rather than explored with consequent vagueness about which aspects of care housing make a difference and how.

In summary, the range of potential outcomes and the many possible factors that influence them have been assumed and have not been derived from the perspective of residents. The relationship between process and outcome has been little explored. Broader questions about access, equity and population impact have been left unanswered. It is very hard to draw comparative conclusions because of the great diversity in cases and lack of standardised methodologies.

#### **2.4.3 Staff satisfaction**

Points of difference between care houses include the degree to which staff were professionally qualified, the ratio of staff during day and night, and the use of existing community services. *Domus* units have the explicit aim of taking staff needs into account and hence satisfaction and psychological well-being were taken as outcome measures, with information on staff absenteeism and job turnover (Lindesay *et al.*, 1991). Satisfaction was found to be higher in the *domus* than in the hospital, but there was no significant difference for psychological well-being, which also applied also to staff absenteeism and turnover for the year preceding the study. In contrast, *cantou* staff were found by Ritchie *et al.* (1992) to have significantly higher work satisfaction and lower staff turnover rates than hospital staff, but this was thought to be explained by the fact that *cantou* staff were less well trained professionally and therefore had lower expectations.

Low rates of absenteeism and turnover were interpreted as a high level of commitment by Plaisier *et al.* (1992) who, from qualitative interviews, observed that the work could be arduous and boring and that staff had to strike a balance between maintaining distance and getting involved, but tended to lose distance. Providing warm care was said to make demands on staff and that the apparently unskilled demands to act naturally and create a normal home were definitely professional activities. The input of domiciliary services was valued, though the role of the GP and the management arrangements were unresolved at the point of evaluation. Staff in *gruppboenden* could both find the work stimulating, but also be exhausted and risk burn-out through caring



for frail and dependent residents in physical settings that had shortcomings (Johansson, 1990:36).

#### 2.4.4 Costs of care housing

Shiell *et al.* (1990) referred to a widespread acceptance, sometimes grudging, that an economic approach has a role in evaluating welfare services. There has been a shift in emphasis in evaluative research, from structure (that is resource consumption or costs) in the 1970s, to process and efficiency in the 1980s, and currently to outcomes, or the effect of process on health status (Harrison and Sheldon, 1994). Conventional evaluative work may have failed to address costs and conventional economic appraisal has failed to tackle outcome and effectiveness, but combining the two is an undeveloped art, and beset by difficulties and disagreement (e.g. Shiell *et al.*, 1990). It is relatively easy to assess the cost of providing a service as accounted by individual agencies, but more difficult to establish the distribution of costs and also the opportunity costs.

Beecham *et al.* (1993) compared the costs for individuals living in *domus* units to those in the hospital from where they came, using the Client Services Receipt Interview to examine the frequency and duration of the receipt of services retrospectively, adopting the production of welfare approach (see 2.8). Plaisier *et al.* (1992) likewise compared costs of those living in the nursing home which Anton Pieck Hofje was an immediate alternative to, using conventional accounting methods to assess total staff costs; food and domestic costs; general costs; medical and care equipment; land costs; and building costs.

These two studies provided conflicting evidence. The Anton Pieck Hofje was found to be a cheaper alternative to a conventional Dutch nursing home while *domus* care was found to be more expensive than hospital. Both studies concluded that the quality of care in the care housing development was superior to that provided by the service to which it was compared. Beecham *et al.* (1993) suggested that although *domus* care might be more expensive, it was worth it because it brought about better quality of life as established by Dean *et al.* (1993). In *domus* units, the significant component in both costs and quality of care was the higher level of staffing. Plaisier *et al.* (1993) urged caution because their findings did not indicate what the cost implications of extending the model would be and the implications for other services were not yet clear.

These findings are inconclusive and cannot be generalised. The services which are compared, the staffing ratio, and the standard to which the project is built may account for different answers. The consequences for the wider balance of care should also be taken into account.



## **2.5 Moves in and out of long stay care**

This section examines why people move to long stay care and argues that the impact of relocation depends on the circumstances of the move. Care houses may accommodate people who have substantial support needs and groups of residents may be broadly comparable with those in institutional alternatives. Observed clinical differences in matched control groups may either be a positive outcome or reflect existing differences between the populations. The impact and frequency of moves out of care housing developments have received little attention.

### **2.5.1 Moving to long stay care**

A move to long stay care, be it hospital or nursing home, is often at a point of crisis when someone living alone or with relatives can no longer cope. The older person may have little choice in this. Sinclair (1988:263) concluded that the idea of moving to residential care was usually someone else's; circumstances did not often permit informed choice, the majority of applicants were at best resigned or ambivalent about the idea, and only a minority made a positive choice. These circumstances are the opposite of those which Schulz and Brenner (1977, see below) considered could mediate the stress of relocation.

Given a widespread preference to stay at home in the community (see 2.3.2), a move to long stay care is likely to have been preceded by a struggle to continue at home (Wilkin and Hughes, 1987). Levin *et al.* (1989) identified practical, behavioural, interpersonal and social problems experienced by supporters of 150 confused older people living at home in contact with community services. Behavioural problems included incontinence, unsafe acts, night disturbance, sitting around between meals and a number of trying behaviours such as repetitious actions, losing or hiding things, restlessness, clinging, crying, odd or embarrassing acts, mistaking the supporter for someone else, being abusive or aggressive, or destroying things. Interpersonal problems included sadness in the change in the old person and a shift from interdependence to dependence on the supporter. Carers noted fewer positive personality traits compared to before the illness and an inability to hold a normal conversation. Social problems included the supporter being restricted in terms of quality and quantity of social contacts, holidays and leisure, and consequently feeling lonely. The strain may have been influenced by the degree and nature of the dependency, the health of the carer and the type of relationship, and could have been reduced by domiciliary support, day care and respite care. Possibly carers' attitudes to residential care predicted the move; a noteworthy finding was that a move into long stay care was the only intervention leading to significant improvement in carers' mental health (Levin *et*



*al.* 1989). Wells and Jorm (1987) established that psychological symptoms of caregivers could be reduced after a person with dementia moved to full-time care.

### **2.5.2 Relocation: effects and their causes**

The effects of moving in later life have been studied over the past thirty years, with specific attention to vulnerable older people being 're-settled' either between or to institutions. A recent study by Robertson *et al.* (1993) included 120 older people with dementia moving between hospitals in Aberdeen. Overall, the mortality rate before and after the relocation did not increase but where patients were most disrupted because the ward closed, there was a significant increase in mortality. Lyons *et al.* (1995) also recorded excessive morbidity following relocation from Glaswegian hospitals to nursing home care. Such findings are not unique (Schulz and Brenner, 1977) but are shocking especially if participants had been persuaded to make the move. Mortality and morbidity rates are pessimistic and blunt instruments by which to measure the effects of relocation: symptoms, disability, social patterns, and psychological and psychiatric states are more subtle outcomes to investigate. Researchers should be concerned firstly with the effects of relocation, secondly with the conditions under which they occur, and thirdly with the individuals involved (Lieberman, 1991).

Relocation research has conventionally taken a 'homeostatic' view of relocation: change, whether in previous functioning or in a control group, has been assumed to be negative, and the absence of change has been regarded as a positive outcome (Lieberman, 1991:134). Positive outcomes of relocation have been associated with people with specific personality characteristics raising the possibility of an 'enhancement model' of relocation; 'environmental discrepancy' should be taken into account meaning that the difference between environments can have a significant impact on individual's adaptation (Lieberman and Tobin, 1983, cited by Lieberman, 1991). An environmental measure, developed by these authors, took into account eleven dimensions: achievement, individuation, dependency, warmth, affiliation, recognition, stimulation, physical attractiveness, cue richness, tolerance for deviancy, and adequacy of health care.

Lieberman (1991) argued that differences in outcome should be assessed to understand the process and that it should not be assumed that effects are homogeneous. Characteristics which place individuals at risk or enable them to benefit from an enhanced environment, are not well understood. Characteristics of moves have been taken into account by researchers, whether between different kinds of housing, institutions, from home to institution, with attention to whether moving was 'voluntary' or not, and the degree of preparation. Nay (1995) drew attention to the relocation literature's concern with outcome, and the relative lack of knowledge about process. Interviews with nurses and people entering nursing home care indicated that even



where the move could be classed as 'voluntary', older people had felt they had no real choice:

They had lost everything and felt compelled, albeit for good reasons, into a situation and status that had no value. Consequently they felt devalued as individuals. They had come to the end of the line: there was no future, only the hope that those into whose 'care' they were going would indeed care. It was possible to reduce the impact of this experience by distancing themselves from it. (Nay, 1995:324)

The role of cognitive impairment in relocation is not well understood. Lieberman (1991) argued that cognitive impairment did not necessarily further impair ability to adjust to a new setting but discontinuity of physical environment is more often put forward as a particular problem for people with cognitive impairment (Regnier and Pynoos, 1992). This raises questions about the ability of people with dementia to learn. Wertheimer *et al.* (1992) reviewed re-educational work with people with dementia and concluded that learning was possible within an increasingly limited neurological infrastructure, but that social interaction between people with dementia facilitated this. Choice, the predictability of a new environment, and differences in how controllable the different environments are may be important factors in mediating the stress of a move (Schulz and Brenner, 1977). Drawing conclusions about the effects of relocation from research is very difficult because the circumstances in which studies have taken place preclude the use of randomised studies and matched controls, and because there is a lack of consistency between studies in theoretical models and methods used.

### **2.5.3 Entry and exclusion criteria of care housing developments**

Having asked why people move to long stay care and what the effects of this may be, this section notes the entry and exclusion criteria of care housing developments, which aim to provide an enhanced environment. This leads to a review of work on both moves in and out of these developments.

There is no information about selection criteria for *cantou* (Ritchie *et al.*, 1992). *Domus* units seek to provide a service for 'severely disturbed demented elderly people who cannot be cared for at home or in other public sector or residential care settings' (Lindesay *et al.*, 1991:733). People moving to Anton Pieck Hofje were the most urgent referrals made and met criteria for nursing homes. *Gruppboenden* are envisaged as 'an alternative for people with dementia who can no longer be maintained in other community settings' (Malmberg and Zarit (1993:682). Entry criteria vary between *gruppboenden*; extensive psychiatric symptoms, such as agitation and destructive behaviour or being physically frail and requiring constant assistance may be grounds for exclusion (Johansson, 1990:36). CADE units differ from both *domus* units and *gruppboenden* as they select people with disturbed behaviour but if they become physically frail, they are discharged into nursing homes.



The most specific exclusion criteria were articulated by Annerstedt *et al.* (1993) who identified people with certain causes of dementia, namely primary frontal lobe or vascular dementia who had uninhibited behaviour as a result, people with psychotic problems, and younger people with dementia through brain damage or the abuse of alcohol, as needing the skills of psychogeriatric services and not being suitable for group-living. It was preferred that people moved in while still mobile and able to understand verbal instructions, but they would need to move out if they were unable to communicate, could no longer assimilate the specific features of the group-living environment or otherwise need more care than the staff group could offer. Annerstedt (1993) reported that *gruppboenden* were estimated to be the best solution for between 12% and 24% of people with dementia. The *gruppboenden* could achieve better quality of care but concluded that this depended upon the selection of well diagnosed, homogeneous group of residents and the development and maintenance of professionalism in staff.

In short, some units have been developed to replace long stay hospital care and have to provide a home for life but other units target residents with specific problems or aim to help individuals avoid or postpone hospital care. Social and housing criteria are not explicitly identified despite the espousal of a social model of care: care housing articulates its entry and exclusion criteria on the basis of clinical criteria deriving from a medical model.

#### **2.5.4 The debate: a home for life?**

By defining who suits different care settings, the implication is that people may have to move between different types of accommodation (Age Concern Scotland *et al.*, 1992). There may be undesirable consequences.

A system which 'perfectly' matched care setting to behavioural characteristics would be frequently and inhumanely shifting patients from one 'compartment' to another. (Wattis and Fairbairn, 1996:164)

Should there be a classification of norms for provision? Dementia, being progressive, poses acute problems for a continuum of care. Believing that classification was nevertheless essential, the SHHD (1988) proposed that this should be as non-restrictive as possible to avoid the need to transfer residents frequently. Moves would still be necessary sometimes:

Where behaviour becomes aggressive and disruptive, long-stay hospital care becomes necessary. The presence of one seriously disturbed patient can have a very disruptive effect on residents and staff alike in group homes. (SHHD, 1988:48)



Bleeker (1994) raised the possibility that people may be moved to larger groups because the disruption of disturbed behaviour is felt more keenly in small-scale settings but may be dispersed between the larger group of residents and staff in nursing homes or hospital wards, though this is not necessarily beneficial for the person moved. He argued that when living conditions are normalised, deviations from the norm may be more disruptive than in hospitals but this was not based on research evidence.

Bleeker (1994) suggested that European experience showed that people who have multiple pathologies alongside dementia test the limits of social models of care that need the support of specialised medical and psychiatric facilities, albeit on a reduced scale. There is little discussion of the operation of exclusion criteria in care housing developments but the Swedish experience would seem particularly important. From a study tour in 1992 to Uppsala and Sundsvall, I encountered different opinions about whether residents should be asked to move out or not. One view was that rigid criteria were inappropriate and decisions should be made according to what any unit could cope with at that specific time. Elsewhere, it was asserted no-one should be asked to move out as this could only be for the benefit of staff.

### **2.5.5 Outcomes: the effects of moving into care housing**

While differences in the entry and exclusion criteria may influence the characteristics of the residents, there has been no comparison between different care housing developments and each study has used a different measure.

Looking at *cantou* residents, Ritchie *et al.* (1992) followed a cross-sectional study by matching 27 residents with hospital patients according to age, sex, education, associated pathology, and degree and type of dementia. They were followed for assessment of clinical dementia rating, degree and type of cognitive deficit, depressive symptoms, associated pathologies and medication, and functional capacity. The latter was measured specifically by independent functioning for activities of daily living, physical capacity, communication skills, occupation and social functioning.

The cross sectional study found that residents were comparable with hospital patients for age and length of stay but in *cantou* there were significantly more female residents (85% rather than 80%) and a significantly lower mean age (81.3 years compared to 85.3 years). In both settings, Alzheimer's disease accounted for most moves in, but there were significantly more people with vascular dementia admitted to hospital, with associated cardio-vascular and neurological problems. Whereas 41% of *cantou* residents came from their own home before the move, this applied to only 11% of long-stay hospital residents. There were further significant differences in cognitive and behavioural characteristics: *cantou* residents had significantly fewer depressive symptoms and this may have led to better performance in the test for constructional apraxia. *Cantou* residents had relatively better receptive language scores. These



findings were found not to be related to the different kinds of dementia found in the two settings. Significant differences occurred on all areas of the functional capacity examined in *cantou* residents but this was found to interact with level of dementia. *Cantou* residents were found to be more mobile six months after they had moved though this diminished over time. The follow-up study found no difference in the degree of dementia between matched controls after one year with the possibility that the previously recorded differences between populations were due to the characteristics of the residents rather than the environment. The authors argued that their findings showed that the relatively better functional capacity of *cantou* residents, compared to hospital residents, diminished as dementia progressed. Despite the impression given by the above data and reports by relatives, the authors advised caution in concluding that *cantou* benefit residents.

Lindesay *et al.* (1991) compared *domus* residents with psychogeriatric hospital residents for diagnosis, cognitive impairment, level of depression, and impairment in functioning in self care, mobility, mental and social function. The two populations were found to be comparable for age, time in long stay care, mean levels of cognitive impairment and depressive signs. However, *domus* residents (who had moved from hospital) were rated by staff as less functionally impaired in self care, communication and orientation. Dean *et al.* (1993) made a subsequent prospective study, where residents were used as their own controls. In *domus A*, which accommodated people with dementia, patients' cognitive impairment decreased rapidly within 3 months of the move. The authors suggested that communication abilities improved because residents had more attention paid to them. Some residents, who had been mute and could not be rated while in hospital began to speak when *domus* staff made the effort to understand them; one spoke for the first time in five years within a week of moving to the *domus* (Dean *et al.*, 1993:815). The authors believed that such rapid and significant improvements indicated that traditional institutional care worsened existing cognitive impairment and that this could be changed by an improved social environment. *Domus* residents had reduced depressive signs and modest improvements in daily living skills, which were explained by the possibility that staff allowed residents sufficient time to complete tasks such as feeding and washing. The fact that these changes were less dramatic than suggested by the earlier cross-sectional study was explained by the progression of dementia.

Anton Pieck Hofje was found to be providing care for its target group, but residents needed less care, and had fewer behavioural problems than comparable residents of psychogeriatric nursing homes. Annerstedt (1995) compared 28 residents in *gruppboenden* to a sample of 1040 hospital patients, matched on age, diagnosis and level of dementia over three years. Changes in behaviour and practical functioning were less prominent in *gruppboenden* in the first year and emotional functioning improved. These positive results were more evident for people with Alzheimer's



disease than those with vascular dementia. However, after three years, as at the outset, there were no differences between the two groups for function in activities of daily living, clinical assessment of dementia severity, or survival time. The positive results were explained by the better physical environment and staff training offered which was thought to increase the security and self esteem of residents.

These studies are consistent in finding that residents of care housing developments may have improved dependency profiles compared to hospital patients. That changes are reported following a change in environment is consistent with contemporary psychosocial therapeutic priorities, and a biopsychosocial view of dementia. Studies have neglected comparison of the environments from where individuals moved, the process of the move, and differences between individual outcomes. Ritchie *et al.* (1992) explained positive differences by the population characteristics, while Dean *et al.* (1993) tended to explain the data by good quality of care. All work suggests that if positive changes occur, they are most visible within a short period after the move, and tend to diminish over time. One possibility is that instruments used to measure change in severity may be less sensitive in later stages (Ramsay *et al.*, 1995). Residents may have been worse off if they were transferred to hospital wards and this could not be tested.

#### **2.5.6 The outcome: a home for life?**

If care housing developments are to provide a home for life, then staff and residents have to adapt to people who may become very physically frail, or have developed very disturbed behaviour. No study has specifically investigated moves in and out of care housing, but evaluative research has examined the effects of the move as an outcome measure, and has noted resident turnover. *Cantou* residents stayed on average 2.4 years which was not significantly different to hospital patients (Ritchie *et al.*, 1992). *Domus* residents had a median length of stay of 37 months, with an inter-quartile range of 24 to 29 months, calculated from the first move into any psychogeriatric hospital (Lindesay *et al.*, 1991). By 1993, all the first sample of *domus* residents had died (Dean *et al.*, 1993). There was again no significant difference in length of stay compared to the hospital sample. Over four years, 8 of 16 residents of *gruppboenden* in Sundsvall had died (Wimo, 1992). Of the 8 who were still alive, 4 had moved from *gruppboenden* because of their aggression, presumably to hospital. Those who had died spent either no time in hospital or only short intervals. In Jöngköping (Malmberg and Zarit, 1993), four homes accommodated 40 residents altogether. After one year, 36 still lived there, 2 had died, and 2 had moved elsewhere because of behaviour problems. On follow up at four years in 2 homes and 5 years in the other two, 12 of the 40 original residents still lived in *gruppboenden*. Ten had died as residents and 18 had moved; according to retrospective accounts this was mainly



because of declining health and mobility but with a smaller number moving because they could not be managed in *gruppboenden*. Annerstedt (1995) found that after three years, 4 out of 28 residents remained in *gruppboenden*, having lived there for a median of 20 months.

In Anton Pieck Hofje the aim that people would not be discharged was achieved in almost all cases (Plaisier *et al.*, 1992). Within the first 18 months of opening in April 1991, two of the 36 residents had moves out. Interview data suggested that one woman had been admitted at the age of 65 after a difficult life, in the belief that dementia was the main problem. She did not settle in with the other residents, which staff related to the presence of psychiatric disorder and had recommended a move to more structured psychiatric hospital. Another resident moved in when relatively young (68) and at first her behaviour problems of restlessness, anxiety, repetitive questioning, and shouting and screaming settled. However, alongside physical problems, her behaviour deteriorated and was not successfully treated with medication. Residents and staff were tested by her, and eventually she moved to a nursing home. No-one had had to move because of an increase in support needs but still the researchers believed that these two cases had implications for selection. Possibly capacity depended on the tolerance of the residents in a particular house. After four years of operation, with 36 places, 33 people had died as residents and five had moved (Plaisier *et al.* 1995). The average length of stay was about two years.

These findings should be seen in context: generally, the proportion of people dying in hospital or institutions is currently 75% of all deaths and this proportion is rising (Johnson, 1995). Netten *et al.* (1995) attempted to predict length of stay in residential care for the sake of financial planning by following a sample in one home. Their findings indicated a sub-group were in the process of dying at the time of the move and at the outset survival and length of stay could be predicted.

In summary, section 2.5 has shown that a move to long stay care may often be harmful to old people. Clearly the causes of these effects are multi-factorial, and a move may have therapeutic effects. Evaluative research findings into care housing developments are consistent with this latter possibility though it is far from proven. Insufficient attention has been paid to the process of the move, environmental discrepancy and individual differences. Moves out occur in some care housing developments; their implications have not been addressed.



## **2.6 Activity: a dimension of quality of care**

A positive relationship between activities and well-being for people with dementia is widely assumed and inactivity is often associated with institutional care. This assumed relationship underpins the principle of household care but the nature of activity in domestic settings and the success of household care is little understood.

### **2.6.1 Activity as beneficial**

Current approaches to dementia care implicitly reject disengagement theory (Cumming and Henry, 1961) which suggested that in preparation for death, ageing individuals progressively detach from their relationships and activities. The opposing argument that successful ageing requires maintenance of the activity and values of middle age into later life has been described as idealistic and unrealistic, given biological changes and socio-economic structural constraints (Bond *et al.*, 1990). Hughes (1990) suggested that 'purposeful activity' is a component of good quality of life.

For people with dementia, constructive activity is thought to be helpful in a number of ways, such as to assist assessment, behaviour management, maintaining and enhancing well-being in terms of self-esteem, confidence and social interaction but despite this may be a neglected aspect of care (Archibald, 1990). 'Occupational need' has been identified as particularly acute for people with dementia who have been progressively affected by loss of paid work, leisure interests, changing relationships, and diminished ability for self care (Perrin, 1996). Evaluative research may measure levels of activity to discriminate between the quality of care in different settings. 'Engagement' is taken as a positive state, meaning 'interaction with people or materials in a manner that is likely to maintain or develop adaptive behaviour' (Wright *et al.*, 1994:88). Its measurement has been developed for people with learning disabilities, and applied to services for older people (Bond and Bond, 1990).

### **2.6.2 Being active at home?**

Community care legislation is underlain by the assumption that promoting independence at home is a core aim of welfare services. Taking part in everyday and normal activities of ordinary living at home is part of the ideal of normalisation. For example, Mansell *et al.* (1984, citing a previous paper of 1982) asserted the advantages of involving residents with learning disabilities in household activity, consisting of tasks the staff needed to do anyway, if this were adjusted to a level that suited individual residents. This was thought an improvement over more artificial recreational activities.



Such activities may be individually more rewarding for people living in the home if they involve more control over their environment. Staff may also find them more meaningful than occupational activities and may be more likely to maintain them. In addition, housework in the home meets the goal that the handicapped person is presented in activities and settings which are culturally normative or valued in the sense described by Wolfsonberger (1980). (Mansell *et al.*, 1984:23)

The assessment of older people's dependency may centre on their functional ability in personal care and the instrumental activities of daily living (see Kovar and Lawton, 1994). The latter have been defined as ability to use the telephone, shopping, food preparation, housekeeping, laundry, transportation, administration of medication, handling finances (Steele, 1994, adapting Lawton and Brody, 1969).

### 2.6.3 Being Inactive In Institutions?

The degree to which people in institutional care can control their own daily timetable, the degree to which it reflects their choices, and the flexibility of scheduled activities have been regarded as an aspect of quality of care (Lidz *et al.*, 1992). Observation suggested that patients who were 'moderately to severely demented' in long stay care had their daily routines highly structured by the staff, in contrast to other residents who could largely spend the day as they liked. Staff tried to persuade residents to join in activities, arguing that it would be beneficial which was interpreted as a conflict between beneficence and autonomy values (Lidz *et al.*, 1992, citing Collopy, 1986) with the irony that activity was being promoted to enhance capacity for autonomy. According to Kitwood, Buckland, and Petre (1995), staff should provide a structured, but not rigid, daily routine for residents with dementia, based on individual needs and preferences. Being left to their own devices is not necessarily conducive to well-being of people with dementia, especially for those most cognitively impaired who, it was stated, lose power of independent action.

Residents of psychogeriatric wards have recently been found to be inactive, or engaged in purposeless or inappropriate activity for most of the waking day (Bowie and Mountain, 1993). Earlier studies made the same point, for example Macdonald *et al.* (1985) found that residents in hospital and residential care spent 63% of the day sitting without talking to anyone. Lidz *et al.* (1992) described the rigid schedule in a North American hospital where patients were all roused at the same time each day to eat an early breakfast, had lunch at midday and the schedule was then reversed for patients to eat before bed. Patients with the most marked dementia 'spent their days in the lounge with the TV blaring' (Lidz *et al.*, 1992) while others might have the choice of how they spent the rest of the day, between meals. Observational methods have been developed to compare quality of care in different settings by examining both activity and interaction (e.g. Godlove *et al.*, 1982; Robertson *et al.*, 1995). Brooker (1995) reviewed those methods applied to people with dementia, including the instruments referred to in the



next section, but the difficulty of examining quality of life for people who have cognitive impairment is often raised (e.g. Ritchie *et al.*, 1992; Dean *et al.*, 1993).

#### 2.6.4 Quality of activity and interaction in care housing developments

In the study comparing *cantou* to hospital residents, Ritchie *et al.* (1992) proposed that the interaction of the person with the environment was the important focus of attention. An observational method was developed and used on a matched sample that recorded both frequency and duration of communication of each individual as well as walking, including both goal-oriented and aimless wandering. In addition, indicators of poor quality care were identified and recorded, including familiar or pejorative address or physical stigmata such as ungroomed or inappropriate appearance. As the researchers acknowledged, these could only be crude indicators of well-being, but interesting differences were found between the populations. *Cantou* residents communicated with other residents more frequently, although this did not apply to communication with staff or visitors. They moved around more, and this was independent of capacity to walk. They did not, however, spend more time on domestic tasks, despite this being an activity that *cantou* intended to encourage. The absence of subjective assessment meant that one does not know whether this was the residents' preference. *Cantou* residents did spend more time in group activities and less time in their rooms than their hospital counterparts. Although residents of hospitals and *cantou* were equally likely to be addressed in the familiar or a pejorative way, instances of 'stigmata in physical presentation' were confined to hospital care. From this, it appeared that *cantou* could offer benefits of increased interaction between residents, increased mobility and decreased bedsores as a result, and an increased amount of time in group activities. Frequency or duration of communication with staff or visitors and the amount of time spent in aimless wandering were not influenced.

The first *domus* study (Lindesay *et al.*, 1991) used the Short Observation Method (SOM, Macdonald *et al.*, 1985) to record the activity of residents according to 10 codes, in a one hour period before lunch, which was compared to the hospital sample. Interactions with staff during this time were also recorded. The *domus* was better than hospital wards, where the residents had moved from, in that residents were more active (they spent less time sitting down) and in that there was more frequent interaction with staff.

The Quality of Interactions Scale (QUIS), developed for use in the *domus* prospective study, addressed the quality of staff-resident interactions (Dean *et al.*, 1993). In reliability tests, concordance was lowest for neutral interactions and highest for positive social interactions, but satisfactory overall. This time-sampling method was used across the entire working day, over a two week period, and details of verbal interactions involving residents were later classified into categories developed by Clark



and Bowling (1989). Compared to the baseline observation in a hospital ward, three months later in the *domus* there were significantly more interactions and this was most noticeable during morning and afternoon periods between meals. In terms of quality, the greatest changes were that there was a decline in 'negative' interactions and negative interactions became more 'protective' and less 'restrictive' over time. There was a decrease in interactions classified as 'neutral' and an increase in those classified as 'positive'. The conclusion was that both *domus* units provided greatly improved social care in the first year of operation, at least for the quality of interpersonal interactions as recorded by QUIS.

Macdonald *et al.* (1985) found mealtimes were the only time of day when activity was increased and suggested the pre-lunch hour was representative of the activities observed; further indication that the time of day may influence activity level was supplied by McFayden (1984, cited by Brooker, 1995) who found that people were least active after lunch, but that individuals were consistent in their level of activity whenever observed. Dean *et al.* (1993) however concluded that the assumption, made by Macdonald *et al.* (1985), that the pre-lunch hour could be taken as representative was not true for *domus* units, where residents were more active.

### **2.6.5 Mealtimes**

Not only is eating vital for life, but how meals are taken can be of symbolic importance and demonstrate much about social relationships. For people with dementia, Malone (1996) summarised the literature on environmental effects on eating behaviour in institutional care, noting interventions intended to counter changed eating habits and to promote mealtimes as sociable and pleasurable occasions. That eating habits may change in dementia is well established; people may eat both more and less, and develop different tastes and disturbed eating patterns (Morris *et al.*, 1989). Adams and Gilloran (1996) suggested that mealtimes in institutions may be grim affairs with a lack of attention to social care. Malone (1996) emphasised that environmental factors can be manipulated to maintain skills despite the progression of dementia, in alliance with the view that the promotion of personal household skills and activities is an important part of the role of staff.

### **2.6.6 Preferences and differences**

The missing dimension in the assessment of activity described above is knowledge and consideration of what is normal and preferred by older people. The observation instruments for people with dementia described by Brooker (1995) used group aggregate scores and did not tune the observation to evaluate what was appropriate for that particular individual on that particular day. As Baldwin *et al.* (1993)



pointed out, the important finding that patterns of inactivity in residential care can be predicted from behaviour before the move (see 2.3.2) has not been followed up by research into what happens at home. There is little information about the way that older people with dementia use their time, space and facilities when at home and how this may change with time.

Individuals develop different types and degree of skills over their lives. Broad social divisions may be reflected in the work that people are used to doing in the home, for example, a gender difference in household work is well recognised. A consistent finding has been that housework takes fifty to seventy hours per week per household, but men undertake very little of this compared to women who, it may be expected, do this for love (Leonard and Speakman, 1986). For men who return from paid work outside the home, the home is not a work-place and they may well go out to socialise, while for housewives, the home is both where most work and most leisure takes place. While men may be used to having longer periods of time off paid work, for women, leisure may be something snatched for brief periods (Leonard and Speakman, 1986). Of course, unemployment may change this pattern, as does retirement. For women, housework is something to be endured rather than enjoyed, according to Oakley (1985), who found that 70% of housewives were dissatisfied overall with housework, finding it low in status, monotonous and lonely. The experience of autonomy could provide some compensation, with satisfaction potentially derived from keeping to self-imposed routines and standards. The experience could also be improved by being able to talk to others, having enough time and the setting. Working class women were reportedly more closely involved in the role and identifying with this role led to higher standards; women with higher status work outside the home were all dissatisfied with housework (Oakley, 1985).

In summary, being active, and purposefully so, is a current emphasis of policy and practice. There has been too little attention to individual preferences for activity, how activity compares between home and long stay care settings, and how it may change with dementia. Patterns of activity have been developed over lifetimes and reflect circumstances of gender and social class as well as personal preference. Housework, conventionally done by housewives, is low in status and unpopular. As Bond *et al.* (1989) pointed out, in institutional care there may be little to choose between enforced activity and enforced inactivity.

## **2.7 Social Interactions: living in pragmatic groups**

The literature already reviewed strongly suggests that aspects of the social and physical environment may have a substantial influence on both the behaviour and well-



being of older people and especially those with dementia who are less able to adapt. This section addresses the interactions and development of relationships of people with dementia in 'pragmatic groups' such as care housing. It is argued that relationships in group living are an important, but neglected, aspect of quality of care.

### 2.7.1 People with dementia in groups

Therapeutic groups are convened to support participants engaging in a psychological treatment. The term 'pragmatic group' is used here to describe the more common situation, when people with dementia are brought together to receive care, such as day care, medical assessment, respite for their informal carers, or residential care, because they share a need that is professionally defined. Pragmatic groups give care collectively, presumably because this is cheaper and easier to organise than delivering it to individuals at home. Members of pragmatic groups are unlikely to have either the choice of whom they share with or who cares for them and have to spend time with 'erstwhile strangers' (Willcocks et al., 1987:2). It is generally very unusual for older people to live with non-relatives.

Hence the shift to residential living with strangers is essentially alien and may demand substantial adjustment from a group which is ill-equipped to respond. (Willcocks *et al.*, 1987:3)

There is a considerable psychological literature on people in groups, and the group dynamics of residential care are well set out by Douglas (1986) who does not consider specifically the impact of cognitive impairment on group relations. Living as a group in supported accommodation has been investigated for people with mental health problems (Pritlove, 1985; Petch, 1992) and people with learning disabilities (Malin, 1983). This work raised the issue of compatibility of residents; for Pritlove (1985) this outweighed age, sex and diagnosis as a factor to take into account when assessing whether someone should move in and he argued that existing residents should be involved in the decision. Petch (1992) pointed out that few people in supported accommodation have the privilege of deciding who they live with. Petch's study suggested that it could not be assumed that living in close proximity engendered commitment; living in groups as small as three could be difficult, particularly if space was limited, if people did not know each other already or had not been selected carefully. A larger group of five could allow people to withdraw if they wanted. For Malin (1983), it was important that people with learning difficulties should be encouraged to be interdependent and that co-residents' skills and personalities should be complementary. An ongoing and central question for staff was when to intervene to promote independence and integration and prevent decline (Pritlove, 1985).



Some research has considered people with dementia in therapeutic groups (e.g. Bleathman and Morton, 1994) but the more common pragmatic groups have received little attention. Evaluative research findings about interactions between residents and staff were noted in section 2.6. Generally in long stay care, residents have been found to spend large amounts of time sitting in public space in each other's company and relatively small amounts of time interacting with staff (McGlew *et al.*, 1991). People with learning disabilities have also been found to spend less time in therapeutic, educational or recreational activities in hospital than in other settings (Baker and Urquhart, 1987). Interactions between residents should be examined as an equally important facet of quality of care, being one of the determinants of residents' experience suggested by Sinclair (1988, see 2.2.3). The way older people get on together has been studied (e.g. Jerrome, 1992; Okely, 1990) and used as a measure of social environment (Moos and Lemke, 1984) but has not been investigated in any detail in care housing. According to Kitwood, Buckland, and Petre (1995), social contact per se is not directly associated with better well-being (as indicated by DCM), but may be more marked for those with good friendships with other residents than for those with frequent but poorer quality contact. This finding led to the recommendation that staff should promote maximum contact between residents and visitors, while helping with relationships that residents found distressing.

In residential care, group-living was promoted during the 1980s to mitigate the impersonality of living in institutions (Booth and Phillips, 1987) but results were disappointing in that tensions were reported by both staff and residents. Relationships have been studied between lucid and confused residents in the context of the capacity of residential care to support people with dementia. Evans *et al.* (1981) concluded that there was a limit to which residential homes could accommodate people with severe dementia, taken to be 30% of the total. Since residents' needs are likely to change over time, it has been argued that all types of care should be equipped to deal with a broad range (Wade *et al.* 1983); the result of either approach is that residents have to adjust to others different to themselves. People with dementia can be less popular in 'mixed' settings, for example lucid residents may tend to favour segregation, though this may depend on their personal characteristics (Willcocks *et al.*, 1987). Allen *et al.* (1992) asked a sample of 101 older people without dementia in local authority and private homes what they thought of other residents. For those who were unhappy about living with others, an important reason (mentioned by 14% of the sample) was that other residents were confused. From other literature reviewed (see 2.1 and 2.5.1) on the impact of dementia on individuals and the difficulties of their relationships with informal carers, it is evident that dementia diminishes ability to sustain mutually satisfying relationships.

Following a study focusing on friendship between residents, Reed and Payton (1995) suggested that confused residents may be befriended by lucid residents as an



altruistic act that served to distinguish the helper from the confused. Work in care homes addressed a gap in the literature about social relations between residents, and challenged the view that residents are passive within the residential environment. It was found that residents were concerned to respect and guard privacy, but mutual support and development of friendships were an important feature of residential life (Reed and Payton, 1995). The nature of social relationships at home and in residential care was mentioned in 2.3.2.

Lindesay *et al.* (1991) noted that higher levels of interaction did not in themselves mean improved quality of care, but might instead represent an invasion of privacy. Annerstedt *et al.* (1993) proposed that specific clinical criteria, associated with the progression of dementia and specific kinds of dementia, can predictably interfere with one's ability to fit in a group. Plaisier *et al.* (1992) described the development of supportive friendships between residents of a care housing project. My own previous work has suggested that clients at a 'Drop-in Centre', which included both people with dementia and their carers, could benefit from meeting others with dementia in a setting where memory problems were understood and accepted (Foster, 1991).

### 2.7.2 Group size

Cohen and Weisman (1991) argued that organisational and architectural design should make people with dementia feel part of a 'small' group, that is between eight and 16 people; Marshall (1993) argued that when groups are larger than eight it is questionable whether this can still be called 'small scale'. A principle of group work theory is that eight promotes maximum interaction (Preston-Shoot, cited by Marshall, 1992). A high ratio of staff to residents, with consistent staff contact, may also be important.

Smaller group sizes can make group living more manageable for people with dementia as anonymity is reduced. Such a non-institutional and family-like environment could encourage more visitation by family and friends by allowing the establishment of social ties between unrelated families of residents who might belong to the same small group or 'household'. (Cohen and Weisman, 1991: 46-49)

For care housing developments, the smallest group reported is in Jönköping, Sweden, where five people share a common living area (Malmberg and Zarit, 1993). This unit was twinned to another of the same size, enabling groups to be kept small but staff to be part of a larger management structure. *Gruppboenden* are usually between 6 and 8 in size (Johansson, 1990). The largest care house in the literature is the first *domus* unit in London, which was larger than envisaged by the developers with 32 residents, and is exceptional. *Domus A* which was built later had 12 residents, making it comparable with *cantou*, which have 12 to 15 residents.



In summary, evaluative research in care housing developments has concentrated on the nature and frequency of observed interactions between staff and residents, with less attention to the development of relationships between residents. The absence of subjective assessment means that it cannot be assumed that increased interaction indicates better quality of care or resident well-being. Arguably, a smaller group size and staff input can promote the development of good relationships between residents, their relatives, and staff but at the same time, communal living may be particularly demanding for people with dementia. Groups may be convened for pragmatic as well as therapeutic reasons. Existing work on group dynamics, residential care and supported accommodation for other client groups needs to be extended through the exploration of interactions and relationships between residents with dementia.

## **2.8 Care housing and evaluative research**

The themes in the literature have been summarised in each section and will be returned to in the following chapters. The work reviewed has implications for evaluative methodology, some points noted already in 2.3.3 and 2.4.2. Different approaches to evaluation reflect ideological positions that may be in conflict. This section considers contemporary debate in evaluative research and summarises the themes relevant to the design of this study.

Effectiveness may be defined as achieving predetermined objectives and efficiency as doing so at the lowest possible cost; one view is that evaluation should be about effectiveness and efficiency, being 'an examination of the objectives of service provision, how well these objectives are achieved and at what cost.' (Wright *et al.*, 1994:10). As these authors note, it is very important to specify and agree the objectives by which effectiveness is assessed. Cost effectiveness can be taken as the 'ratio of financial inputs to units of some concept of outcome' (Harrison and Sheldon, 1994:260). A model of the production of welfare contributes a method of identifying relationships between inputs and outcomes (Davies and Knapp, 1981; Challis and Darton, 1990; Wright *et al.*, 1994). This model depends upon making an analogy with industrial production (Shiell *et al.*, 1990) and is a development of the distinction between structure, process and outcome (Donabedian, 1980) that conventionally underlies evaluative research. Economists assume that inputs, that is of labour and capital, combine to produce outputs, that is, goods and services (Knapp, 1984:24), which may be extended to include quality of life and other benefits derived from residential care (Davies and Knapp, 1981:4). Noting the complex situations empirical work has to take into account, proponents stated they did not seek to reduce the many inter-relationships between outcomes and costs, nor to supply summary formulae; the relationship



between input and output can be suggested only at a very general level (Knapp *et al.*, 1992:55). Ideally, the production of welfare model is able to test the relationship between specific inputs and outputs using a large sample and multi-variate analysis. Shiell *et al.* (1990) observed that for residential care, in economic terms the act of production and consumption are hard to separate, meaning that process and output are merged. The model of production of welfare may neglect the organisational context, the process, and the value attached to services received and hence should be used to complement qualitative methods (Shiell *et al.*, 1990).

A production of welfare model demands that care housing developments be conceptualised as closed systems. The approach that has become known as systems thinking was described by Angyal (1941) who argued that although scientific thinking consists largely of the logical manipulation of relationships, this is inadequate to describe wholes. Sayer (1992) argued that there is a temptation, which is a fallacy, to break a complex object into its constituent parts in order to understand it. A realist perspective in social science, according to Sayer:

... reflects upon the conditions which must hold if regularities are actually to occur, that is, it asks what a system and its constituent objects must be like for regularities to be produced. (Sayer, 1992:122)

Regularities can only occur if there is no change in the system nor a change in the relationship with the system and its external conditions. When precise and enduring regularities cannot be elucidated, the field may mistakenly be regarded as immature. Instead social science needs to recognise that the characteristics of human activity and learning leads to open systems. Social sciences have preferred to avoid dealing with open systems in two ways: firstly by recognising multiple causes but assuming that any irregularities are the combined effect of separable regular processes. Alternatively, as in economic theories of equilibrium, the system can be assumed to be closed. If you look at a slowly developing system for a short enough time, this assumption may not be challenged (Sayer, 1992:125).

The literature review so far has indicated that current approaches to dementia care emphasise the characteristics of the environment, particularly the social environment, which is reflected in the emphasis of this study. Care housing developments aim to provide, through support within a household, an enhanced environment. There is at least a theoretical possibility of dementia, that is improvement of symptoms, following a move to an enhanced setting, but this is very difficult to establish given the unpredictable, but progressive nature of dementia.

Care housing developments ambitiously seek to improve quality of life, which is a complex and multi-dimensional concept, best appraised subjectively. In the same way, 'homeliness' combines a number of ideals that may vary individually and culturally. Following the environmental docility hypothesis (Lawton, 1982), as people age and



develop dementia they become more dependent upon their environment. Consequently physical and social environment may be relatively more important in determining quality of life, though environment remains but one factor amongst several (see 2.3.1).

Identifying outcome depends upon distinguishing which aspects of quality of life and the experience of dementia may be influenced by improved quality of care. The concepts of well-being, quality of care and quality of life are separate, but evaluative methods may investigate the first two as a proxy for the latter. Quasi-experimental studies have sought to measure dependency characteristics and to compare quality of care with institutional alternatives, but the process of care and potential differences between individuals have been neglected.

In summary, drawing comparison is at the core of evaluation: the possibilities include drawing comparison between different services' performance; investigating discrepancy between stated aims and performance, either for the projects as a whole or for specific residents; a pluralist approach comparing perceived success between different interest groups; drawing comparison with specific guidelines for service provision; and finally (adopting a normative approach) looking to wider social values.

The wider political and economic context suggests multiple, and conflicting, influences on care housing developments. This study took the position that in evaluating care housing, success had to be recognised as a plural concept. Ideally the experience of people with dementia should be held central in evaluative comparison, but for practical reasons this may have to be derived indirectly. The selection of research questions and evaluative methods is the subject of Chapter Three.



**CHAPTER THREE**  
**THE RESEARCH STRATEGY**

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Chapter Three presents the methodology selected to address the research questions. Each method is presented in turn, with a review of strengths and weaknesses. The chapter ends with a discussion of the research strategy of the study as a whole.

### **3.1 The research questions**

The study aimed to evaluate care housing for people with dementia, considered to be an innovative service whose aims were consistent with contemporary views of how good quality long stay care should be developed. Contact with the three case studies existed at the start of the study, which indicated that participants were learning how to implement the aims of care housing and what the capacity and limits of the model was, while the external context was changing and outwith their control. In the context of the extended implementation of Community Care legislation, considerable uncertainty and insecurity was evident about the case studies' own survival as well as the development of further care houses. In these circumstances, it was important to identify research questions that would be of enduring and wider interest. They are:

1. What were participants' hopes and expectations of care housing and how did they perceive its success ?
2. Did care houses offer a 'home for life', and if so for whom?
3. What were participants' perceptions of homeliness and to what extent were care houses perceived as homely ?
4. By what process was household care implemented, and how was this reflected in residents' activities and well-being?
5. What was the nature of group-living for people with dementia, and what factors influenced the way that residents interacted with each other?

This study explores the implementation of this model of care in three case studies, and suggests factors contributing to both success and constraints. In addition, the study sought to review methodologies suitable for the evaluation of a complex and constantly changing area of investigation.

### **3.2 The research design**

The research questions required both qualitative exploration and structured confirmation of effectiveness of outcome. In brief, the design appropriate to these questions was a naturalistic enquiry using multiple methods and multiple case studies. Three care houses were taken as case studies. A pluralistic view was obtained from



semi-structured interviews with kin, staff and agency representatives, which gathered data on the process of care, as well as hopes and satisfaction. This qualitative and contextual data about success was triangulated with cross-sectional structured observation of residents' activities and well-being, together with field notes. Data about moves in and out of care housing and characteristics of the resident population were obtained, respectively, by use of postal questionnaires to all existing Scottish care houses and dependency assessment of case study residents.

### **3.2.1 Multiple case study**

The three first care houses to open in Scotland provided opportunistic, self-selected case studies. Each care house was an organisational entity. At the core of the organisation were the residents and staff. Relatives and other visitors, including formal care providers and managerial staff, were peripheral to the staff-resident group. Each care house existed within a complex infrastructure with a network of agencies supporting its development, funding and management. The care houses were in different administrative regions, and were portrayed as having actual or potential links to the 'community'. The care houses were natural settings, in that they were not established for the purposes of the study and I did not seek to control any aspect of their operation (Judd *et al.*, 1991).

In considering three different care houses as multiple cases, it was necessary to assume that they were examples of the same model, despite some differences in structure, as noted and discussed in Chapter Four. The use of three case studies limited the depth of exploration in each, but offered the possibility of examining process and outcome in three projects evolving in isolation of each other, and increased the range of experience drawn upon in the interviews. Data collected through observation provided the chance to explore contextual explanations where differences appeared.

The three case studies were investigated sequentially at each stage of data collection. The broader base gave confidence in suggesting dilemmas inherent to this model of care, as well as suggesting differences in priorities and outcome. Huberman and Miles (1994) noted a contemporary trend where sets of individuals are studied within different settings, using multiple methods. While the use of multiple case studies enhances the ability to generalise findings and helps identify configurations holding in some settings and not others, inevitably a tension remains in reconciling the particular and the universal.

#### **The case studies and their organisational context.**

There were a number of participating organisations including Scottish Homes, who provided capital finance to the care houses and funded this study, and the Housing



Associations who led their development. Representatives of the Health Board and Social Work Departments helped to manage the units and supplemented Department of Social Security allowances to ensure revenue funding. These organisations had already formulated expectations of the research, some of which conflicted with each other, and proposed relevant outcomes for investigation. A steering group consisting of representatives of the participating agencies managed the various interests of stakeholders, facilitated access to the field-sites and acted as a source of practical advice.

The participating agencies' perspectives and relationships to each other were important to the development of both the case studies themselves and this study. The Housing Associations and other managing agencies hoped that evaluative research would demonstrate the success of the case studies and the strength of care housing as a model, as well as meeting their own monitoring needs. In the operation of care housing, there was particular concern that the sources and terms of funding should be both clarified and adequate. The managing agencies agreed to a study of less immediate utility but which would inform a wider audience about a progressive model of care because this was a condition of both the Dementia Services Development Centre's involvement and funding.

Scottish Homes was primarily interested in an assessment of value for money, or cost-effectiveness, and hoped for an evaluative method and monitoring criteria that could be standardised and applied elsewhere. The management groups resisted comparison between the costs and effectiveness of the three different units, asserting that differences between the units would make such findings meaningless and that, generally, the study should be primarily concerned with quality of care, which they believed was superior to institutional alternatives. They opposed any comparison of outcomes between case studies.

Housing Associations at that time were uneasy with the newly established funding body, Scottish Homes, whom some saw as a vehicle to implement unpopular central government policy. Mutual suspicion was also apparent between Health Boards and Social Work Departments.

Whilst residents were both the main group that care houses intended to benefit and were potentially the most vulnerable group of potential participants, neither they nor their relatives were represented in setting up the study, nor in identifying research questions and methods. To help address this, a representative of the, then, Scottish Action on Dementia was seconded to the advisory group.

### **The case studies**

Each care house was within a short walking distance of shops and other amenities, such as general practitioner surgeries, pubs and community centres. They were in reasonably safe and pleasant areas of a city or town, served by frequent buses.



All were newly-built, but not necessarily purpose-built. The agency responsible for managing the staff was in one instance the Social Work Department, a second house was managed by a Housing Association, and the third by a voluntary social services organisation.

### *Nash Drive*

This was a purpose-built single-storey unit in a cul-de-sac, described as 'ranch-style', with a garden surrounded by railings about five feet high. Twelve people lived here. The unit consisted of two corridors, each with six bed-sits with en-suite toilet and wash-basin, converging on the office and sitting areas. A conservatory gave access to the garden, which had a terraced sitting area with garden furniture. The lounge led to the dining room, which had a hatch and a doorway into the kitchen. From the kitchen, staff had access to a back green. The office was central, overlooking the two main corridors. At the back of the office were the staff room, laundry and kitchen. There were two bathrooms, with showers; one in each corridor. There was an additional bathroom with facilities for people who were physically frail. Locked cupboards in the hall were used for medicines and cleaning materials. Food and administrative files were kept in areas which were only used by staff.

Each corridor had different coloured doors, painted in primary colours. The doors were numbered and some were named. A reality orientation board stood in the hallway, between the main entrance and the office. There were communication cords in each bed-sit and bathroom, for use by both staff and residents. Pressure pads were fitted under the carpets in the bed-sits for staff to monitor residents' movements. Staff could also communicate via push-button and speaking units in all communal areas.

Residents could walk through the corridors and into all internal rooms, but if they went into the garden, an alarm sounded. There were alarms on the main doors, with red flashing lights acting as an indicator at night. It was designed to be accessible to someone in a wheelchair.

There was a project manager and two senior staff. Nine care officers, one domestic worker and two cooks were employed, making a total of nineteen staff, all of whom were full-time.

### *Redpath*

This was on a cul-de-sac, with no external sign that it was a care house, but with its own place name displayed. It was newly-built on one level as an annexe to sheltered housing and had its own fenced garden and gate. Its final purpose was decided after the building plans were made. Eight people lived here in single 'flatlets' which acted as bedrooms with sitting area, toilet and shower. In the flatlets, there was a small kitchen



area, with a sink for dishes and a cupboard where residents could keep a kettle and toaster. Each flatlet had its own letter box. Telephone and television sockets were installed. The house was accessible to someone in a wheelchair.

The shared areas consisted of a dining room, sitting room, and conservatory leading to a garden area. A kitchen off the dining area led to the back green. The laundry had a domestic washing machine and domestic tumble-dryer. Tumble-dryers in the sheltered housing complex next door could be used if needed. The guest room in the neighbouring sheltered housing was used for staff sleep-over and, potentially, was a guest room. Staff had access to an office, locked sluice and medicine cupboard, and a small changing room where they could keep coats and bags.

There was a map of the care house by the entrance to comply with fire regulations, but this was not intended to help with orientation. Each door had a number and residents could put what they wanted on the door, such as their name and a door-knocker. There was no colour coding. The office overlooked the front door. There was no buzzer on the front door, but one on the linking door with the sheltered housing which had a dual role of surveillance and security. Residents could walk anywhere inside, and out through the front and garden doors, without an alarm sounding.

There was a full-time project manager with two full-time senior staff. Six care staff were employed; one had responsibility for cooking, another for domestic work. Two of these care staff were full time. There were three night care workers, making a total of twelve staff of whom four were part time.

### *Heartfield*

The house was in red brick, marked only by its street number and looked exactly like neighbouring houses apart from having a ramped entrance as well as steps. It was just off a busy main road. A gap-site stood next to the unit, which was built on in 1995 to extend the care house. This unit's final purpose was decided in a relatively late stage of the development. It was created by joining two houses together along the street. The ground storey only was used by the care house. The upper two storeys were initially used by staff, who gained access through a backdoor and up external stairs to an office and staff area, and what could be used as a guest-room. During 1993/4 the care house gave up the upper storeys, which were then rented out as mainstream housing. A small room in the care house was subsequently converted to an office.

Eight people lived in Heartfield. The residents' accommodation consisted of six bed-sits, including two double rooms, with en-suite toilet and wash-basin. These were on both sides of a single long corridor that led to a locked fire door to the back green. The lounge and dining room were open plan, with the kitchen off the dining area. The laundry stood behind the kitchen. There was also a bathroom with bath-lift and sluice, and a toilet used by staff. A very small office was created out of what had been a



shower-room, at the end of the corridor. There was a terrace behind the house, accessible from the dining room. There was a locked cleaning cupboard off the laundry, and a further free-standing locked cupboard in the hall-way contained case notes, medicines, and financial records. There were no internal steps, but someone in a wheelchair would have difficulty using the small bathrooms and the narrow corridor.

Residents could walk around the sitting room, dining area, kitchen and corridor, but normally doors to the garden and the street were locked. There was no reality orientation board nor other written identification, except for the fire exit. Residents' doors were distinguished by their names. Alarms on external doors acted as indicators if a resident left the care house. There were emergency pulls in bedrooms and an intercom.

There was a full-time project manager and senior care officer and five care officers working during the daytime, two of whom were part time. Four night care officers were employed, making a total of eleven staff, of whom two were part time. No-one was employed as cook or domestic; these responsibilities were shared between care officers.

### **3.2.2 Multiple methods**

This study adopted multiple methods as no single method could answer all research questions. Multiple methods were complementary, with different methods achieving different tasks. For example, systematic observation and dependency assessments provided some quantifiable descriptive data, while semi-structured interviews obtained qualitative data about ideals and aspirations. Secondly, multiple methods permitted triangulation, hence playing a role in verification (Huberman and Miles, 1994). Subjective accounts from different participants, potentially in conflict, could be compared with independent investigations of process and outcome. Comparison was possible between different groups of interview respondents, as well as between methods. This increased the trustworthiness, if also the complexity, of the study.

Brewer and Hunter (1989:24) optimistically suggest that since diversity exists in social science, confronting this within a study and attempting to reconcile contradictions at this level can be helpful. The use of multiple methods may however be criticised because each may represent different and irreconcilable methodological positions (Douglas, 1976). While the interview methods employed in this study stemmed from standard sociological practice, the dependency assessments were borrowed from clinical psychology, and the observation method was developed within social psychology. It was demanding to learn about the different methods and integrate different data sets and this considerably extended the study. The breadth of a study that uses multiple methods possibly diminishes the depth of enquiry, but was appropriate to



the task of this study. In conclusion, a multiple method approach was ambitious and had practical disadvantages which restricted the depth of the study, but permitted a broad-ranging investigation that was appropriate, given the lack of knowledge about care houses at the outset of the study and the methodological issues surrounding the evaluation of services for people with dementia.

### **3.2.3 Purposive sampling**

This sub-section provides a summary of sampling decisions for all methods used. Within the multiple case study design, purposive sampling was necessary to address the research questions. The three care houses had a combined capacity for 28 residents, each of whom had a named next of kin. Forty two staff were employed within the units and ten agencies were directly involved in their development and management, including health, housing and social work agencies.

The broadest definition of the interested parties would include all those who could benefit from care housing. This would include those connected with developing or managing care housing; those who were employed by care housing or who participated in the day to day life of the schemes; those who delivered a service to care housing; and anyone with a financial relationship to care housing. Practicality demanded assessment of the perspectives of a narrower range in this study, including residents' next of kin, the staff employed by care housing, and the development and managing agencies. Residents' perspectives were only indirectly obtained. The stake-holders omitted include General Practitioners and community health services, the Department of Social Security, Area Social Work teams, private services such as hairdressers and chiropodists, other community facilities and neighbours. Another important group are those who did not receive benefit from care housing but wished to, for example those on the waiting list.

At two units I asked for staff co-operation in selecting for interview the people who had worked in the units longest and to ensure someone in each grade employed was interviewed. Staff insisted at one unit that they should all be interviewed. I sought to interview the person most involved in developing and managing the case study from each of the agencies involved, but in the event had to make compromises as some personnel had moved on. The systematic observation method required time sampling which was of necessity confined to normal waking hours during the weekday in shared areas of the house and over a period of two weeks or less. Residents of two houses were observed for a minimum of 9 hours and 40 minutes each. At the third house, unstructured observation was used for a comparable time period.

A survey method was used to establish what the outcome of providing a home for life was in Scottish care housing. Data was gathered on every resident admitted to all seven Scottish care houses from their opening date until October 1994.



### **3.3 Negotiating mutually satisfactory relationships**

Different degrees of explanation and protection were needed for each of the proposed participant groups. People with dementia were the most vulnerable but, paradoxically, it was hardest to ensure their informed consent was gained because of their cognitive impairment. Given the many agencies involved in this study, it was both impracticable and inappropriate to consult an Ethics Committee. The British Sociological Association (BSA) statement on ethical practice (1991) acted as a guideline. Advisory group representatives, care house managers and project staff were gate-keepers and were approached sequentially. These individuals were used to being approached by professionals who wanted to visit the units and vetted each application. Their objections or questions were concerned with maintaining the good name of the care housing, the utility of the study, and the implications for staff in terms of burden, or residents in terms of privacy and dignity. Obtaining consent was a process subject to re-negotiation (BSA, 1991) as communications between gate-keepers could never be assumed and needed to be repeated at each stage of the study.

Managers expected their staff to co-operate but staff were assured that their participation was voluntary, though I emphasised that their experience was important to the study. At one unit, I was informally but systematically introduced to all staff. At another, I was invited to a staff meeting. At a third, I was directly introduced to senior staff but had to seek out junior staff on my own initiative. Winning the co-operation of the staff and overcoming their suspicion required considerable work. At one unit staff were dissatisfied with the conduct and findings of a previous small-scale evaluative study and wanted to prevent negative conclusions being drawn. There was considerable anxiety, even hostility, to my study. That I am English did not help; it was treated as a joke but did not help create immediate rapport. Staff checked that I could understand what they and the residents were saying. Through discussion, we agreed to ensure that each stage of the study was discussed. Thereafter, though I was under continual scrutiny, the staff consented to the study. In another unit, staff stated their anxieties concerning the privacy of residents but also their willingness to help. In the third, senior staff expressed keen interest in the research and the hope that this model of care would be vindicated, and at no point challenged the methods.

Staff shared the general desire to ensure that the good name of care housing was preserved; they were employed by an innovative small-scale project with precarious revenue funding. In addition, if they had criticisms of management or their colleagues, they wanted to ensure that they could not be identified as having made these comments.



Staff were gate-keepers to relatives and residents. The project managers sent a letter to next of kin asking if they would be prepared to let me approach them directly, enclosing a reply slip. In spring 1993 I sent a letter providing information about the study and stating my preparedness to answer any questions and asked for an interview. In May 1994 I prepared a letter for all next of kin to be sent at the discretion of project managers, to let them know that the observation stage was in progress, and assuring them that I would respect the confidentiality and privacy of residents. Following the BSA (1991) recommendation that participants should give permission directly, I did not believe it was necessary to gain next of kin's explicit permission to involve residents in the observation study, but felt that it was important to give them the opportunity to express any objections they had on their own behalf or that of residents. Letters sent to kin are set out in Appendix Four.

At interview, kin were concerned that their comments about care housing, if at all critical, did not rebound on them personally or endanger the opportunity for their relative to continue to live in care housing.

The way staff introduced me to residents varied. In one unit, I met residents at every visit; and staff continued to introduce me until they felt residents recognised me. At the other two units, staff met me in rooms residents did not regularly use, such as the office or conservatory, and I did not meet residents until the observation stage. At one I was carefully introduced to residents, at another I was left to introduce myself. At each house, managerial and care staff reiterated that they felt it was their responsibility to protect the privacy of residents and screened me carefully.

The study could be classified as non-therapeutic; it was not likely to result in direct benefit to the residents which, according to Berghmans and Ter Meulen (1995), makes ethical issues more acute. Their definition of research was narrow, involving clinical and potentially invasive studies, rather than social research into environmental interventions. I decided to approach people with dementia directly and explain the study as best as I could, and whenever required, do so again. I did not assume their consent, even though staff and their relatives had agreed to the study. Given observance of the BSA guidelines, I did not think that my presence was likely to cause loss of privacy or dignity.

Staff support and advice was sought prior to observation. The negotiation required, at all levels, was time-consuming, but reduced the anxiety of staff. In one unit, DCM was not accepted, and was substituted by a less structured observation which contributed qualitative data. It was not assumed that agreement of senior staff meant that staff on duty, or the residents, also consented to observation on a particular day. I explained to residents that I was here for the day to learn what went on in the unit, and what they were doing, and asked if this was acceptable. I was welcomed by residents who could converse. I cannot be sure to what extent I won active and informed consent from all residents: it depended on how alert and interested they were in my presence



and whether they engaged me. It was hard to be sure they all knew what I was doing. In these circumstances it is tempting to take any kind of friendly welcome as consent but I gave as much information as I thought would be understood. Some did not respond to my approach, and I had to rely on non-verbal signs. One resident was anxiously waiting for their spouse, and clearly did not wish to relate to anyone else, so was not observed on that occasion.

### **Preserving openness, protecting confidentiality**

The utility of the study was necessarily limited by the need to protect the confidentiality of informants but offering anonymity was complicated by participants at all levels drawing attention to the evaluation. Interviewees were invited to check interview notes for accuracy. Three staff members accepted; one correction was made to a detail unclear from my notes. No kin took the offer up. No agency representatives asked for changes after receiving copies of the notes. Not being interviewed, residents had no opportunity for validation of this kind. Two meetings of the advisory group, in January and March 1995, were used to present summaries of the survey of admissions and the structured observation. Comments about the interpretation of this data were made and contributed to its further analysis.

The gap between data collection and submitting the thesis meant that the issue of identification of individuals has diminished. Several staff and residents have moved on, and it may be assumed that memory of specific incidents has dimmed.

### **3.4 Preparation and initial data collection**

Informal meetings with advisory group members explored agendas and expectations of both the case studies and my work. Following this, a descriptive checklist (adapting Norman, 1987; Tinker, 1989) was completed with the help of senior staff and project documents, such as operational policies and information pamphlets. The superficial meaning of written statements of practice was sufficient for my purposes and no textual analysis was needed. The checklist addressed the organisational structure; aims; resources (including staff and use of external services) and facilities available; regime; and the resident population. This was written up and respondent validation from staff and the advisory group preceded the publication of a paper describing care housing and drawing up a research agenda (Foster, 1994). This exercise helped build working relationships with the case studies, select practical methods for the main stage of data collection, and generated useful discussion.



I was able to visit Swedish projects in Sundsvall, Gavle, Uppsala and Stockholm, and the Anton Pieck Hofje in the Netherlands. Contact with staff and researchers helped identify the foci of this thesis.

### **3.5 Dependency assessment**

As noted in 2.4.2 and 2.5.5, dependency characteristics have been used as outcome measures in evaluation of care housing developments. No single instrument is available that can provide information on a desired range of outcomes because, amongst other reasons, transferring diagnostic and severity scales into outcome measures for community services is ill-advised. They are unlikely to be validated for such a setting, may well not be sensitive to change and do not cover the desired domains (Ramsay *et al.*, 1995).

The case study design, in addition, did not allow assessment of dependency characteristics to measure outcome. Descriptive data were, however, needed to compare resident groups with the stated entry criteria, and repeat assessment permitted a cautious comparison of dependency at group level at the beginning of data collection (winter 1992, Time 1) and the end (summer 1994, Time 2).

Wilkin (1990) pointed out that most existing dependency assessment instruments share a fundamental failure since the problem is defined in terms of the individual rather than in their relationship with the social environment. Assessment of daily living would have contributed but, given limited time, investigating involvement in household activity was limited to interview and observational methods.

#### **Instrument and procedure adopted**

While staff at each care house stated they regularly assessed residents' dependency, each unit used a different method and none collected data that could be directly compared to resident populations elsewhere. This was a finding in itself, and confirmed the difficulties of harmonising assessment between sectors. A new tool, the Revised Elderly Person's Disability Scale (REPDS) was concurrently being promoted by the Dementia Services Development Centre which aimed to address this problem.

The REPDS (Fleming, 1990) is a 53-item scale that is divided into seven sub-scales: physical problems; self help problems; confusion; behavioural problems; sociability; psychiatric symptomatology; and nursing dependency (see Appendix One). REPDS, like the Clifton Assessment Procedure for the Elderly (CAPE, Pattie and Gilleard, 1976) was developed for use with a hospital population, but also used in CADE units in New South Wales, Australia (Fleming, 1991a). It was advertised as a practical assessment tool for monitoring individual residents over time and also for preparing



group profiles which enable comparison with an individual profile, or with other group profiles. A computer package (Fleming, 1991b) was intended to assist process the data and compare individual and group scores between settings, and was available at the Dementia Services Development Centre.

Staff at two units were interested in learning about this method with a view to using it themselves; at the third there was considerable initial opposition to a process that was perceived as dehumanising, with the belief that it was humiliating for residents to complete a performance test. The procedure requires that a member of staff who provides direct care to the resident completes the schedule according to the last 3 days performance. A component of the confusion sub-scale requires that the resident be asked questions, though this can be disguised in conversation, making the process less threatening (Holden, 1995). This aspect made the instrument preferable to CAPE, which includes a formal performance test.

REPDS assessments were completed on 28 residents on two occasions: in November and December, 1992 and between May and September, 1994. The second period was extended because I wished to assess residents included in the observation. The procedure adopted was to explain to staff the applications of REPDS and guidelines for completion. One assessment was completed with my direct help. Following completion of the remainder, typically over a two or three week period, I went through any queries. Guidance notes were not initially available but I gained clarification through consultation with other users and Richard Fleming.

To date the reliability and validity of REPDS has not been satisfactorily independently assessed. For REPDS, the inter-rater reliability for hospital nurses having one hour of training was said to be satisfactory, but this is not clear from the evidence given (Fleming and Bowles, 1993). Inter-rater reliability for the psychiatric sub-scale was low, with a correlation of 0.58. Test re-test reliability is generally problematic in assessment of mental health (Dworkin 1992:69). The face validity of the method is asserted by its authors; criterion validity has not been established by factor analysis, which puts into question the use of total scores, both for the sub-scales and as an aggregate. The content validity may be acceptable for an in-patient population but needs adaptation to accommodate to contemporary views of what activities long stay patients should be involved in. CAPE is superior in that it has established reliability and validity, at least within institutional populations (Wilkin and Thompson, 1989).

Ethical requirements were met in that the tool did not collect unnecessary information, did not take unreasonable amounts of care staff time, and did not cause distress to individuals being assessed (see Wilkin and Thompson, 1989:13). Assessment was already part of staff work and the findings were made available to staff, so residents' specific consent for this was not sought.



## **Data analysis and management**

The computer programme for REPDS (Fleming, 1991b) had problems in operation and did not have the flexibility needed, being designed for case management with a predetermined menu. A standard spreadsheet (Excel) was therefore used, which was better able to generate summary statistics, and break the data down for frequency distribution to individual questions at case study level. In the prescribed analysis (Fleming, 1991b), percentages are used to summarise the problems experienced by individuals on each sub-scale, and group scores can be expressed in terms of mean percentage and standard deviation on a box and whiskers plot to allow comparison. REPDS scores are more appropriately regarded as nominal than ordinal, and in this thesis the average total score for each unit is summarised by the median and the inter-quartile range. I created three ranges of severity, corresponding with the categories of being a minor, moderate, or major problem, as rated by REPDS. Totals of sub-scales were graded into three equal categories (0-8; 9-16; 17-24 where there are 8 questions, and 0-9; 10-18; 19-27 when there are 9). This was broken down to case study level. The psychiatric sub-scale was omitted because of dubious reliability. The global score was also rejected: the nature of dementia means that it is problematic to use uni-dimensional hierarchical scales as a measure of severity (Carr and Marshall, 1993).

Despite initial expectations, no comparative data was available to compare this study's findings with dependency characteristics of those in other settings. There were no normative standards for different institutional settings, unlike CAPE.

Differences between the two assessments are presented. Eleven people who had repeat assessments were used to explore reported changes. This suggested that either marked changes had occurred, or that the tool was not sensitive to change and/or test re-test reliability was poor.

The case study design meant that descriptive statistics were sufficient. Multi-variate analysis to link data sets would have been inappropriate given my growing reservations about the trustworthiness of both REPDS and DCM (see 3.8.7).

### **3.6 Survey of Scottish specialist care houses**

During the first stage of the study, base-line data were collected on each resident to establish where people moved from, how long they stayed, and what, if any, use was made of hospital services. Any moves to other sectors were also recorded on a form developed for this purpose. This was necessary to get a complete record, not provided by kin interviews, and addressed the question of whether the units were succeeding in their aim of providing 'a home for life'. This acted as a pilot for the postal questionnaire sent to all Scottish care houses in operation by 1994, in collaboration with the Priority



Services Research Team (PSRT), Aberdeen University. This postal survey (see Appendix Two) covered the following topics:

- Where people move from and why.
- The routes of referral.
- Why people moved.
- Where people move to if they did, and why.
- The length of stay .
- Age and gender of residents.
- Admissions to hospital during the stay in care housing.

The questionnaire was developed so that staff could complete one for each resident who had moved to the unit since it opened, until October 31st 1994. The options in the questionnaire about where people moved to and from were suggested by analysis of the pilot data-set. I approached a gate-keeper in the managing agency of each scheme known to be open in Scotland. Using the Dementia Services Development Centre to establish this information and having gained permission to proceed, a joint letter from PSRT and the Dementia Services Development Centre was sent to the manager, and a phone-call made to follow this up. Questionnaires were then supplied to each unit and collected or posted. A 100% response was achieved by this method, recording all residents who moved to Scottish care housing units between the unit opening date and October 1994.

### **Management and analysis**

The data were analysed at a descriptive level and Excel provided the spreadsheet facility necessary. Some data, provided by the checklist about each resident included in the observation, were amenable to frequency counts.

### **Addressing cost-effectiveness**

Cost-effectiveness is an important consideration in the evaluation of care housing (see 2.8) and was important to the participating agencies. However, this question was outwith the scope of the study presented here. A wider study, the Balance of Care study conducted by PSRT, has considered marginal costs in relation to dependency across a range of settings and was extended to include the three case studies. This has not been completed at the time of writing.



### **3.7 Semi-structured Interviews**

Semi-structured interviews (SSI) were conducted with 12 next of kin, 11 representatives of developing and managing agencies and 31 staff, and contributed to each research question. SSI were the main method for the pluralist evaluation; they provided information about problems faced by residents and their carers before and after the move and they were important to the exploration of care housing as a homely setting. They elicited factual information, aspirations, descriptions of behaviour, and satisfaction. While unstructured interviews might have been the preferred instrument for a single case study where a pluralistic evaluation was the only research aim, SSI ensured that data were consistent across the case studies.

It was necessary to construct a schedule to address the specific research questions. Schedules became more focused following each set of interviews and were tailored to the specific experience of the respective group being interviewed.

#### **3.7.1 Kin Interviews**

Next of kin were likely to have provided informal care and been involved in their relatives' move to care housing. They might have directly benefited from care housing, and could evaluate its success from their own point of view and for their relative, although it could not be assumed that kin accurately presented the residents' perspectives. A semi-structured schedule covered the points, summarised in Box 3.7.1. The full schedule is given in Appendix Three.

#### **Box 3.7.1 Kin interview topic list.**

- 1. Background Information about the resident (R)**
  - 1.1 About the communities in which R has lived
  - 1.2 About the type of work that R has done
  - 1.3 About the type of accommodation that R is used to living in
  - 1.4 About the things that R did in his/her own time
  - 1.5 Summary
  - 1.6 People who are important to R at the present time
  
- 2. About the move to care housing**
  - 2.1 Things leading up to the move
  - 2.2 About care housing and its alternatives
  - 2.3 Expectations
  - 2.4 Preparing to move and the trial stay
  
- 3. About R's life in care housing now**
  - 3.1 About the facilities themselves
  - 3.2 About kin's contact with R and visiting
  - 3.3 About the support that R is given
  - 3.4 Dimensions of R's life in care housing
  - 3.5 Concluding points: kin's evaluation



### *Piloting kin interviews*

The questionnaire could not be piloted in care housing but five volunteers with relatives living in a care home or hospital were found. As a result of these pilots, breaks were built in to the interview schedule, and the schedule was laid out so that interviewees could look at it. I had intended to use Inside Quality Assurance (IQA) framework (Centre for Environmental and Social Studies in Ageing, 1992) as a framework for their evaluation, but this was dropped after interviewing three kin from care housing. This was due both to shortage of time and confidence that each interviewee had had the chance to make the points they felt most relevant to their situation. A direct question of whether care housing felt homely to the respondent was substituted.

### *The kin sample*

Altogether 28 kin were invited to take part in the study in December 1992; half of these (14) agreed to interview and 12 were eventually interviewed between March and May 1993. By this time, one resident concerned had left care housing. Staff advised me it would be inappropriate to attempt to contact this family who had found the move difficult. Possibly I was shielded from hearing a critical view, but I agreed that I should not contact them, as at that point the resident was very ill. Another interview was abandoned because of the illness of the resident concerned. By observation in summer 1994, only six of the residents whose kin were interviewed were still resident.

While only a quarter of kin (2) were interviewed at one house, three quarters (8) were interviewed in another (Nash Drive). Seven were involved in a move from community housing: two had moved in with relatives prior to moving, and five had lived on their own (one in sheltered housing). Five had been involved in a move from institutional care and four from hospital provision, which shaped the comparison they made. Two interviewees were siblings; the rest were daughters (5), sons (4) or a niece (1). Seven interviewees were female.

### *The method in practice*

Kin were effectively prepared by a letter sent beforehand (see Appendix Four). Five interviews included spouses, who in each case assumed they should be present and contributed. I directed questions to the next of kin, who sometimes invited their partners' opinion. There were no refusals to the use of a tape recorder. Interviews lasted from between one hour to two and a half. The first section, being



straightforward, helped establish a relationship and gave an opportunity to 'introduce' the resident to me.

Interviewees, with one exception, were able to give information about the residents daily life prior to the move to care housing, and all were able to describe the reasons for the move and its process. It was apparent all moves were initiated by kin rather than residents. Whether kin could assess the effects of the move may have depended on how well they knew the resident, whether they kept regular contact and their insight into the process of dementia. Most did not have a very detailed knowledge of life in care housing. Some interviewees were very concerned about residents' well-being and sought to interpret residents' reactions and signs of how they were settling into care housing, but others gave fewer details and found it difficult to comment, particularly if the resident had lost speech. In the absence of direct information, kin referred to their knowledge of residents' habitual likes and dislikes and how they had normally behaved and reacted to situations. Some could base their answers on what residents actually said about care housing and observed non-verbal communication. They reported what the resident didn't say; for example, the fact that the resident had never complained about something was taken as a good sign.

Most kin had no criticisms but only praise for the staff. The pattern of positive responses from satisfaction surveys has already been noted in 2.3.4. Any criticism was about details of the staff's practice and only expressed when interviewees had impressed upon me that they thought care housing was in the main the best option. The sample may have been biased towards those most involved with their relatives, and prepared to give their time to contribute to their care. Kin may have wanted to believe that the move was successful, because it had been largely their decision, and might therefore have been biased towards seeing the signs of well-being. The initial aim was to establish residents' pattern of daily life prior to the move in order to assess continuity of the residents' preferred lifestyle in care housing. Both the low response from kin and the turnover of residents between interviews and observation made this impracticable.

### **3.7.2 Agency representatives**

As a first step, Housing Association representatives were consulted about the development of each project. My initial intention was to read documents generated during the development stage (see National Federation of Housing Associations, 1986) but only one Housing Association was able easily to locate the relevant documents; otherwise I was advised that the files would be overwhelming or that it would take too long to locate the material. For two case studies, I gained information directly from meetings with people who had been most closely involved in the development process. For one case study, turnover of staff and re-organisation meant that less detailed information could be obtained. Reviewing the data collected, I decided to approach



people involved in both development and managing the units in Health Boards and Social Work Departments, to provide a fuller picture at interview. The aim was to identify what motivated each agency's involvement, and to establish whether the respondent viewed the project as successful. The basic format of the interviews is summarised in Box 3.7.2.

### **Box 3.7.2 Agency representative Interview topic list**

#### Introduction:

- How would you describe [ the care house]?
- Can you outline the ways you have been involved with this unit?
  - in what capacity?
- Who/which departments in your agency are/have also been involved in the project?
- What would you hope that an evaluative study would cover?

#### Expectations:

- What is/was your remit in this involvement - as understood with your department / employing agency?
- What, more generally, do/did you hope this project could achieve?
- What benefits could this bring specifically to you/your department?
- Do you have any worries or reservations about this project
  - generally?
  - affecting you/your department's work more specifically?

#### Experience:

- How successful do you think the project has been to date?
- Are there any problems that have emerged with regard to the project
  - generally ?
  - affecting you/your department's work more specifically?

#### Other:

- Would you recommend this as a model of care to be repeated?
  - actually planning another?
- Were you to develop another unit, is there anything you would do differently?
- Is there anything else you think is important to take into account in evaluating these projects?

These interviews were completed in August and September, 1993. The external manager responsible for staff for each unit was interviewed. For the two projects not managed by statutory social services, a Social Work Department representative was also interviewed. In addition, Health Board representatives on the managing group, who were clinicians and had been involved in developing the projects, and two development managers from Scottish Homes were interviewed. The reform of statutory agencies meant that there had been changes in personnel and at times a lack of clarity over where responsibility had been delegated. Some key players in the projects' development could not be contacted, and sometimes file notes had been lost. Those who were interviewed were actively involved in care housing and committed to it. More severe critics of care housing may have been excluded from the sample by this process of selection.



### 3.7.3 Staff interviews

Staff interviews sought the staff perspective on the success of care housing and how they compared it to its alternatives. They were asked their own point of view, as well as how things worked for other parties. Specific questions were prepared for the topics summarised in Box 3.7.3.

#### Box 3.7.3 Staff interview topic list

##### **Topic list**

- Your involvement with the project
- About your work here, how things work out in practice
  - \* the people that live here
  - \* what happens over time
  - \* this being someone's home
  - \* people living together
  - \* the activities that people do
  - \* keeping independent
  - \* friends and families
- How things work out for the different people connected to it:
  - \* residents
  - \* relatives
  - \* staff
  - \* agencies who fund and/or manage it
  - \* anyone else?
- A little more about your job

The seven topics about how things worked out in practice were derived from the aims of the units, and the specific research questions. Each section was intended to generate examples of how these aims were interpreted in practice and when they were more or less successful. A question asking staff to summarise how things worked out in practice for each different group effectively repeated the question of what the unit could offer, but coming at the end of the interview gave a chance to re-state and elaborate their views.

The staff were keen to know why I needed this information and I wanted to reassure them and clarify the purpose of the study. I designed the schedule so that they could handle it themselves and prepared guidance notes which they read at the beginning of the interview (see Appendix Five).

Review after the first three interviews suggested small changes were needed for clarity and to build in space to raise important points and negative aspects of the work as opinions about inappropriate aspects of their work were voiced repeatedly. Since these were minor changes these interviews were included in the main analysis.



## *Staff interviews: the method in practice*

In two units one member of staff tested out the interview on behalf of their colleagues; once they had approved it, others agreed. All staff in one house were interviewed because of their insistent expectation that everyone's view would be taken into account and the necessity of winning confidence for observation to proceed. In the other two houses, the senior staff helped select staff (see 3.2.3). Their anticipation that most staff would want to be interviewed proved correct; no-one refused.

**Table 3.7.3 Grades of staff interviewed**

Care staff (including seniors)	12
Designated domestic	2
Designated cook	2
Night care staff	5
Seconded staff nurse	1
Seconded student	1
Project managers	3

Interviews were held between May and August 1994. In one unit no night staff were available for interview because of long term sickness. In two instances seconded staff, who permanent staff referred to as making a particular contribution, were interviewed. Interviews with the project managers specifically sought information about how they expected staff to work regarding each topic.

Interviews lasted about an hour and were completed within staff working hours, when there was sufficient staff to cover. Each unit found a room where we were undisturbed for most of the interviews, although occasionally a resident would join us for a short time. Staff appeared to enjoy the opportunity to talk and reflect about their work. One comment about the interview was: 'I'm enjoying it, its like a debriefing after two years'. Staff were aware of pressure on their colleagues and were keen to finish the interview. In about a quarter of the interviews the full schedule was not completed because staff needed to return to work, particularly in one house which was at this point short staffed.

Using a portable computer and a tape-recorder reduced the time needed to take notes and helped check their accuracy. All agreed to the portable, but four refused the tape recorder, not wishing their own voice, which they disliked, to be recorded. Most took the opportunity to handle the schedule and read the questions themselves. During any pause they could look at the screen and see what I was writing, which helped allay anxieties some interviewees had that I would misquote them.



### *Self-completed questionnaire to staff*

A self-completed questionnaire to staff, excluding the project managers, provided base-line data on age, gender, job-title, hours worked, length of employment, professional qualifications and relevant experience. It also included a question about the main activities of their job over the last day and week. It was tested in the first three interviews by asking staff members to complete it in my presence. This led to small improvements in question wording. Its completion was co-ordinated through the project manager, who distributed an information sheet, questionnaire, and envelope for return to each staff member. Thirty of 42 staff responded, distributed almost equally between the houses. These data were entered into a word-processing package (Word) and summarised.

#### **3.7.4 Management and analysis of semi-structured interviews**

The tape-recorded interviews were transcribed; where the material was repetitive or of limited value, it was summarised, but most was recorded as actually spoken, enabling its use for quotes. While this was an accurate record of verbal content, transcription did not record details of hesitation or repetition. Where a computer had been used for note taking, I checked this against the tape for accuracy after the interview. If not tape recorded, I checked the transcript as soon as possible after the interview for errors or lack of clarity.

The transcript was entered into Hypersoft (Dey, 1992) and coded using categories suggested by the interview schedule itself (see Appendix Six). Further use of memos and summaries and sub-categorisation of the data was abandoned because I needed to limit the use of a keyboard. Hypersoft allowed a complete hard copy to be printed with wide margins of 'data-bits' generated for each code. Having summarised each data-bit manually on the right margin, the left margin was used to record sub-categories.

Sub-categories were derived as most appropriate for the theme. Some codes did not require inductive sub-categorisation, but other codes were analysed with greater depth, particularly staff reports about group-living. This was first sub-categorised into the points as identified on the schedule. Patterns in the data-bits suggested further classification. A summary was prepared taking account of all the data. I examined differences in responses occurring between case studies with the aim of developing explanations of these.

In the interactive process that is qualitative research, data management is important in order to re-visit the data. A reference system was developed, using a matrix for each coding category. The interviewees' identification codes were used on one axis, and the sub-categories on the other. By recording the data-bits' reference numbers, the



source could be readily located. This provided a visual record of how many respondents had contributed relevant data, and how many data-bits were relevant. This gave an impression of where data were rich, and hence more likely to be saturated, and where it was thinner and descriptions and explanations generated should be tentative. The breadth of the research questions and the volume of data meant that this process of analysis was constrained in the amount of inductive analysis that could be achieved.

Codes used in this thesis identify contributors, but disguise the unit as well as the individual. These codes consist of a letter ('A' for agency representatives; 'K' for kin; 'S' for staff) and a number, e.g. A7. Residents have been allocated a number if they were included in the observation. In presenting quotes, the coding category and the data-bit number are also included, e.g. A7 hopes 12. Occasionally this is omitted to prevent cross-identification. If it has been necessary to remove material for confidentiality or clarity, this is indicated by the use of square brackets. If irrelevant to the point being drawn out, omitted material is indicated by '...'. If I have probed for material but the wording was not recorded in the notes taken, this is indicated by '//'. Some changes to gender or other disguises have been made if necessary.

### **3.8 Systematic Observation**

#### **3.8.1 Choice of method**

Systematic observation, based on the method of Dementia Care Mapping (DCM) was preceded and interspersed by episodes of unstructured observation and participation. Systematic observation in this study provided information about the range and type of daily activity, the frequency and quality of interactions residents had with others, and the use of the rooms in the care houses. DCM is a value-laden observational tool developed by Kitwood and Bredin (1992a), referred to in section 2.1.2. It aims to generate a score that reflects well-being supposed to indicate the quality of care, or the quality of social life, received. This could be interpreted according to standards proposed by the authors. Observation thus promised the investigation of both process and outcome, which are hard to separate in residential care (see 2.8). Systematic observation enabled exploration of differences between individuals and groups. The argument for using observation to assess the quality of care in residential settings, in terms of the social environment, was recorded in section 2.3.4 and its use in care housing developments in 2.6.4. Clark and Bowling (1990) used an observational tool recording activities and quality of interactions, which included a qualitative observational log. Dean and Proudfoot (1993) reviewed this and other observational tools, including Macdonald (1985) and Godlove *et al.* (1982), and developed the Quality of Interaction Schedule (QUIS) for use in the *domus* units. According to Brooker (1995),



who reviewed structured observational methods available for people with dementia, DCM sets its standards for quality of care higher than other instruments.

DCM has gained popularity as the Bradford Dementia Research Group publicised their method and trained practitioners and is used by the Dementia Services Development Centre as a staff development tool. I completed training in January 1994, but subsequently the authors have improved the coding systems and specified appropriate uses. DCM is seen as appropriate for research as long as a person-centred approach is adopted and reliability and validity is addressed. It is not seen as a tool suitable to be used in people's own homes (Bradford Dementia Group, 1997, seventh edition). While its main use has been for staff development, its authors asserted its research potential. Papers using it in research have appeared latterly (Wilkinson 1993, Bredin and Kitwood, 1995). This study provides a chance to evaluate its use as a research method.

### **3.8.2 The DCM method**

DCM tracks the activities and well-being of up to five people, making records at five minute Time Frames (TF). As a form of interval coding this is unusually long. No time out is given to make records. Twenty two Behaviour Category Codes (called here activity codes) were generated from the authors' unstructured observation in formal care settings. If more than one activity occurs within a TF, precedence is given to activity over inactivity. For example, doing work gains precedence over sitting passively. For each activity code, a care value is generated according to a 6 point scale consisting of 3 grades for both states of ill being and well-being. The authors describe this method as a compromise between time and event sampling, described by the term 'event summation'. Both sets of categories are defined in the DCM handbook (Kitwood and Bredin, 1994, Sixth Edition). The care values can be aggregated as a measure of 'well-being' and an equation between this and the quality of care is made. A further set of codes, the Personal Detraction Codes, were not used in this study.

### **3.8.3 The DCM method adapted**

Three additional recordings at each 5 minute period were made, and the standard form adapted (see Appendix Seven).

Firstly, I systematically noted general activity, such as 'radio on; staff at tea-break', if it appeared relevant to the activity or well-being of those observed. Specific notes about the person observed could also be made, such as 'hair being dressed; her birthday'.

Secondly, anyone with whom the resident had spoken was recorded in each TF, using codes for a resident (R); visitor (V) and staff member (S). If this involved more

than one other resident, for example, I recorded this as 'R+'. Neither non-verbal communication nor exchanges between staff were recorded.

Thirdly, I recorded which room the resident had been in for each TF, using codes for private rooms; shared sitting areas (dining room, lounge and conservatory); shared facilities (bathroom, laundry, kitchen, hallway, office); and being out of the house. Mostly residents stayed in the same area but if they moved, the place where the activity that took precedence in the DCM method was recorded. For example, if work took place in the kitchen this was recorded, rather than sitting passively in the lounge. Walking presented problems: the place residents were walking to was recorded, unless they took a long time to get there, in which case, for example, the hallway was recorded. This record is therefore a slightly rough guide, but sufficient to indicate which areas residents used most.

The form was piloted in a hospital setting and proved practical. The codes for the rooms and interactions required no reflection, unlike the activity codes and care values. The time taken to write notes was minimal.

A 'check-back' stage was added to the DCM method. Following observation, I went through prepared questions with a care staff member who had been on duty. This established whether the period observed was typical for that time, both generally and for the observed residents. I checked for any indication that my presence had made a difference to what happened. Field notes written after each observation session permitted further reflection.

A social history checklist was completed for each of the 28 residents observed with a key-worker or other care staff member who knew them well. This gathered information about previous occupation, marital status, education, people in contact and the nature of this contact, and the possessions brought to the care house. In five cases the staff account could be checked with kin interview data.

#### **3.8.4 Sampling**

I aimed to observe each resident over one normal waking weekday in communal areas, over three observation sessions. This was comparable with Dean and Proudfoot, (1993) and Clark and Bowling (1989). Observation time was not restricted to a pre-lunch hour period (Macdonald *et al.*, 1985) as the aim was to explore activity over a whole day. I anticipated unpredictable interruptions from staff and residents.

Heartfield's staff rejected DCM, arguing that the non-participant observation threatened residents' privacy and the scoring system was objectionable. It was perceived as dehumanising to attempt to summarise human behaviour and well-being numerically. A compromise was agreed. I could spend time in the house as long as I would participate, but with the understanding that I would need to use the office to make



notes every half hour. I observed each resident in this way, and checked back with staff to validate my observation of residents' activity, well-being and other activity in the house. In addition, I accompanied residents and staff on an evening outing.

Systematic observation was carried out immediately after staff interviews and piloted for a half day in each unit. Observation was conducted on seventeen weekdays between May and September 1994. The sessions began at earliest at 8.20, and ended at latest at 22.00. For the adapted DCM method, twenty residents in two case studies were observed for a mean of just over 10 hours and 40 minutes (range 9:40 to 12:20) on three or more different days. Altogether 2564 time frames were covered, each with a series of 4 observations. This total of 2564 includes episodes where no code could be ascribed because observation was not possible for one or more of the series; details are given in section 6.4. Interruptions occurred, for example, to introduce myself to a resident or visitor, or being approached in conversation.

Seven sessions were needed at Nash Drive. The twelve residents were subdivided into two groups; I observed each group in turn. Interruptions during one session meant that it was necessary to return. In Redpath, four people were observed during each of six sessions. I always stayed for the midday meal after the morning observation (explaining a disproportionate number of 'afternoon' sessions recorded, noted in 6.3) and for one evening meal following an afternoon observation.

For comparative purposes, I was permitted to use DCM data gathered with colleagues in the Dementia Services Development Centre in a long stay psychogeriatric ward. Five male patients were included who were selected by staff on the basis of having dementia; the adapted form was used.

### **3.8.5 Trustworthiness of systematic observation**

#### *Observer effect and participation*

The method was accepted by residents and staff in the small-scale setting of care housing, as long as I was prepared to allay staff anxiety and be prepared to break off non-participant observation required. Visits to the unit and conducting interviews before the observation meant that staff were used to my presence. Pilot observation meant that residents had started to get to know me.

The experience of observation in care housing was very different to hospital wards, where most patients had been visible and passive. In care housing, most residents were active and moved between their flats and the shared areas; the more domestic design meant that they had access to different rooms for different activities. In hospital settings, I struggled to distinguish the people I was mapping from other patients. In the care houses I learnt people's names quickly, and learnt about residents' and staff's individual characteristics. There were demands that I, too, should become known

as an individual. The conversations between staff and residents sometimes deliberately included me, which did not happen in hospital settings.

While DCM demands non-participation, this was at times impossible without causing offence. I devised a strategy of minimal interaction which would be consistent with other activities. I had to move to observe residents, but limited this to what seemed unobtrusive. I did not wish to mimic staff activity too closely, as then residents might approach me for help in the same way that they did staff, and I did not want to mislead them about my identity. I sat away from the residents being observed but learned that residents could become anxious or puzzled if they could not see me clearly. Doing mending and knitting were useful as they legitimised sitting quietly in a corner. Some residents checked that I was comfortable and enjoying myself; if I was purposefully occupied they were less concerned. Sweeping or polishing also explained my presence, but in care housing residents are supposed to participate in this so I confined this to tasks that staff usually undertook. I explained to staff and residents, if they appeared interested, why I needed to make notes. I was open about this, explaining the kind of things I was writing to staff, as recommended by Lyman (1994).

#### *Representativeness: the time sample.*

By systematically checking back with staff, I confirmed that the periods observed were not out of the ordinary. This helped contextualise the data, by for example learning that the resident had had a late night. The season, with warm weather and light evenings, was said to increase the number of times residents were able to go out. However, my structured observation was negotiated to include times when most residents were likely to be in.

#### *Reliability*

Training in DCM advocated tests of inter-rater reliability but this was only possible in two hospital wards, where I observed with colleagues. This gave a satisfactory correlation (0.8) but was limited to half an hour's observation. The care houses rejected the idea that I should observe with a colleague from the Dementia Services Development Centre, though one later accepted an offer to use DCM as a developmental tool. Comparing my data with this would have confused test re-test reliability with inter-rater reliability and would not have been helpful; discussion with colleagues, however, indicated our observations were consistent.

According to Kitwood, the larger the number of people observed at any one time, the less reliable the findings; the authors recommend a maximum of 5 (Kitwood and Bredin, 1994). Although in Nash Drive I included six people, it was extremely unusual for all to be present at any one time. The more active the residents, the less reliable the



activity codes and care values; the time frame of 5 minutes was perhaps inappropriately long for this setting.

There was possible inconsistency with the record of care values between settings. I was aware of adjusting to the norms of each setting: what I perceived as a high level of well-being in hospital settings began to seem normal in care housing. Care houses varied too; in one unit residents were habitually helpful to each other but on review I found I still used the highest score sparingly. I also tended to give the benefit of doubt about signs of ill-being. The combined effect of these tendencies would be to reduce the frequency of high scores of both ill-being or well-being. I enjoyed being in the smaller units more, and cross checking my memory with observation notes suggested a bias in that I could selectively forget episodes of good quality care in the places where I enjoyed observation less.

### **3.8.6 Data analysis and management**

The data were entered into a spreadsheet package, Excel, after manual methods proved impracticable. The analysis was guided by the method advocated by Kitwood and Bredin (1994), but additional analysis was needed to address the research questions.

Twenty residents in two care houses were observed for a total of 2564 Time Frames, each being a five minute period where four recordings were made. In hospital, observing five patients gave a total of 360 time frames (TF). The extent of the record varied between categories and individuals. The record of where people were is most complete, because often this could be noted confidently even though the activity could not be observed. Activity codes and care values had to be discounted if I interacted with the observed resident (2% in care housing and 5% in hospital). When the residents moved around a lot, or there was much activity, a record could not be made. Care values were particularly difficult to record confidently. The proportion of TF recorded was higher in hospital for each category, even though this was in a larger scale setting and there were twenty patients living there. This was partly because there was a vantage point where all people in communal areas could be seen. More frequent gaps in records occurred in care housing because I broke off to participate at the initiative of staff and residents. The wider range of activities in care houses also made it harder to observe.

**Table 3.8.6 The percentage of the total time frames recorded for each category**

<b>Category</b>	<b>Nash Drive</b>	<b>Redpath</b>	<b>Total: care houses</b>	<b>Hospital</b>
<b>Activity codes</b>	71 % (1012)	72 % (819)	71 % (1831)	80 % (289)
<b>Care Values</b>	65 % (931)	68 % (774)	67% (1705)	79 % (283)
<b>Interaction</b>	73% (1040)	76 % (861)	74 % (1901)	85 % (305)
<b>Place</b>	95 % (1349)	99 % (1126)	97 % (2475)	97 % (350)

For practical reasons, some residents were mapped for longer periods than others (range: 116 to 149 TF). Kitwood and Bredin (1994) suggest that only six hours of observation (72 TF) is sufficient to produce reliable care scores. The range and frequency of activities is a more difficult question: the times chosen were possibly biased towards less active days and, through experience, I learned that days could vary. The activity codes have been used to indicate broad patterns and to generate case studies and vignettes. Rather than bias the time sample by selecting which TF to analyse, I have included all frames. The data are summarised by expressing frequency of sub-categories as percentages of the *recorded* time frames, expressed in shorthand as RTF%.

My prior aim was to describe and explore what went on in shared areas of care housing over normal waking hours of weekdays rather than compare between houses, or with hospitals. No hypothesis is tested and the report concentrates on explaining the findings with reference to qualitative data rather than examining the significance of differences. Care housing aimed to support different individually preferred daily patterns, which directed my attention to the range and variety of activity rather than to generalisations about populations. Hence the data are summarised descriptively, and explanations for differences are sought within the context of the case studies.

To investigate the daily pattern of activity in care housing, the waking day was divided into three periods. 'Morning' consisted of the first observation made until residents in the dining area began the midday meal. 'Afternoon' was taken to be the time from when the midday meal began to the start of the evening meal, at which point 'evening' began which lasted until the last observation made at night. The occasion of the meal itself rather than clock-time is used to make this distinction. When the data were divided in this way, morning times were observed on four separate sessions, afternoons on ten occasions, and evenings on five.

Field notes were coded according to categories developed for the interview data. Because of the volume of data and difficulty in typing out field notes it was difficult to



integrate the analysis of interviews and field notes. I therefore used field notes to verify the interview analysis. Some material provided vignettes. Using the field notes, generated during the systematic observation, a rich analysis of the data on activities and well-being was possible.

Field notes that fell neither into these codes, nor related to the research methods used, were also checked for consistency. Their main contribution was to provide a contextual background.

### **3.8.7 Conclusions: DCM as a measure of quality of care in care housing.**

The comment that 'institutions are ideal settings within which participant or non-participant observation can take place in a relatively unobtrusive manner' (Clark and Bowling, 1989:125) did not apply to care housing. My experience suggested that success in de-institutionalising care may increase observer effect. Possibly, as quality of care improves, it is harder to observe without participating. DCM requires that the observer adopts a passive role, but this was difficult in care housing where most residents were active and alert. Ensuring informed consent for people with dementia may be particularly difficult, as an observer can be repeatedly misidentified and seeking to orientate residents may conflict with the need to reduce observer effect. One introduction is not enough; too many make observation impossible.

The activity codes were not subtle enough to describe participation in household activities. For example, the scoring system did not distinguish when residents did work on their own behalf, independently and without being prompted, reflecting that the tool was developed in more conventional residential and day care settings.

Most recently (Bradford Dementia Group, 1997, seventh edition) the authors of DCM have acknowledged that an over-simple link was made between quality of life and quality of care. The tool may tend to over-state the importance of social environment. Quality of life is only partially determined by quality of social environment, though this may be of especial importance to older people with dementia (see 2.3). Inter-personal interaction, the focus of DCM's well-being score, is only one aspect of quality of care. The method does not draw attention to other variables in quality of care such as physical setting, the resident group and resources and services available to the staff. Measuring well-being through observable signs is only a proxy for subjective appraisal. The validity of DCM in indicating well-being, and then using this as measure of quality of care, is therefore debatable. The exercise is justified by its authors on the grounds that:

those with even moderate dementia cannot make the kind of cumulative value judgements that are involved in giving an opinion about whether or not a service has met their needs and expectations (Bredin and Kitwood, 1995:968).

Precisely because people with dementia are unlikely to be able to validate findings, the care values should be interpreted with great caution. Care values should be presented as categories rather than a score which may be misinterpreted, especially if it is unclear whether it can be equated to quality of care. The care scores may be taken in isolation as an outcome measure (see Bredin and Kitwood, 1995). It could be tempting but misleading to extend the use of DCM to assess cost-effectiveness. The characteristics associated with increased well-being were recorded by Kitwood, Buckland and Petre, (1995, see 2.1.2). Since individuals may benefit differently from the care offered, and this might be related to their personality or biography, well-being should really be considered in the individual context rather than used as an aggregate score by which to judge a care setting. Qualitative observations inform how the data are interpreted and systematic note-taking of general activities taking place is essential. DCM users should be trained in qualitative analysis as well as doing frequency counts of the quantitative data generated.

In conclusion, DCM, if used as an evaluative research tool to investigate outcome, should be combined with systematic investigation of the characteristics of the physical and social environment and the individuals observed. All users, whether for developmental or research purposes, should consider building up a profile of each resident observed, in terms of specific problems, care plan aims, and their subjective preferences for activities to be involved in. While DCM may be appropriate for its original purpose, that is staff development in institutional forms of care, it becomes less appropriate to smaller scale settings where there may be more activity and engagement. Whatever its application, users have to be careful not to attach spurious meaning to the care scores generated.

### **3.9 Research timetable**

In order to clarify the various stages of this study, the research timetable is given.

#### **October 1991- September 1992**

- Review of the literature
- Consultation with academic researchers about cost-effectiveness studies
- Meetings with members of the advisory group
- Meetings with staff to allay anxieties
- August 1992: descriptive data collection (development, structure and procedures)
- September 1992: study tour: Sweden and the Netherlands.

#### **October 1992- September 1993**

- Semi-structured interviews with relatives and agency representative
- Pilot survey of residents who had moved
- Dependency assessment for each resident.
- Case studies contracted into the Balance of Care Study



## **October 1993- September 1994**

- Preparation for observation and staff interviews in each unit
- May 1994 - September 1994: staff interviews and observation
- Extension of 'moves' survey to all Scottish Care Houses
- Dependency assessments repeated

## **September 1994 - August 1997**

- Data analysis and writing up.

### **3.10 Summary of the research strategy and methods**

This study aimed to inform policy and practice through evaluation of aspects of the effectiveness of care housing. This chapter has argued that a pluralistic approach was, in the first instance, most appropriate, given the multiple interests in the case studies and the difficulty in obtaining the perspectives of people with dementia. The possibility of differences within, as well as between, groups of stake-holders needs to be considered. Qualitative and exploratory methods were best suited for pluralistic evaluation, and enabled definition of the perceived advantages and disadvantages of care housing in comparison with its alternatives, presented in Chapter Four. Respondents articulated what they thought were the most significant inputs and outcomes and the links between these.

More specific questions emerged as the study progressed, which required a more structured approach to ensure data collection was consistent between case studies. The survey of moves in and out of care houses and the use of DCM to indicate well-being were independent measures of outcome. Dependency assessments investigated whether there was a discrepancy between entry criteria and the characteristics of the resident population. The interviews were semi-structured, though they included open questions.

The multiple methods complemented each other and permitted triangulation. Interview data enabled discussion of what underlay observed practice and indicated discrepancies between staff and kin that otherwise would not have been apparent. Being able to compare what residents said and did during observation with the statements staff and kin made at interview was important. Interview data allowed the survey data of moves in and out of care housing to be discussed. Using multiple methods however created problems, in that it was difficult to reconcile methodological assumptions inherent in each. In addition, it required a great deal of time to gain confidence in applying different methods and analysing a range of data types. It was particularly difficult to combine inductive and deductive patterns of analysis and

integrating the data sets was time consuming. The depth of analysis that could be achieved was limited by the breadth of the study's scope.

Using multiple case studies contributed to confidence in the study's findings. For example, each care house found it difficult to provide a home for life for all its residents. There were consistent patterns about who staff thought they could and could not care for, but variation between the case studies suggested reasons for differential success (see Chapter Five). The disadvantage of using multiple case studies was to decrease the depth of investigation in favour of breadth. The many participating organisations each had a stake in the study, which meant that negotiation was time consuming, as was further reassurance to staff, residents and kin, who had their own anxieties. At the outset of the study, when I was most unsure of what it would encompass, I faced most critical questioning from participants. Agencies wanted the study findings as soon as possible, which had to be balanced with the demands of a research studentship and reluctance to present partial or poorly processed evidence.

The volume of work on dementia care has amplified and this study ran parallel with other work making important contributions (see Marshall, 1997). The context in which care houses operate continues to change rapidly, and at least one of the case studies, at the time of writing, faces acute problems in securing revenue funding and may close. Participating agencies and staff groups are more experienced than in 1991 when the study began, and their experience informed further developments.

Necessarily, the evaluation could not be all things to all stake-holders. A discussion of the methods is not equivalent to a protocol for further evaluative assessment. The cost-effectiveness of care housing has only been indirectly addressed. The study does not address equity or access. The attention to the processes of care and the discrepancy in achieving aims diverts attention from the positive outcomes that some participants were keen to establish. Evaluation is applied research, where theory and method, developed through other academic research, both contributes and is tested. It requires skills in relating to academic and professional audiences, and confidence to assert principles, such as the participation of service users. The high hopes for the study's utility, widely expressed at the outset, were intimidating. Doing a research studentship funded by a policy, rather than academic, body required agility and assertion of its function in academic training.

Selecting evaluative criteria and measures of outcome are a potentially controversial task of evaluation. While adopting a pluralistic and, through DCM, a normative approach, this study did not systematically elucidate the subjective appraisal of the residents. The initial plan of evaluating according to individuals' preferences and in a biographical context was abandoned but should be considered in any further work in this field.

The management groups envisaged that evaluation could bring benefits indirectly, mainly in negotiation with other agencies, but also possibly in relation to



operational practice. This position meant that the process of the evaluation was cast as an undesirable, but necessary, prelude to dissemination of its findings. To the participating agencies, the study, if it had any utility, was important to negotiations with each other. Models of action research suggest the process of research itself may enable mutual learning (Guba and Lincoln, 1989) but the study was initially cast in a judgmental mould and this was set by the time the studentship commenced. Ironically, while a judgmental role was ascribed, a novice researcher was clearly inexperienced in the issues. The ascribed non-participant role proved to be in conflict with the gatekeepers' assertion that observation should be as 'natural' as possible to make residents and staff feel at ease. Some respondents chose to check the accuracy of the data recorded about them. For practical reasons, discussion of findings was limited and was confined to those providing the service, and did not include the residents with dementia.

The structured methods used, DCM and REPDS, were developed for use in formal care settings and did not cover the domains most relevant to household care. For example, assessment of instrumental activities of daily living and a more subtle category of 'work' than DCM provides would have contributed to the study. I was able to compare the use of a systematic, non-participant observation method in both small and large-scale residential settings and the method was evaluated in section 3.8. This experience strongly suggested that a disengaged observer is not easily tolerated in household care, where the emphasis is on engagement and participation. The DCM method did ensure that each resident was observed, which countered the temptation to focus on the more active residents, and contributed quantitative data used in Chapter Six. However, it was not necessarily the best way of establishing and contextualising well-being in this study. It could, for example, be used in conjunction with individual care plans. When observing non-participantly and systematically, you have to resist interruption, which precludes opportunistic interviews. For people with dementia, this is particularly important and I did occasionally break observation at residents' initiative, sometimes deliberately to give me some information. I became convinced that the best way to establish subjective views in this setting would be for an observer to spend time in shared areas establishing familiarity and trust while being explicit about the reasons for being there and letting residents approach on their own accord. Meanwhile an observer could be unobtrusively involved in household affairs. This approach would offer advantages over pre-arranged interviews, in that people with dementia control the timing and the agenda. In addition they would have had time to get to know the researcher and the researcher would be able to assess the validity of the data generated through other qualitative observation. The ethical concerns about gaining informed consent would be thereby reduced.

Some possible bias has been raised in Chapter Three. The methods used examined social rather than physical environment, though this has been justified as of particular importance to people with dementia. The range of perspectives presented is

biased towards those who received the service (but kin, rather than residents), those who developed and managed it, and those employed to support residents. For kin and agency representatives, the people who responded may have been biased towards those with most interest, or contact with care housing. A possible bias in the interview data towards a positive presentation of care housing was countered by observation, which was an important part of the study design. Comparisons between settings have largely depended on the subjective appraisal of interviewees. Observation was not conducted at night, nor at weekends, when activities and well-being may have varied from the weekday pattern. Like other evaluative studies, this has been completed relatively early in the developments' history. Nevertheless, as the next chapters show, this study has generated findings that are of relevance to dementia care practice and the development of further services, particularly when particular dependency characteristics are targeted and care is offered in pragmatic groups.

This study complements previous work, such as Dean *et al.* (1993) and Ritchie *et al.* (1992) and its concerns contribute to the evaluation of an important development in dementia care.



## **CHAPTER FOUR**

### **PERSPECTIVES AND COMPARISONS**

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This chapter addresses the first research question, presenting a pluralistic evaluation. Care housing is examined from the perspective of agency representatives, staff and kin and identifies both the perceived benefits and successes of care housing and inherent problems. The chapter opens with a review of the similarities and differences between case studies with respect to stated aims, physical design and staffing establishment. The participating agencies' interests in developing the case studies and the components of the staff's work and their satisfaction with it are noted. The events leading up to the move preface a section on kin's satisfaction. Respondents evaluated care housing in comparison with its alternatives and this is summarised to indicate what they perceived to be the important inputs and benefits of care housing.

#### **4.1 One, or three, models of care?**

While each care house was the product of collaboration between a Housing Association and statutory agencies, the resulting units were slightly different in design, staffing, and management structure. Were there differences in inputs that should be remembered in considering outcomes? This section compares the houses and discusses this point in relation to stated aims, physical environment, staffing and management structure, and also notes similarities and differences with other care housing developments referred to in 2.4. Some information about the case studies has already been given in section 3.2.1.

##### **4.1.1 The case studies' stated aims**

The operational policies and other documents devised collaboratively during the development stages articulated the philosophy and guidelines for practical care, the specific aims and objectives and the strategies that staff should adopt. The *raison d'être* for each was very similar, the following being a typical statement.

The [care house] aims to offer a domestic type of living in a small group setting for up to eight people who suffer from mild to moderate dementia. The objective is to encourage and promote ordinary daily living, respecting the rights and dignity of tenants; to ensure the maintenance of tenants' independence and choice; to support relatives and carers, as well as to encourage their involvement in the daily life of the unit... Residents also maintain or are enabled to maintain (or develop) their links with the outside community, using all the usual local community facilities.

Each unit endorsed household care, where individual patterns were to be preserved, with residents living in a homely setting and using it as fully as possible. Residents were to be helped to be as independent as possible, to be offered choice and to be involved in the day to day activities of home-life and in the running of the scheme. They were able to bring in their own possessions. Families and friends were to be enabled to share residents' daily lives as they wished. Family involvement was



envisaged as including direct care, going out with residents, and participating in a support group. Residents' participation in community life was to be facilitated. Each unit specified a local catchment area.

A domestic environment was seen as a positive social setting where the well-being of residents could be promoted. The care to be offered revolved around the daily life of the house; purposeful activity was a main plank of the anticipated quality of care. The role of more formal therapies was unclear from these documents.

As specialist units, care houses set out entry criteria. Nash Drive's entry criteria were for people who were moderately to severely affected by dementia while the smaller houses specified they were for people with mild to moderate dementia. Otherwise, criteria were the same: support was to be offered to people with a diagnosis of dementia; people who were unable to manage in their prior location; those who did not have specific problems, such as incontinence or aggressive behaviour; and those who did not need specialised medical or nursing care. Difficult behaviour and being too physically ill were reasons why someone might not be able to move in, and being able to live with others was an important consideration. The progression of dementia was not in itself specified as a reason to move out of the case studies. The principle that care houses should provide a home for life was clear, but not promised. Occupancy agreements allowed for the possibility that residents would be asked to move. Referral and assessment procedures regulated who moved in; after that review procedures were in place.

Whilst the stated aims of the three houses were broadly consonant, one difference was that the larger unit specified it was for people worse affected by dementia than the other two. Since dementia does not progress predictably, it is more helpful to describe aspects of behaviour and the type of physical problems that may or may not be acceptable. These were not well defined by any unit. During development stages there may not have been a clear view of what would be manageable, nor was it possible to predict what would be acceptable for specific resident and staff groups. The houses specifically noted they were unlikely to be able to accommodate people who had aggressive behaviour, severe incontinence, and who could not walk. Each unit placed emphasis on a social model of care, and one centred upon daily life in a communal household, with the assertion that this was beneficial to residents and their families. Formal therapies (e.g. reality orientation and reminiscence) were given some status in the larger unit, but the smaller units paid more attention to the benefits of household care and how staff should support residents in this.

#### **4.1.2 Physical environment**

All care houses had the advantage of being situated in areas of mainstream housing, in easy reach of shops and accessible by bus. Heartfield was the only one to

appear externally the same as its neighbours, an advantage according to proponents of normalisation (e.g. Regnier, 1995). It would be difficult to have mistaken Nash Drive for an ordinary house since it was large and stood alone in grounds, unlike houses next door. In terms of personal space, at least half of Heartfield's residents had to share rooms, while Redpath had the most private facilities for residents. Redpath's 'flat-lets' were consonant with recommendations made by Willcocks *et al.* (1987, see 2.2.3). For shared living areas, Heartfield's residents only had one sitting area while in other houses residents could choose where to sit and also go outside into a garden. Heartfield had a locked door onto a paved back green. The kitchen was least accessible to Nash Drive's residents because it lay within areas used exclusively by staff and had industrial-scale equipment. In the smaller units the kitchen was easily accessible from the dining area and more homely in appearance. Redpath had the only kitchen large enough to have a table where residents could sit, consistent with the recommendation by Foster (1991, see 2.2.3). Heartfield was the only house where the laundry lay on the route between bedrooms and living areas. Staff had most space in Nash Drive, which had the largest office, and a staff room with lockers where they could sit down and eat their meals. Overall, Heartfield felt cramped, unlike the other houses. Nash Drive had four more residents which meant longer corridors and the need to have more capacity for cooking, laundry and storage.

In short, while Heartfield would seem most satisfactory in being domestic in scale and in mainstream housing, it had the disadvantages of being comparatively small for the number of residents and also having shared rooms. Nash Drive had the advantage of being purpose-built, but its design made greater distinction between staff and residential space and assumed that staff, rather than residents, would do household work. Redpath's design would seem to offer most potential for residents to have both the opportunities for privacy and taking part in household life. Each house intended that residents should be able to live privately as well as take part in household activities, but the physical design made this easier for some than others.

#### **4.1.3 Staff establishment**

Different types of agency managed the staff in each unit and supervised the care given. This appeared to influence the formal procedures adopted and the ethos imparted to staff. The voluntary agencies managing the smaller houses had articulated philosophies of care that emphasised a social model of care to a greater degree than at Nash Drive, which was managed by a Social Work Department. Management committees were formed from the development working groups, including representatives of Housing Associations and statutory partners. Committees typically met quarterly, with a remit which gave them responsibility to determine overall policy and



monitor performance for the budget, for senior staff appointments and to negotiate with other agencies.

Each unit had a manager from within the managing agency who supervised the project managers and staff. Only one of these external managers supervised more than one care house, although this possibly had the advantage of allowing expertise to develop. The remit of the external managers included supervision of the project managers through regular (monthly or more) visits and to work with staff to ensure the care house was meeting its aims and objectives.

Nash Drive had the most hierarchical division of work, akin to local authority residential care. The two smaller units had a more egalitarian staff structure, either employing staff who were supposed to be inter-changeable, or designating caring as a primary role for all staff, with management, cleaning or cooking as a secondary role. This was intended to permit staff to respond flexibly to residents' needs.

The apparent advantage the smaller units had of a nominal 1:4 care staff ratio was offset by the additional input the larger unit had with cooking and cleaning. In each house there was expected to be a minimum of two waking staff on duty at any one time, except at night in Redpath, where there was only one. In Nash Drive and Redpath, night-workers were designated 'care assistants' and a senior staff member was on 'sleep-over' duty. There was usually fewer staff on duty at Heartfield (between two and three) than at the other units, and most at Nash Drive (between two and six, including secondees). In Heartfield there was relatively less cover by senior care staff, but all care staff had the status of being care officers rather than care assistants. Each house had additional seconded staff. In Redpath, a staff nurse employed by the nearby psychogeriatric hospital spent two hours in the house, three afternoons a week. In Nash Drive, a home help worked in the house 20 hours a week and Youth Training Scheme (YTS) trainees worked shifts with the care staff, but did not give personal care. In Heartfield, social work students worked on long term placements with the staff, for example 3 shifts a week, and offered more skilled input.

The qualifications and previous experience of staff was broadly similar for each care house. Induction and continued support was intended at all units, but had fallen behind at Heartfield, which was less well prepared than the others to cover staff sickness and holidays.

There were broad differences between units regarding the age of staff. At Heartfield there were no staff under 30, at Nash Drive the majority of the staff were in their 20s or 30s while in Redpath the staff were spread fairly evenly across the age range, from under 21 to people in their 50s. No house employed anyone over 60. At Redpath there were no male staff; Heartfield and Nash Drive employed one and three male staff respectively.

The two longest established units had retained up to half of their original staff by the study period, although at Redpath, there had been a complete turnover of senior staff. From the dates when staff joined the team, it would seem there were between one and three new permanent staff members each year joining the team in each care house.

Most care staff, excluding senior staff, were unqualified, though about a third had certificates such as State Enrolled Nurse, Scotvec modules and other basic social care courses, or City Guilds catering qualifications. Two of the project managers had Registered Mental Nurse certificates, but were not employed as nurses. Both of these had additional social work training, though neither had formal qualifications. Formerly, senior staff at Redpath had also had nursing qualifications, but not at the time of this study. Previous jobs held by questionnaire responders were broadly similar to their current work. Most care staff had previously worked in a similar capacity in residential care, hospitals, or nursing homes. More information on the content and organisation of the work is given in section 4.3.

## Summary

In summary, the care houses were similar enough to be seen as sharing a vision of household care, but the larger unit diverged in that its outlook was more formalised and less assertive about a social model of care. Some differences may have been related to its decision to care for people with more advanced dementia, but also the style of the managing agency was reflected. Each unit was differently endowed with the means to fulfil its aims. Heartfield was disadvantaged in some respects, but did have an intimate homely design that externally resembled housing. Redpath perhaps had the overall advantage, providing most personal space and facilities to its residents, and being homely in design and equipment, with a staff group who had the ethos of care strongly instilled in them and were well supported externally by seconded support and regular supervision and training. It would seem that if the model of care investigated in this study was to be effective in its own terms, success was perhaps most likely in either of the smaller units.

The aims of the case studies were consistent with contemporary views of good practice and endorsed principles of normalisation (e.g. Lubinski, 1991; Kings Fund, 1986) and revolved around the household. Of the care housing developments reviewed, Swedish *gruppboenden* are the most directly comparable to care housing except that they are a substantial sector in long stay care. Like care housing, *gruppboenden* varied in their location, design, scale managerial agency and staffing arrangements. Ability to provide a home for life depended on circumstances, unlike *domus* units in London that were developed as a substitute for hospital and always provided continuing care. CADE units saw themselves as primarily for people with difficult behaviour while Scottish care houses excluded people with behavioural problems.



## **4.2 The agency perspectives: interests and relationships**

This section considers the achievement of collaboration during development, a stage when the agencies' interests could be conflicting. The perceived success in operation is established, regarding quality of care, relationships with other agencies and further developments.

### **4.2.1 Collaborative development**

Each care house regarded itself as pioneering, and was seen by its advocates as a precursor to further similar developments. Heartfield was opened in June 1990, Redpath a month later, and Nash Drive in December 1991. Development was preceded by a lengthy discussion period. Initial informal discussions between agencies were followed, typically, by a year or more of intensive negotiation, when arrangements for funding, staffing and management were agreed by working parties established for the task.

In one area, the statutory agencies had been discussing joint projects for people with dementia since the late 1970s but had not hitherto been simultaneously able to commit resources. One Housing Association assiduously sought support from the area Joint Development Group, which consisted of statutory, community and voluntary agencies, for four years before opening. For two projects, a Housing Association offered an opportunity when building was already in progress, with capital funding allocated by Scottish Homes.

The interviews indicated that people involved in the planning stages welcomed the opportunity to put plans into action through collaboration. People involved were senior in their organisation. Good relationships were attributed largely to the commitment of the individuals concerned. A representative of Scottish Homes said:

Everyone was keen to see something like this done, we were pushing at an open door to do this. (A10 development 8)

The care houses were 'bottom up' developments in that they were planned locally (Baldock and Evers, 1991; see 2.2.2). The developments were, all the same, professionally led, with no representation of either people who might live in the units or their relatives. In the development documents, phrases such as 'admission', 'allocation', and 'were placed' occur repeatedly which, being in the passive voice, seem to contradict the ideal that people with dementia would be making choices. In the planning stages, more attention was focused on what would happen within the unit than on links with the community, presumably hoping that wider links would develop later. Whilst relatives were supposed to be involved in planning care, this was only possible after the structure of the case studies and the operational policies had been professionally defined.

## *The housing agencies*

The Housing Associations were pivotal in bringing the agencies together, especially because they could apply to Scottish Homes for capital funding. Two Housing Associations were national specialists and operated across Scotland, having built up expertise in providing sheltered housing, but were diversifying their activities. Housing Associations were keen to assert their potential contribution to Community Care to their statutory partners. In response to an increasing number of people moving from sheltered housing, including people developing dementia, these Housing Associations decided to develop projects providing additional support. Each association sought collaboration with social services and consultant psychiatrists to help provide expertise of working with people with dementia.

Tension between Scottish Homes and Housing Associations was noted in 3.2.1. All housing agency representatives agreed that at the time care houses were developed, there was no clear policy of what Scottish Homes was prepared to fund. Within Scottish Homes, opinion was divided whether it was appropriate to provide capital funding for care housing for people with dementia. One interviewee acknowledged that from Scottish Homes' perspective, it was helpful to be seen to support an innovative project in community care at a point that the agency was under criticism in the press and from Housing Associations. The development also fulfilled other policy aims, as it levered private funding sources and was located in a targeted development area. Despite this success, there were reservations about making further similar developments because the division of responsibility around 'housing' and 'care' was then unresolved. The critical question was posed as follows:

Are we stepping in and doing what the Health Board should actually be doing? That is where we are stuck at present. (A10 development 2)

Since Scottish Homes was unsure whether it should be doing the Health Board such a 'good turn', no similar developments were being made in this area. Another respondent suggested that another development for people with dementia, a hospital resettlement project, pushed the 'outer margins' of what was 'housing' rather than 'care'.

## *The Health Services*

Clinicians interviewed were committed to the ideal of providing good quality care in a domestic setting, which they thought had advantages over institutional care, and were part of a range of services that were needed for people with dementia. They agreed that care housing ideally would take pressure off in-patient facilities, to fill a



perceived gap between 'Part IV' local authority residential care and long stay hospital or nursing home care, and help some people avoid a move to hospital.

Two care houses played a role in resettlement policies, with the planned eventual closure of large psychogeriatric hospitals. In both units, half of the first cohort of residents came from continuing care wards. At Redpath a different policy was adopted from the outset. It was decided not to take people from continuing care into care housing, as this fitted better with the long term strategy of reserving long stay psychogeriatric care for people who were more disabled. Reportedly, there was a decreased demand for long-stay facilities, which was attributed to the development of care housing and other facilities in the area. Psychogeriatric services were being reserved for the most disabled people with dementia with difficult behavioural and psychotic symptoms. This psychogeriatric team gave considerable support to care housing by playing a role in assessment of prospective residents, in providing in-patient assessment and treatment as needed, and supporting the unit through regular input by a staff nurse.

Reportedly, the determination of a Health Board to secure nomination rights to ensure the resettlement of long stay patients created friction in the negotiation in the development of one care house. The Health Board managerial perspective was not obtained, but personnel in other agencies saw Health Boards as needing to resettle in-patients and keen to shed responsibility to other agencies before the new legislation was implemented.

### *The Regional Councils*

According to one representative by 1989 the then Regional Councils were becoming dependent on other agencies to develop services. The Councils, like Health Boards, faced pressure on services for people with dementia when demand was predicted to increase. Like clinicians, Social Work Department representatives wanted to find models of care that were more acceptable than existing institutional care, and were cheap. Care housing was seen to suit people with dementia who were not too demanding on care staff but who could no longer manage to live at home. One view was that the care house provided a pilot project to illustrate questions such as who could benefit from this provision, what appropriate staff levels and training were, what the cost was, and what appropriate boundaries between 'health' and 'care' were.

Regional Councils may have been reluctant to provide revenue funding for dementia projects that otherwise the Health Boards would be responsible for, especially in the reported absence of bridging finance from the health services, mediated by the Scottish Office, with which to develop such new services.

At the time the care houses were being developed, strategies for dementia care were undeveloped, as were the formal means of joint working. A practical constraint of multi-agency development work was that agencies had different financial infrastructures and planning cycles. In the context of the imminent implementation of the Community Care Act, there was considerable uncertainty about what strategic policies would be adopted and what the role of the local authorities would be. Decision-making in this context could only be pragmatic.

Since each agency was short of money for its own work, it was perhaps unrealistic to expect significant exchange of funds. Developing care housing was described, by a Housing Association representative, as a 'pinball machine' which required fitting the association's own strategic plans into the resources Scottish Homes, the Social Work Departments and Health Boards would commit. Thinking back, another interviewee commented that it had been a 'lucky chance' that collaborative working had been possible.

Collaborative working involved making compromises, which affected the physical design and the staffing arrangements. In the development stages of care housing, some changes were enforced to make the houses cheaper to build or to run, in the scale, personal space and facilities, or staffing establishment. The relationships between agencies were tested in two important areas: who paid for what, and who decided who should move in. Possibly, the involvement of Housing Associations meant that the developments were on a smaller scale than they would be otherwise.

Negotiation about respective roles and responsibilities was ongoing at the time of data collection. Redpath was unusual in that the managing agency felt equally well supported by its statutory partners. Elsewhere, problems had arisen, for example about the role of area Social Work Teams and community health services, and particularly in securing revenue funding. Respondents were well aware of potential pitfalls; even those who had local problems were pleased with the achievement of collaboration in developing a care house.

#### **4.2.2 The success of care housing**

Overall agency representatives were satisfied with the quality of care offered, but reported most difficulties in relationships with other agencies and services, and in securing funding.



## *The quality of care*

All respondents asserted that the houses offered good quality, innovative care to its residents, believing that residents were offered choice and an opportunity to exercise independence in a homely, non-institutional setting. The model was seen as having proven itself, offering considerable advantages to residents. All were emphatic that care houses were better than institutional alternatives.

Some managers suggested the quality of care prevented deterioration of dementia. Small size was felt to be important; those with experience of units for eight residents thought this should be the upper limit.

Some dilemmas in practice were noted, including risk management and how to promote the role relatives played and the use made of the community. Each care house was found to have problems created by its design. One opinion was that self-contained flats would have been better than bed-sits, as ultimately this would have given greater flexibility to the housing stock. Each unit was addressing issues concerning the management of staff, though managers had faith in the quality of care offered. A potential problem was that staff worked in isolation.

It was, by this point, becoming clear that the care houses were not providing a home for life in all cases; one reason suggested for this was that people were too dependent when they moved in. Every unit had to deal with the progression of dementia and increasing physical frailty. Decisions about whether and where individual residents should move to had not always been easy. Some interviewees aspired to providing in situ care in each case, others believed that a move may be in the best interests of all concerned, and that staff might keep people for longer than was ideal. One interviewee summed up concerns about care housing as follows:

Should someone live there until they die; what level of nursing care should be provided; what level of behavioural disturbance should be tolerated. (A11 hopes 5)

Apart from the challenge of providing a home for life, care housing was presented as a workable model which offered advantages to residents, and about which managers had gathered expertise. They felt supported in this view by good feedback from relatives and considerable interest from other organisations considering similar developments.

## *Inter-agency issues*

Each management group found that securing sufficient funds required ongoing negotiation. The specific arrangements for revenue funding varied; each house had to negotiate with the statutory agencies to meet extra costs not covered by the Department of Social Security allowances which most residents received. The implementation of Community Care required re-negotiation of a care package from multiple sources. If a

memo of agreement had not been agreed, annual negotiations were described as fraught and anxiety-provoking. This problem was compounded at one house by an initial underestimation of staff costs, with insufficient money to cover annual leave, sickness cover and training. To resolve a crisis in the short term, management restructuring and freezing of staff vacancies had been necessary. Some attempts were made to make the care houses more economically viable. For example, an increase of scale to fourteen residents had been approved at one unit by the end of the study period.

A trusting relationship between care house staff and the psychogeriatric team was highly valued but only existed in one house, where it was seen to benefit both parties. As noted above, the care house relieved the psychogeriatric service by supporting people who otherwise would be referred to them, and the psychogeriatric team helped to resolve difficult problems. Although believing nurses generally had an inappropriately medicalised approach, managers welcomed the secondment of a practising nurse, who had specialised skills to provide ongoing support and direct contact with relevant psychogeriatric services. The implementation of Community Care affected referral patterns and delayed, on some occasions, filling resident vacancies while waiting for financial assessment.

The principle was adopted that residents should receive support services within the care house only if they could not go out, but otherwise should receive services on the same basis as anyone else living in the community. General Practitioners were the first line for physical illnesses and filtered referrals to psychogeriatric services. At first some General Practitioners had assumed staff could manage specialised nursing procedures. There were local variations in community services available; for example some residents could attend lunch clubs, or transport could be borrowed. The use made of Home Help services varied from daily input, on weekdays, to none. Hairdressers came routinely to one unit but exceptionally to the other two.

### *The hopes of further developments*

All interviewees were aware of a need to demonstrate that care housing was cost-effective if it were to expand. Idealists argued that its effectiveness should be judged by the quality of care compared to institutional provision; pragmatists pointed to the competition for insufficient resources, and were apprehensive that cheaper, larger-scale models, such as nursing homes, would be developed instead. Those interviewed who were responsible for strategic planning tended to feel that care housing had not yet proven its case and that several points required evaluation. Reasons for this ranged from general financial viability of the model to more detailed questions about its contribution. What aspect of the model, if any, was superior to nursing home care? What were the inputs that made a difference?



Proponents saw themselves as piloting a new model of care. Housing Association representatives especially were interested in expanding the model, believing that what they had learnt would inform further developments. However, care housing made a very small numerical contribution to the Scottish long stay care sector, and had not developed to the extent its advocates had hoped. A range of reasons why further developments were difficult were suggested, including 'planning blight' while the impact of Community Care legislation was unclear, and an undeveloped infrastructure for collaborative work.

The issue of where care housing lay in terms of 'housing', 'health' or 'social' responsibilities, made agreement for both capital and revenue funding difficult; it seemed possible that funding agencies were 'stone-walling' when approached with plans for further developments. Scottish Homes referred to limited resources with which to develop Community Care projects; Health Boards were said to be increasingly reluctant to enter such agreements.

The advocates of care housing tended to be pessimistic about the future, thinking that the model would be compared to other provision by cost rather than for the advantages it conferred to residents. Generally, the opportunity to develop innovative, one-off projects was said to be diminishing, with purchasers showing conservatism towards 'tried and tested' models that had already been found to be relatively cheap.

Conceptually, care housing offered an alternative but, as one interviewee suggested, far more units were necessary to give true choice to individuals.

### **4.3 The support staff perspective**

This section considers staff satisfaction with the conditions and the nature of their job. It starts by briefly noting the content and organisation of the work and then considers its satisfaction and demands.

#### **4.3.1 The content and organisation of the work**

Staff worked three shifts, conventional for care work. During the mornings observed there were at least three staff of all grades working, which included the domestic and home helps. There were between two to five staff on duty until the night staff arrived.

In this study no attempt was made to quantify different duties but the self-completed questionnaire to staff (see 3.7.3) asked them to note the four main activities of their last shift. The morning shift demanded heavier physical work, with more leisure time in the afternoon. All care staff at Nash Drive recorded paperwork as a significant part of their work and administrative duties formed the bulk of the work recorded for senior staff. At other units care staff listed care tasks, and administration appeared to be a less

significant part of the senior staff's work. A number of staff at each care house included talking with residents as a main activity but at Heartfield the balance was heavily weighted to household work and personal care. For one staff member, talking with residents happened in 'left over' time after personal and household chores were done. The staff at Redpath appeared to have had more time with residents and tended to be more specific about the nature of this time, including baking, leisure activities such as a sing song, reminiscence and board games.

The personal care given consisted of washing, dressing, undressing, bathing, changing, helping people with the toilet, helping people with a meal and medication. Household care included helping tenants clean their flats, changing beds, shopping, cooking, cleaning, helping tenants with meals, serving meals and, at Redpath, helping with mail. Reassurance to people when they were disorientated at night was a feature of night staff's work as was helping residents who might be incontinent.

At Nash Drive the cooks' formal role was limited to the preparation or serving of food. Kitchen staff wore 'whites' and did not undertake personal care. The domestic sometimes worked in the kitchen, but normally worked with a Home Help to make sure that each of the residents' rooms and all the public areas were cleaned each day. The way the domestic at Redpath talked about her work was less task-oriented; here the emphasis was on helping residents keep their flats as they would like them, and on the way she interspersed conversations, and personal care such as helping people dress, with the cleaning. She did not however bath people. The cook at Redpath also did caring tasks, and at her request, worked a late shift each week where she acted as a care assistant rather than cook.

The staff nurse seconded to Redpath arrived in time for hand-over, discussed any problems raised by staff, and then organised a group activity, or individual assessments if required. Her remit required her to liaise between the hospital psychiatric services and the care house staff, and to support the staff with care management and medication, and to set up group work.

Each resident had a key-worker whose responsibilities included liaising with relatives, updating care-plans, and preparing reports for review meetings. At Redpath, the cook and cleaner were expected to become key-workers, unlike at Nash Drive. Nash Drive had 'split' shifts where each care officer worked only on one 'side', that is for the six residents living in one wing.

#### **4.3.2 The conditions of the work**

Staff were asked at interview for their views on what would help make their job better and improve the quality of care they gave. They mentioned the components of the work, design, the conditions of employment, the staffing establishment and training.



Staff at the smaller units supported the principle that roles should be flexible. However, Heartfield's staff were unanimous that employing a domestic was important, because the household tasks, namely cleaning, cooking and laundry, were excessive and this prevented staff spending time with residents. Staff at the other two care houses responded differently to the question about any inappropriate aspects of their work. At Redpath, no aspect of the work was reported to be inappropriate. At Nash Drive, specific points mentioned had been acted on. For example, a male member of staff had found female residents were unhappy when he gave personal care and this had been taken over by female staff members.

The work could be made more difficult if the unit had not been designed with the needs of someone who was physically frail in mind. In Nash Drive, doubts were expressed about the appropriateness of the design, especially of the industrially equipped kitchen. In Heartfield, bathrooms were reportedly too small, the laundry equipment inadequate, and the bedrooms were poorly designed if residents needed to be lifted. Apart from the very small office space, there was nowhere where staff could have meals in privacy, or recuperate from difficult situations. Ironically, staff with the least space available were divided on whether a staff room was necessary, but the staff in the house where there was already most space, wanted more.

Staff at each house thought it was unfair that they did not get extra money for working anti-social hours or holidays. Even where staffing levels were recognised to be very good compared to residential care, extra staff were wanted, firstly to deal with heavy work when residents became physically frail, and secondly to enable staff and residents to go out of the house more than they were currently able to. Staff thought that more staff time, or specialist input, for activities with residents would improve the quality of care.

At each house, there was demand, expressed in both interviews and questionnaires, for more training to be provided. Care-staff wanted to learn more about the process of dementia, new approaches developed in dementia care, and also specific skills, such as lifting and first aid. A course by Tom Kitwood was very popular with staff at one house who had gone because it was felt to endorse the approach they took to dementia care.

The care house that was managed by an experienced specialist Housing Association appeared to have been particularly successful in providing training and supervision. This was valued by the staff for supporting the work that they did. Staff were notably less satisfied where there had been a history of lack of supervision and training had fallen behind as a priority. With some exceptions, staff thought training important and wanted more, for example to gain recognised qualifications and in specific aspects of the disease process and care for people with dementia.

A controversy emerged about whether nursing training was helpful to work in care housing. One member of staff, who had nursing training, had been criticised for bringing this approach into her work. Expectations about equipment were one aspect of this; why should staff and residents be put at risk by using 'domestic' items? More subtly, some comments implied that people with nursing experience were assumed to undermine residents' independence because they were too inclined to take control and give instructions rather than offer choice.

#### **4.3.3 The nature of the work: its satisfaction, and demands**

In interviews many staff stressed that their work was rewarding and enjoyable and that they were proud to be associated with care housing. Heartfield's staff in particular thought that satisfaction came from it being a small-scale house, with its 'family' atmosphere and ethos of fitting in with residents rather than performing routine tasks. When drawing comparisons, staff described working in care house favourably with other caring jobs:

S22: Why is this the best job that I have had? I'm saying I'm tired, maybe I have less stamina now, but the workload (in the hospital) was much greater. When I came here (I found) it was easier but you had more time for what the job was really about, making them happy, getting to know them - that makes it a better job, they know us, our faces, recognise us when we come in. That's where it benefits, it's a more personal thing.  
(S22 staff job 35)

Staff at each care house enjoyed being able to talk to residents, to get to know them, to go out with them, and learn from them. 'Breakthroughs' were additionally rewarding, such as receiving a comment from a resident who rarely spoke, or seeing people who had recently moved in improve or relax; for example:

S8: What I enjoy mostly is seeing the enjoyment of the tenants of a particular thing at the time, relaxed, happy, the only thing you can enjoy is that, you can see you are doing something good, you see someone coming in distressed, see them settle down with a good quality of life. (S8 staff job 68)

Enjoying the company of colleagues and having hours that suited could also be important. The cooks found the kitchen side of their work less rewarding than the interaction with residents. Staff found it satisfying if they thought that their care produced improvements or helped residents. They were focused on the immediate, day to day, achievements of people with dementia. The other side of the coin was when residents' dementia worsened, and they died.

KF: Is there anything about your job that you particularly enjoy?

S27: I enjoy working with tenants, and the client group that we have. It gets harder as dementia gets worse because you have seen this person at their best, and suddenly there is this person who does not know we're here ...

KF: Is there anything about the work that you find hard to handle?



S27: The dementia side of it, I can handle physical frailty but as their memory gets worse, it's hard - for the tenant too, you have to explain why she cannot see her mother - both of you can be in tears, it's really difficult at times, they can be brilliant then five minutes later have lost it again, it is hard to handle. (S27 staff job 13)

From day to day, dealing with the deterioration caused by dementia was physically and emotionally demanding. One staff member said it could be 'hard and thankless work'. Repetitive questioning was found especially wearing.

KF: Is there anything about the work that you find hard to handle?

S5: So many things - the tenants not being able to understand what you are trying to do, hitting your head off brick wall - or else they may be a bit abusive, when you are doing your best, for no reason - you need to forget that, because they have forgotten it, you have to put it behind you, not take it personally. (S5 staff job 69)

Decline in residents' health could mean the loss of people staff had become attached to. Several staff asserted that 'giving a bit of yourself' was an essential part of the job, and this was because the group was small. Not all staff were prepared to become involved to the same degree; some felt a need to protect themselves, for example if they had themselves been bereaved recently:

Not out of sight, out of mind. You do get involved as small house, but you can't get so it takes over your life, you need to be sensible. (S8 staff job 111)

An ex-nursing auxiliary wished to limit her contribution to giving 'TLC' (tender loving care), and leave the work behind her when she left.

As I see it, I am here to care for them 8 hours a day and I do that 100%. But I am not here to take over their life, but to bath, comfort, them. When I go out of the door, my job stops. If there are things to be done, there is more the families could do. That is a difficult one, not every family can. They are not my parents, I am here as their carer, for the 8 hours of their shift, not to be their minder. (S22 staff job 26)

The work was described as being hard, difficult, and sometimes draining, needing both a thick skin and dedication. It could be emotionally too much if a staff member had to care for someone with dementia at home as well. One opinion was that this work should not be done for too long, say for two or three years, as the demands and relationships of this kind of work in a small house were peculiarly intense. It seemed important that staff felt valued in order to continue to derive satisfaction from caring for people with dementia. Being associated with an innovative model of care helped staff feel that their work was recognised.

#### 4.4 Kin's perspective

Kin's accounts of the events leading up to the move indicated that supporting their relatives with dementia was demanding, and required skill and flexibility. The interview data also told of the problems facing the people with dementia. From the descriptions

given, it appeared that a move from home was initiated by kin in liaison with formal care services. The satisfaction kin had with care housing was entwined with the benefits they perceived for their relatives; this section ends with a resume of the benefits kin experienced.

#### **4.4.1 Providing support at home**

This section examines what led up to the move. The survey data suggested that over and above having dementia, people moved from home to care housing because they were in danger, and kin were having problems in supporting them. Kin interview data indicated that support had been needed for up to five years before the move, and this had intensified in the last year or two. All but one interviewee, who was elderly, had provided direct and regular support, and it seemed that those caring for a parent had been able to offer most help. Over time, kin had gradually taken on more tasks. It was a process of continual adjustment:

**K12:** It felt it would even out for a few weeks, then it would hit another snag, like starting to do her shopping, and then she'd start hiding things... (K12 lead up 19)

Kin had mentioned in particular the difficulties in ensuring that their relative ate regularly.

**K11:** I know that she was having her lunch because I made it, I would say "Have you had your breakfast?". "Yes, I had an egg and a bit of toast" - and I'd count the eggs the day before and there hadn't been one used, but you didn't argue with her. Again I was leaving stuff for her tea and it was untouched when I went in the next day, but if I left biscuits, I could leave two packets and they'd be finished, eventually what I had to do with the biscuits was leave her so many and hide the biscuit tin. Her neighbour down the stair - anybody who visited her knew where I had put it so if they were coming in and making her a cup of tea or having a cup of tea with her they could have biscuits. (K11 lead up 64)

The elderly people lost weight. If they did cook for themselves it was also worrying. Kettles were often a problem, for example plastic or electric ones could be put on the stove. Gas stoves or fires were also hazardous.

**K2:** He would put the gas cooker on, walk away and not light it, then walk back maybe fifteen minutes later and: "Oh I've not lit that!" and light a match and pouf.  
(K2 Lead up 70)

Having started to provide personal care and help with household tasks, the next step was often undertaking responsibility for finances, particularly paying bills. This was part of the process where kin took more decisions on behalf of their relatives. Commonly, kin visited daily and sometimes more often, with consequent strain on themselves and their families. They saw changes in relatives, such as an uncharacteristic apathy or lack of concern for appearances. One described how she found it increasingly difficult to persuade her father to care for himself, and could no longer reason with him or cajole him, as she had before.



K2: I think he got frightened as well because he knew within himself there was something different about him and I think he got scared. He certainly got scared at night, because when we were going away, he wanted one of us to go and one of us to stay, but he wouldn't come and stay with us, he wouldn't give up his house. I wanted to give up this house with all the steps and take a house with a flat and bring him to stay with us and we would have taken an extra room and just let him get some of his furniture, as he is now, but he wouldn't come here. (K2 lead up 71)

While people with dementia may have wanted to move in with their family, most kin did not feel they could manage this, though all interviewed had considered it. Family commitments, other practicalities, or the nature of the relationship prevented this. Where families had tried such a move, it was not marked by success. One example of someone who had particularly good informal support (K11) was a woman who moved to her daughter's house, but the daughter could not manage. She moved back to her own house and her son supported her for over a year, but he and his siblings were now retired and facing problems of old age themselves.

Some people with dementia were evidently anxious, perhaps repeatedly phoning for advice and reassurance. People living on their own became isolated and dependent on carers' visits and community services for contact, and may have been on their own for large parts of the day and at night. This was worrying should they fall, or cause fires.

Even those who had a network of informal support could not rely on this support and over time it reportedly diminished. For the woman described above (K11) a 'small core' of neighbours and friends sustained practical support until the move, but others had dropped away, perhaps because they were sometimes blamed for removing things the person with dementia herself had mislaid. People were on their own for long periods, perhaps from early afternoon until the home help came the next morning. Another woman, who was fond of company, had in her relative's opinion (K1), latterly been 'buying friendship' and had become lonely. Perhaps visitors became bored by her conversation, as she disguised her confusion by agreeing with them. One or two neighbours did however continue to provide regular practical help.

Kin built up knowledge of the services available to them, though referring to initial lack of information. Some families were comparatively well supported. For example one man had home help twice daily, a community nurse in the mornings, a 'tuck-in' service three evenings a week and regular respite care (K2). This support was praised highly by the carer, who referred to an 'army of helpers' who worked closely with herself and her husband. In contrast, another man living on his own only received home help twice a week for an hour (K4). Some services were found inappropriate, particularly meals on wheels that seem to have frequently lain uneaten.

Kin could be angry if they felt they or their relative were not consulted individually and respectfully by professional carers. They could also be irritated when professionals offered the people with dementia choice, for example to use respite care, and they

refused. Kin believed that support was desperately needed, but because of their illness, their relatives could deny this.

Getting support was the main reason all interviewees gave for the move, which was not driven by housing need, though for one (K4) the neighbours and locality had been one of the biggest problems. Unsympathetic neighbours would assume that he was drunk, and not let him in the door entry when he had lost his key. He would then be blamed for 'messing in the close' when he could not get to his own flat. He was allegedly being cheated in the corner shop, and the situation could not be improved. While features of the house, such as stairs, or living next to a busy and dangerous road, had been problematic for some, housing need was in no case the drive behind the move.

A changed physical setting could worsen matters. One woman moved to be nearer to where her carers lived (K9), but was said to have never settled and deteriorated. Another man was 'bamboozled' by renovation work in his house, which had been kept to a minimum because he had refused to leave his council house.

K2: So the outward appearance of his home changed although it was just the colours and the paper and the carpet, things like that, but it was too big a change for him, I think, and I really saw a difference after that. It was more confusing to him after that, it confused him more. Even with the central heating, you would go in and you'd be frozen, he would have switched it off, he liked to play with buttons. (K2 lead up 75)

Critical incidents, such as flooding a bathroom or wandering on to the central reservation of a motor way, occurred. Being phoned repeatedly at night by the person with dementia or by concerned neighbours was a common problem. Eventually, the strain became too much for the carer and their family. Having described the situation, one interviewee said:

K7: I don't think any family can, or should, cope with that. For each family, a point will come at [some] stage - she went way beyond that point. (K7 lead up 32 )

In summary, the kin's account left one in no doubt that the support needed by people with dementia was substantial. It included help with the activities of daily living but incontinence and aggressive behaviour were not mentioned as problems. Kin had used up their resources of energy and ingenuity to deal with the situation, and the community services were inadequate, even when a substantial amount of daily help was provided. Informal support could not be relied upon, even where people with dementia enjoyed good relations with neighbours and friends. Kin portrayed their residents on one hand as becoming more anxious, and on the other, finding it difficult to recognise their own needs for support. Kin compared their relatives with how they had been in health and the changes were distressing.



#### 4.4.2 Taking the decision

Kin, rather than their relatives, were the ones to raise the possibility of a move from community housing. They prioritised getting 24-hour support. People with dementia appeared to be either passive or resistant to the decision that they should move, whether this was from community housing or other settings. A period of negotiation, both with their relatives, and with health and social services, preceded the move into care.

K4: So I felt it was time for action. I was offered hospital, to put my [relative] in there, but it felt to me that was not on. Then my [relative's] social worker told me about this place. (K4 lead up 5)

Kin who were involved in a move from community housing worked directly with formal services on behalf of their relative. GPs were important in mediating and legitimising the move, and had advised some interviewees to take a break from the strain. This seemed to reassure kin that they had taken the only possible decision.

Even when generally good relationships within families were reported, people with dementia did not appear to have insight into the degree of strain kin were under, but were instead portrayed as being demanding and anxious. In the quote below, the last sentence was said in a resigned tone, implying both sadness and acceptance of a poor memory.

KF: What did you say to her about the move?

K5: I said: "Mum this is the best, people looking after you". "I don't need people looking after me, I'm perfectly capable of looking after myself." Trying to explain that this was best, was difficult, difficult for her to accept. Eventually - though even now she will say occasionally: "When am I going home to my own wee house? They all do it. They say: "The son - sold your house, sent you in here, out the road." We always laugh at it.  
(K5 hopes 27)

Kin had had different degrees of success in persuading their relatives that the move was for the better. The stigma with which the residents' generation regarded the former asylums was one factor. Residents who moved from hospital, if they talked about it with their relatives, were glad to leave a setting they disliked and had complained about. People did vary in their attitude to residential care. Exceptionally, one woman had, while still healthy, declared that she would prefer to go into care home rather than be a burden on her children (K11). Once the dementia was evident, and although her children supported her as best they could, in her clearer moments, she repeated this wish and discussed the care homes that she would prefer to move to.

K11: She used to say: "I'll need to see the doctor about going into care, because [the home help] is going to come in some morning and find me lying". When she had her brighter periods she would think about it. You have your qualms seeing your mother going into care

but at the same time I had no qualms because she always said: "That's what I want to do". (K11 hopes 179)

This resident did not know about care housing, and named a Local Authority residential care home as her first choice and this was interpreted as a strategy to maintain her independence, in that she would not be dependent on her children. If residents had a different attitude, it could make the decision very painful for kin.

K12: She used to say: "If I ever get put in a home, I'll jump in the river". So I felt mixed emotions - relieved - that was not to the fore. The worst emotion was: "I'm putting her away." That was the hardest part. (K12 hopes 10)

In the event, both these residents were said to move willingly. One resident, whose relative was exceptionally pleased with the benefits he derived from care housing, had strongly resisted the move (K2). He was described as 'rebellious' and had wanted 'his army of carers' to continue their work, but unfortunately they were unable to do so.

Staff were occasionally critical of the way residents had been prepared for the move, for example when someone had been told they were coming in because they were ill and now thought she should go home, or when someone had left her home in a rush because of the family's anxiety that she should not lose her place.

#### **4.4.3 Kin satisfaction**

Kin's satisfaction with care housing derived in part from the benefits they perceived residents to gain. It was difficult to distinguish their hopes before the move and subsequent reflection. The staff had actively reassured kin that they had taken the right decision, and most had by this point come to terms with the move. Some kin still reproached themselves, but in interviews re-iterated that there had been no choice and that things were now considerably better for themselves and their families.

One respondent described her initial reluctance to entrust the care of her relative, for whom she cared deeply, to staff whom she did not know. She had been reassured by getting to know what the house was like.

K4: But when I actually visited [the care house], I got a whole different idea about what it could be, I was actually amazed when I saw the place because what they try to achieve is to keep the person's life as independent as possible. They have privacy, they have the room, they get to go out, they choose the clothes, things like that - that would not happen in a hospital. Still have part of their independence there, making a decision as to whether they want to do something or not. That helped a lot to put my mind at ease. The more I went, the more I liked what I saw, the way the staff treated their patients. (K4 hopes 2)

As the named next of kin, interviewees were the main link between family and the staff. Some wanted to be more active in this role than others. For example one family



was reluctant to entrust care to staff, while another, who was critical of her relative, was very pleased to hand over responsibility. She said:

K6: I have no responsibility for him at all now - they've taken him over, and I've been delighted to hand him over. Not in a rotten way, it's just nice to know that they're looking after him and I don't have to worry. (K6 hopes 16)

Some kin described the staff as being the 'experts', or 'professionals' and were content to leave the details of residents' care to the staff.

K10: As regards how the day to day care, I always feel these people are more qualified than the likes of somebody like myself, they've all been at college to learn all these things, so I would think they would know better how to run things than the likes of me saying to them certain things. (K10 kontakt 70)

Others felt that their own knowledge of the resident meant that they knew what the resident wanted better than the staff could, or they themselves could persuade the resident to do something more easily.

Kin, especially those whose relatives had lived at home on their own, said the move had offered peace of mind. Those closely involved in caring reported that their family lives were less strained, as the following quote suggests.

KF: Has living here offered your mother what you hoped for?

K5: Quite categorically what I hoped for, yes. It may not be her aspirations, obviously they (people with dementia) have a different outlook on things. I said I found a tremendous load off my shoulders when I knew she was getting 24 hour care, with people who understand the problems, in general. (K5 hopes 30)

Peace of mind came from being sure that residents were well cared for, and that staff were alert to their needs over 24 hours. For kin who rejected alternatives, the only choice would have been to provide support at home. For one woman, this could have meant giving up her job which she had not wanted to do. Any worries or reservations about the move related to whether the resident would settle in to care housing. When asked about the future, and what they hoped would happen, kin unanimously hoped that the resident would be able to stay in care housing.

All kin were satisfied with care housing but, like residents themselves, differed in the degree to which they had accepted the move. Some residents were relieved, and were more relaxed than they had been previously, becoming involved in the life of care housing. Others had resigned acceptance, or might complain about being abandoned. Unsurprisingly, relatives of those who had accepted the move relatively well seemed most sure that it was for the best. Some noted that they had not really known what to expect as it was a new model of care with which they were unfamiliar; others said that it had exceeded expectations. Three kin, one from each care house, were particularly well satisfied. Others had found some concerns to temper their general praise for care

housing. That each house had the experience of at least one family who was critical of the care given was acknowledged in staff interviews.

All interviewed were sure that care housing was better than any possible alternative, including living at home, given the circumstances of their relatives' dementia. The physical care and availability of support to the resident was thought to be good; residents had enough to eat, the food was of a high standard, and they lived in a clean warm setting. Having hair regularly done and being well dressed was evidence of this. Kin appreciated the amenities offered by single rooms, with the attached WC, perceived benefits being privacy and the opportunity to keep to a personal daily pattern. Kin whose relatives had shared rooms were critical of the consequent loss of privacy.

Staff, correctly it seems, believed kin were helped by knowing that residents were supported 24 hours a day, in a setting that offered better quality of care than other forms of long stay care. Having seen a number of relationships, staff were aware that it was not easy for families to adapt. The illness had strained and divided some families, and some relatives found it difficult to accept changes and hence might avoid contact. Influences on the type and quality of family contact were suggested, namely the type of kin tie, the quality of existing relationships, family history, how busy kin were, and how far away they lived. Kin interviews also suggested that there were differences in the success of resuming relationships after the move. One daughter said she had taken a long time to adjust and accept the move, and good relations had not recovered.

**K3: I'm the baddie because she doesn't believe that she went there of her own free will, I put her there and she tells everybody that I've put her out the house and won't let her back in the house. (K3 kontakt 175)**

Although all kin were aware that residents had dementia, and did not expect a cure, they were from day to day puzzled and frustrated by the illness and struggled with the way that dementia had interfered with residents' awareness of and involvement in family life. Sadness about the changed relationship was evident: one interviewee, who was resourceful, said that it felt at times as though she were up against a brick wall.

**K1: I said to her on Wednesday: "This is mother's birthday today" and I got no feedback. She just said: "Oh yes, uhuh". I said: "She'd be a hundred if she'd been around today". She said: "Oh would she". But it doesn't mean a thing, and I said: "This is St. Patrick's day today..." (K1 kontakt 103)**

Staff believed that a sense of loss could be mitigated by helping kin play a role, for example in giving direct care.

While maintaining relationships between kin and residents was at times difficult and not always successful, kin and staff agreed that relations between themselves were in the main good. Kin positively described staff as being very nice, friendly, and always



making you welcome. Kin were hesitant in distinguishing between staff, in case this was taken as criticism of individuals, but they did note that some were more or less forthcoming with information, and some were more friendly and hospitable than others. At one unit, kin were inclined to criticise the staff for not communicating about details of residents' care, for example whether a doctor had visited, and why.

Staff thought kin were satisfied with the care given in care housing, since kin had not complained, and kin had said to staff they were pleased that residents lived in care housing. Some staff, perhaps those who had themselves cared for relatives with dementia, could empathise with the position of kin better than others. As one member of staff suggested, privacy was lost on moving to the care house, as residents and kin gained on-lookers on their relationships. Some staff realised kin were likely to be very sensitive to any implication that the staff knew residents better than they did. From kin interviews, a lack of confidence was evident in using the house, in approaching staff and in unwillingness to complain. Several staff seemed to make rather readily assumptions that kin could and did make themselves at home in care housing.

The place of carers' support groups was unresolved at the time of interviews, and there was a varying level of commitment to the idea. Carers' groups had not run as envisaged in any unit, and staff hoped to improve this. Like kin, staff were not clear on what the prime role of these groups was: a means of support to carers; a chance to have a say in running the unit; or as a means of fund-raising. One opinion was that it was generally inappropriate for amateurs, that is relatives, to interfere with what professionals did, and that sharing experiences as a kind of therapy group was a waste of time. Another person wished that kin had a chance to put their point of view across:

K4: If things were happening that you did not really like, you could discuss it as a group, not to put anyone down, just to give our points of view on how they could do things better. Sometimes it's not always the professional level that's right, sometimes an outsider looking in can see things that could be done differently. (K4 kontakt 11)

Most kin were by and large satisfied with the care given and how the unit ran, and did not necessarily wish to exert more influence formally. The informal contact during visits, and their confidence that staff would contact them should any question or problems arise, was often felt sufficient. Instances where there had been grounds for complaint, such as lost items, had been dealt with informally and directly with staff who had responded.

In one case kin reported poor communication by staff and failure to take account of their preferences and expertise. The use of tranquillisers, which did not apparently help but instead subdued the resident, was a particular complaint. This case raised issues. How should staff best learn from kin about individual residents? How much information should staff give kin, and should this extend to information about other residents kin had become friendly with? Should details be regarded as confidential, given



on request, or routinely? How much could and should they expect the residents to communicate? Staff thought problems arose because kin felt guilty and there was dispute about what the personal standards and wishes of this resident actually were. Staff however had responded to comments from a number of relatives by changing some aspects of practice, particularly in giving information.

#### **4.5 Care housing: alternatives and comparisons**

This section considers what respondents compared care housing to, and how they thought it differed from these alternatives. The only realistic alternative to care houses was institutional long stay care, not community housing. Staff and kin were unanimous that a move to the care house had been the best solution in the circumstances. What interviewees thought was wrong with alternatives, and how they thought care housing was better, leads to a discussion of the perceived benefits of care housing.

##### **4.5.1 The alternatives**

From section 4.2, it is already clear that the case studies were developed as an alternative to institutions. While Housing Associations suggested that it was a form of housing, for local authorities care housing offered an alternative for people who were accommodated with difficulty in Part IV residential homes. Health Boards hoped the units would relieve pressure on continuing care in hospitals. In practice, the experience of kin strongly indicated the only possible alternatives to moving to care housing had been institutional long stay care rather than solutions offered by community care.

As section 5.1 will detail, Scottish care housing residents had moved from community housing, including sheltered housing and relatives' houses, from short and long stay care, and from nursing and residential homes. Collectively, the kin interviewed had experience of all these settings that the residents had moved from. Three of the five kin whose relatives had been in hospital had actively sought a move because they were dissatisfied with what was offered. Kin of people living in community housing had turned to long stay care as it appeared that neither sheltered housing nor community services could offer the care needed. Hospital was seen as a last resort, to be avoided if possible, and care homes only slightly better. One person with dementia had refused to move to a residential home and one kin had rejected nursing home because it was not affordable. Having learnt of the existence of care housing in their locality, two kin were particularly insistent that their relatives should move there, rejecting all other possibilities, as one explained:



K4: I visited a lot of homes, to me they were basically institutions, I felt if I was putting my Dad in there he would have given up, he would have wasted away, it would have been the end of it, and I don't think I would have been able to live with myself if I had agreed to anything like that. So when Heartfield came up I thought that was the place I wanted for my dad. Maybe it was being a bit selfish, there's only eight places there, but that was how it was. That or nothing. (K4 comparisons 2)

Others heard about care housing from professionals and, deciding that it seemed better than alternatives, agreed to the proposed move.

Kin drew comparisons with where the resident had lived previously. They also compared care housing with their general experience and impressions of hospital and residential care. Thirdly, some considered it to be the ideal setting for the resident. Staff mainly compared care housing to long stay care settings they had previously worked in, and the references made to community housing tended to be idealised. Staff at the smaller units were markedly more likely to use community housing as a reference point than staff at Nash Drive.

In drawing comparisons with where else residents might have been living, the vast majority of the data from staff and kin related care housing to care homes and hospitals. Distinctions between different kinds of institutional care were usually, but not always made, with comparisons being made to hospital, residential care and nursing homes in decreasing order of frequency. Very occasionally, specific places offering specialist care for people with dementia were mentioned. Intensive support in the community was a hypothetical possibility rather than something interviewees had experience of.

### *Community housing*

The most important limitation of all forms of community housing were that they could not meet residents' support needs. Though sheltered housing offered some support in the early stages to one person, later the warden and kin in combination could not manage and other tenants were disturbed. People who had lived in relatives' homes had grown to need more help than could be provided. Those who had lived on their own may have been lonely, and anxious about looking after themselves. One relative considered whether it would have been preferable for the person with dementia to have stayed at home, but with more support.

K11: No, I don't think people realise that staying at home, the worst thing is the loneliness, it's all right this community care in their own home, but two hours or 1 hour a day of somebody going in, 23 hours a day on their own, maybe not if their family live all round about them with weans and daughters and sons and nieces and nephews coming in and out, but if they are on their own, with no family round about, 22-23 hours a day, it's not a very nice thing for anybody.

KF: Did she ever say she was lonely?

K11: Oh yes, often she used to say: "I never see a soul from one day to the next" and she'd stand at the window. (K11 comparisons 69)



Moving to care housing meant that support was available 24 hours a day, and that both kin and residents could be reassured that household affairs were under control. This was sufficient to remove doubts that this had been the best thing to do. One member of staff explained this as follows:

S9: There is a lot of fear with the illness, they know what is going on and that they are not functioning for most of the time - unlike the myth about dementia - so being in their own home or sheltered housing is frightening for them. Once they have learned they can trust us here, they don't worry about the things that they have not done, like lock the door. It takes a lot of pressure off them. In their own home, they maybe have been up twenty one times at night to check if they have locked the door. So it must be an improvement, but you'd need to ask the residents themselves - I can't answer for them, but looking at the improvement in the residents, I'd think so. (S9 comparisons 2)

### *Hospital*

Every respondent, whether or not they had direct experience of long stay care in hospital, pointed only to its negative features. Hospital was thought necessary only if someone became 'ill'. Hospital care was described as depersonalising and degrading. This was attributed to dormitory accommodation, the low staff ratio, and the lack of opportunity to have personal possessions or to decide how to spend one's time. Respondents believed that people with dementia in hospital did not get the care they needed, and that they might be given less attention than those with acute medical needs.

The five kin whose relatives had stayed in hospital all referred to their experience. Even those who had not actively sought alternatives condemned hospitals. One resident had been in three different hospitals that were seen to vary: at one place the staff had been kindly and had attempted to 'bring him out' by sometimes playing dominoes, whereas at another hospital, the staff had been neglectful and rough with patients. Another bad feature was the other patients, according to this respondent:

K6: The poor souls he was in among, they really were awful. Shouting and shrieking and carrying on, far far beyond what he was, he was quiet, he just sat there. And he was left to sit there. (K6 comparisons 12)

In contrast, staff at the care house were praised for the care they gave, which was seen to have made a positive difference. Indeed, all those describing a move from long stay care to care housing noted subsequent improvements in residents.

KF What difference did you see in him?

K6: Just the fact that they could talk to him, and help him to recall things that he had totally forgotten. They really spent time talking to him and being nice to him generally. He is well looked after with respect to dress, and is fed. I really felt he was lucky to get in there, after all the different places. (K6 comparisons 10)

Such condemnation of the attitude of the nursing staff was untypical. More commonly, kin were reluctant to criticise nurses, blaming instead the high ratio of



patients to staff or the physical setting which made hospital feel 'institutional' compared to care housing. One interviewee explained what had made them want to find an alternative.

**K7:** She recognised [the hospital] as what it used to be, in the old days, a workhouse, asylum, and people of that generation had an in-built opinion of that place, my grandfather was there a while, she was desperately unhappy to be there - the surroundings were very much institutionalised, an organised asylum type of place. Not sterile as I was going to say, a bit smelly, few nurses, no real communication between staff and patients. They were up in the morning, fed, most of the time they were dressed, never in own clothes, clothes got lost, glasses got broken - at five or six in the evening, because of the staff ratio, some of the patients were already being got ready for bed. That went on 'till seven or eight so if you went along to visit for the evening, unless you phoned in advance, you might not find her dressed. It was an upsetting place to visit. The doors were locked, so you felt imprisoned - to take her back, given the scenes we had, you came away more upset than ever. (K7 comparisons 32)

Later in the same interview:

**K7:** Obviously it's better to have the total number of patients small, and not this vast number of vegetables, because it did seem that they were quickly heading for the one level, and that was the bottom level. Definitely the smaller numbers, you can remain as individuals longer.  
**K7's spouse:** In [care housing] they are allowed to just to get up and wander if they really want to in the home, whereas in hospital, if you did get up somewhere, you were immediately plonked down. It felt very much as you imagine an old work house situation would be.

They suggested what the resident herself felt about being in hospital.

**K7:** She was desperately unhappy - at that point she could still speak to us. She could never go to the bathroom without someone else being there. There were a number of baths together. She could still feel: "What were they doing in the baths when I am having a bath?" Not the nurses, but other patients wandering around. She did not have her own furniture, she had a cubicle, other patients could wander in and take it away. A massive place, it would have housed thirty. The nurses were not being cruel, it's just there were so many of them, people wandering around, banging their heads, wet, they did not have enough (staff) to change immediately she had an accident - as now, she is immediately made comfortable again - they were just left sitting. (K7 comparisons 33)

The lack of activity for hospital patients was always contrasted with the efforts taken by staff at care housing, where residents reportedly could go out and walk around. Phrases were often used such as 'being anchored in a chair for hours on end' or 'plonked down'. The emerging image was of people with dementia spending their time in hospital sitting, staring into space. The next section notes what interviewees thought was wrong with alternatives, and specifically how they thought care housing was better.

The physical environment of hospital and care housing were depicted as polar opposites. Whereas hospitals provided dormitory accommodation with curtains at most to separate yourself from other patients, care houses offered residents their own bedrooms which gave more privacy and independence. Their personal possessions were cared for, whereas in hospital clothes were mixed up and other items mislaid.

While visits to hospital could involve complicated bus journeys for kin, at least one family found the care house was much more accessible and it was in an area where the



resident was well known. Hospital visits could be restrictive and uncomfortable, which was compared with care housing.

K8's spouse: Whereas in [hospital] it was a hospital, an institution and it felt like that, whereas Nash Drive you don't feel like your walking into [an institution], you feel  
K8: Like a hotel

K8's spouse: No, not a hotel, it's just a, like a sheltered housing scheme, you just walk in and make yourself at home, at [hospital] you had to wait for them to open the door ... You didn't in [hospital], when you went in you would always get somebody else coming up and saying "I want out of here" and I felt guilty and I really felt sorry for them that they were locked up in this place and they say to me 'I can't get that door open, will you open it for me' and how do you say no? Whereas in the care house Mrs X says: "What am I doing here?" and I say "You're here because [a relative's name] is coming" and if she went to go out the door I would just bring her back, it's just a different atmosphere.

(K8 comparisons 93)

The kin, quoted at length on the previous page, supplied another perceived advantage of the care house.

K7's spouse: Now when we go to visit Gran, the children will come - it has a lot to do with the baking! We go there and can have a cup of tea or coffee. That was another thing with [hospital] - when we went to her house, she would always offer us tea, cake, and she could never could offer us a cup of tea in [hospital] - was always going to offer us a cup of tea but couldn't, you didn't have a cup of tea with her, or if she was having a cup of tea, the cup would only be given to her, whereas at [the care house] it seems almost as you have sat down, would you like a cup of tea or coffee, the children juice? That made her feel better because she was offering us something, it is a nice touch, it feels like visiting. You can go into the conservatory or her bedroom if you want, you can actually visit privately. (K7 comparisons 40)

Kin whose relatives had not been in hospital presented a similar, but less detailed picture, recounting experiences of other people they knew in hospitals or from watching television.

K4: Hospitals remind you too much of an institution, you walk in and it's just full of old people, like geriatrics, and you think, who's bothering, who's caring for them, but you don't get that atmosphere in [the care house], I feel it's homely. You walk in and you feel welcome. (K4 comparisons 5)

The hospital described in some detail above in particular was often mentioned as being synonymous with the asylum, or the workhouse. This meant that it was upsetting for patients to know that they were there and a frightening prospect for people with dementia knowing that they might eventually need to move there.

K11: But she always had a dread: "Don't put me into [hospital]!" // For years it has been an asylum and then they started putting the old people in it. She's even said to me: "If I ever go to [hospital] and I don't want to go, if I die there, don't put it in the paper that I died in [hospital]." It had a stigma. (K11 comparisons 64)

Kin thought of hospital as a place of last resort which would not have met what they perceived to be the needs of the people with dementia. Nobody wanted such a move.



KF: What did you think care housing could offer?

K2: Well I didn't want a hospital type environment because hospital frightens my father, even when he had his heart attack he wouldn't go in, he doesn't see it, I don't know whether it's just because he was getting older, he thought if he went in he wouldn't get back out, that was the one thing I didn't want, I didn't want a ward where everybody just sat. (K2 comparisons 78)

All staff who had experience of working in other forms of long stay care made favourable comparisons with care housing and condemned the task-oriented approach of other settings. The higher staff ratio to residents was held important in making care housing different, as a staff member explained when asked to compare care housing with other places where the residents might have been living.

S13: I would have to compare with my nursing experience, specifically a long term psychogeriatric ward - this kind of house is ideal because it is individualised care, more personal, in a long term ward it is more impersonal - people may be treated well but impersonally because of its size - here there are small amounts of people. The staff ratio is very good compared to a long term ward. The important thing is the personal touch, the care that they have. Maintaining independence is important here and people are encouraged to do things for themselves - in long term care it is easier to do for them rather than encourage them to be independent. There are loads of differences but that is the main thing here. (S13 comparisons 14)

According to one member of staff who had worked in various care settings, once people with dementia were in hospital 'that was it' apart from perhaps a biannual visit to the pantomime, unlike care housing. The advantages staff saw in being able to spend more time with residents were also perceived in comparison with residential and nursing homes.

### *Care homes*

The comparisons made were similar to the criticisms of hospital, since both nursing and residential homes were criticised for providing care on a large scale, having a lack of privacy and no opportunity to have your own possessions, the depersonalised relationships with staff, low staff ratios, and lack of stimulation. If private homes were distinguished from others, it was with the expectation that they would provide poorer quality care and were less well regulated than local authority homes. Local authority homes were still far from ideal.

S24: [The care house] is far superior. I see residents with dementia being better cared for, with higher staffing - size - and because it was purpose built. The differences to part IV are that people with dementia did not get the care they needed compared to other residents. They could not identify their own needs so they were forgotten about. Other residents treated them badly - I don't know if from fear or annoyance. They knew they had "lost their minds". A lot of staff were not trained on how to deal with behavioural problems that dementia can cause, they did not know what to do. (S24 comparisons 11)

A resident (see 5.2.3) who had moved from residential care was described as having greatly benefited by a member of staff who had moved to work in care housing



at the same time and knew her in both settings. This was consonant with information given by this woman's kin at Interview. The advantages both of the personal care, and of it being specialist, were mentioned frequently.

**S14:** It's completely different than previous places I have worked in, in here, you find the residents have the right - unlike in other homes where it is difficult to break a routine with both residents and staff, and people just follow on, but in here we are flexible and there is no routine, people have right of choice, privacy, it is more care free, relaxed. Everyone having the same illness, nobody is jumping on them, they are allowed to be themselves.// It is totally different, is more relaxed, small, friendly, you get to know them personally, it's a home to home set up. (S14 comparisons 3)

Care settings specialising in dementia were perceived to have advantages, though respondents' experience of these was limited and reports of specialist residential settings conflicted.

Reportedly, residents could disturb each other in both mixed and non-mixed settings. In mixed settings, people with dementia were apt to pick up others' possessions, or accuse them, for example, of taking a cardigan. This led to conflicts. People with dementia and those with strokes were described as clashing in a nursing home, but people with dementia had the advantage of forgetting the incident whereas others would retain a memory of, for example, someone 'peeing in a bucket' (S5). Even where everyone had mental illness the range of problems, and the extent of disturbed behaviour in other residents, was seen to upset people with dementia as already noted. At the nursing home mentioned, the people with mild dementia were said to be disturbed by those with severe dementia who 'just shouted'. Such a mixed setting was portrayed as disadvantageous for all residents.

#### **4.5.2 Care housing: the 'next best thing' with 'no comparison'**

In a perfect world, kin and staff agreed that residents would not have dementia and would be living in their own homes. Living with your family was an ideal for many. Given the presence of dementia, care housing was seen as the 'next best thing'. It became abundantly clear that kin and staff thought poorly of institutional alternatives, especially hospitals with which it was frequently said, there could be 'no comparison' to care housing. The following three quotes each from different case studies illustrate this.

**1. KF Are there any other differences?**

**S17:** The main difference is that we don't categorise our residents, they are extremely important, they are a VIP, and an individual, and this is the main area of difference I have seen. Not classified as the demented lot, end of story, boxed together. (S17 comparisons 7)

**2. KF: How does this house compare with other places where the residents might have been living?**

**S14:** A palace, a home! I've been in others, done placements, and they are horrible. This is great. (S14 comparisons 8)



3. S4: I think it is wonderful, and I really mean that, because I came from residential care where there were forty residents, and here there are eight. I can see a complete turn round where residents' needs are actually being met, rather than (just) basic needs like food - but we can do things which elsewhere are impossible. (S4 comparisons 21)

Kin were emphatic that the care housing model was the right, even the ideal, place for their relative to be, and several said that they were lucky to be there. They could think of nowhere that offered the same advantages and said that they would choose it for themselves if ever they needed. The attractions of care housing were articulated by a relative who was sure that her father had not been ill enough to need hospital care.

K2: It would be like having somewhere of his own, with a room to himself, a toilet to himself and we could tell him that the cleaner came in and that was his home help, he had a house where we could say that he was moving to a new house, it was sheltered housing, that's what we told him, we didn't tell him it was care or it was a home and that's what we liked about it, we liked the smallness of it and the homeliness of it and the really totally new concept that it was appealed to us because it was really what we were looking for, it was totally the opposite to what I had thought of a 'home' being...  
(K2 comparisons 79)

Being able to class the care house as 'housing' seemed able to make this option more acceptable to residents. Kin repeatedly mentioned the importance of residents having a room to themselves with a WC and being able to take their own possessions. It could be seen as a move, say to sheltered housing, which offered the potential for independence, and an opportunity to keep a pattern of life that suited the resident. Unlike hospital, as two clinicians who were interviewed suggested, residents could think of themselves as tenants, and have the things around them that they took for granted at home. One staff member reflected that 'you couldn't even pretend' in a larger house that it could be 'home from home'. Instead of being institutional care, care housing could be described as sheltered housing with 24 hour support. A common conclusion by staff and kin is illustrated by this quote.

KF: What does it feel like in the house to you?

Kin: I think it's as near being in her own home as I think it could be really, if they can't look after themselves in their own home, this is the next best thing really, it's comfortable, they have their own places if they want, it's fine. (K3 comparisons 122)

Care housing was attractive because of its 'homeliness' and closer to an abstract ideal. Interviewees described it as 'home' rather than 'a home' and found the difference difficult to express: 'It was like housing within a home if you get what I mean' (K2 comparisons 81).

Respondents did not claim that residents were entirely satisfied and took it for granted that the daily life of someone with dementia was, at times at least, confused and unsettled. Nobody, it was assumed, wanted to be in care and everyone would prefer to be at home as the move inevitably meant a loss of privacy. Whilst one staff member



stated explicitly that care housing was not home and never would be, others described it as a setting that was as home-like as it possibly could be.

Care housing then was portrayed as 'the next best thing' to your own home and being with your family and, given that residents had dementia, was emphatically thought to be the best of the available alternatives.

## **4.6 Summary and discussion**

### **4.6.1 The organisational and policy context**

Each category of respondents, that is agencies, staff, and kin, had distinct priorities for what they wanted from the case studies and views of its perceived success. While all asserted the success of care housing, personally and organisationally, different interests became apparent, especially between agencies.

The agencies' perspectives were, understandably, directed towards survival in an uncertain time. The benefits to agencies included experience of collaborative working, the opportunity to pilot a new model of care, finding partners with whom to share financial responsibility for supporting people with dementia, and the kudos of taking part in an innovative development. The absence of local strategic planning meant that care houses owed their existence to individuals working in different agencies which had different agendas for care housing. The process was characterised by opportunism and compromise, and seems to have been costly in the time and effort of senior personnel.

While this exercise took considerable individual initiative by individuals committed to improving dementia care, collectively the agencies failed to consult directly either with potential users of the service (residents or relatives) or other community services who would provide services. Residents and their kin lacked a structure within which to express their perspective. In shaping what care housing was, and what it was trying to do, the agencies had a central role in determining resource inputs, and staff in implementing aims. Validation of success with its main client group was done on an ad hoc and indirect basis.

Collaboration was not easy despite a shared commitment to provide more long stay care for people with dementia, and to this model of care. The development of care housing should be seen as a positive result of different welfare agencies attempts to allocate, and possibly shed, responsibility for 'health', 'social' and 'housing' needs. In their operation, managing agencies considered ways of increasing their income by seeking economy of scale, which compromised the idea of small, domestic units.

Ongoing collaborative management was tested by the implementation of community care; only one unit managed to retain a supportive partnership with both statutory agencies. The same unit managed to assert that care housing should be a



resource for people living in community housing rather than those considered inappropriately placed in other long stay care settings. Having regular links with a psychogeriatric team was consistent with a vision of the psychogeriatric outreach to non-hospital projects described by Murphy (1996, see 2.2.3).

Care housing sought to decrease group size and increase personal space in line with the proposed reforms to residential care described in 2.2.3. It embodies the assertion that people with dementia can benefit from carefully designed physical and social environments. Despite its claim to be housing, it was an innovation within the tradition of long stay care rather than care in the community. Residents did not share the same status as housing tenants or owners and access was limited to those needing 24 hour support. Further, care houses were registered as residential care establishments.

The model's advocates were disappointed that it had not developed to the extent they had hoped for. The costs of this model compared to the advantages were hard to demonstrate. Revenue funding specifically was an ongoing concern. Events have perhaps overtaken the model of care, the pressure to provide places being stronger than the incentive to experiment with new models of care.

#### **4.6.2 The perceived advantages and inherent problems of the case studies**

Staff preferred working in care housing to institutional alternatives and were proud to be associated with this model of care, as well as the personal benefits of having a job. Kin were given 'peace of mind' in that they believed their relatives were getting the best possible support, as well as relief from the stress and burden of providing support. There were problems too: staff did not all enjoy good employment conditions, were not equally well supported by the managing agencies and career development was an issue for some. Kin perhaps felt guilty at no longer caring for their relative, and some did not have the relationship with staff that they would wish.

All respondents shared a concern about how care houses could and should deal with the progression of dementia. Agency representatives thought about the balance of responsibility between agencies. Staff referred to attachment to residents and difficulties in providing support for certain problems. Kin saw the dementia as making it difficult for the resident to settle in, and some expressed concern that its progression might make it difficult for them to stay in care housing.

Table 4.6.2/1 below summarises the links between perceived successes and issues of concern.

**Table 4.6.2/1 Perceived successes and inherent problems of care housing**

<b>PERCEIVED SUCCESS</b>	<b>INHERENT PROBLEM</b>
<b><i>Agency respondents</i></b>	
• experience and success with collaborative working	• tensions and compromises in planning stages and operation
• opportunity to build a model regarded as innovative	• opportunistic developments - not part of integrated, strategic developments
• finding partners to share responsibility	• ongoing problems with the health, housing and social divide. Problems with revenue funding. Need to demonstrate value for money
• model judged overall successful in operation	• concern about ability to deal with progression of dementia and physical illness • need to support isolated staff and reinforce ethos of care
<b><i>Staff respondents</i></b>	
• personal benefits of employment; more rewarding than other care-work	• wish for career developments; possibility of burn-out and stress
• pride and satisfaction in innovative model of care	• loss of residents; difficulty in caring as dementia progresses
<b><i>Kin respondents</i></b>	
• sharing responsibility for care • preference for housing model - especially single rooms and private amenities.	• self-reproach exacerbated by residents' difficulty in accepting the necessity of the move • shared bed-rooms unpopular
• trust in staff to provide good quality physical and social care; belief in their skilled input	• perhaps not as personalised and caring as could have given themselves • reluctance to suggest changes
• belief that the care benefited people with dementia	• overall dementia progressing; hard to know what promotes a good quality of life • concern about what would happen if could not stay in care housing



All respondents agreed that to live in care housing was the best option, in the circumstances, for its residents. Residents' well-being thus became a yardstick by which each group could assess and justify its actions. Neither the respondents nor this study could claim to have gained the residents' perspective directly, and there is therefore the possibility that perception of residents' needs and satisfaction can be manipulated according to personal and organisational agendas. Readers should remember that not only is reported satisfaction typically high, but also each group of respondents was arguably predisposed to observing signs of well-being rather than ill-being (see 3.10).

In drawing comparisons between care housing and its alternatives, respondents articulated the ways in which they thought care housing was considered superior and what were its important characteristics. There was consistency between categories of respondents, though some points were made more strongly by particular categories or individual interviewees.

Care housing's ability to bring benefits to people with dementia through good quality social and physical environment was a central tenet for respondents, but in interviews they described what they thought helped in more detail than the specific impact this had on residents. In summary, the important inputs were taken to be i) 24 hour staff support, ii) the presence of other residents and staff and iii) its domestic scale design and location. The outcome was seen as a homely setting, which reassured relatives that residents lived in the best possible place, provided a satisfying environment for staff to work within, and was acceptable to people with dementia who benefit from living there. Table 4.6.2/2 summarises the link between inputs and perceived benefits.

The staff input was agreed to be important, and the social rather than material benefits tended to be emphasised by respondents. For the staff, there was some tension in asserting a social model of care, in that some felt more clinical knowledge would be helpful. It was clearly tough work both physically and emotionally.

**Table 4.6.2/2 Inputs to the care house linked to perceived benefits**

INPUTS TO CARE HOUSE	PERCEIVED BENEFITS
Accommodation for people who need it	<ul style="list-style-type: none"> <li>• relief to informal carers</li> <li>• avert move to institution</li> </ul>
24-hour (skilled) staff support	<ul style="list-style-type: none"> <li>• provide physical care and security</li> <li>• high staff ratios promote well-being and nurture individuality</li> </ul>
Company of other residents and staff	<ul style="list-style-type: none"> <li>• company and stimulation</li> <li>• formation of close-knit group</li> </ul>
Design -domestic scale -private rooms -local provision	<ul style="list-style-type: none"> <li>• homely settings</li> <li>• can exercise independence</li> <li>• own possessions</li> <li>• privacy in relationships and activities</li> <li>• prosthetic, orienting features</li> <li>• opportunity for community contact</li> <li>• ease of access</li> </ul>

Respondents left no doubt that they considered care housing to be the best possible available solution, though they regretted the necessity of the move from community housing.

Respondents drew comparisons in two directions. Firstly, they referred to an ideal of home, where it was assumed that residents would be from choice. This ideal place was not the same as the actuality, the circumstances in which people had been living before moving to long stay care. Secondly a negative stereotype of institutional care framed comparisons with any of the existing forms of long stay care. The most detailed comparisons were with hospital wards that, according to policy (SHHD, 1988) and agency representatives, were in urgent need of reform. Such comparison did not severely challenge care housing. The limited experience respondents had of other innovations detracts from the scope of this respondent evaluation. Staff drew comparisons with people with dementia from the time that they moved in, whereas kin looked back to before the illness. This may have meant staff were attuned to smaller changes and if these were positive, to view them optimistically.

Table 4.6.2/3 shows how care housing sat conceptually between community housing and institutional settings in respondents' minds. It ideally offered the advantages of both and the disadvantages of neither.



**Table 4.6.2/3 Ideal, perceived and experienced advantages and disadvantages of care housing in comparison with alternatives**

<b>IDEAL OR PERCEIVED ADVANTAGES</b>		<b>EXPERIENCED OR PERCEIVED DISADVANTAGES</b>
	<b>OWN HOME</b>	
<ul style="list-style-type: none"> <li>• privacy</li> <li>• independence</li> </ul>		<ul style="list-style-type: none"> <li>• unsupported</li> <li>• lonely</li> </ul>
	<b>KIN'S HOME</b>	
<ul style="list-style-type: none"> <li>• supported by kin</li> <li>• family obligations fulfilled</li> </ul>		<ul style="list-style-type: none"> <li>• imposing strain on kin</li> </ul>
	<b>SHELTERED HOUSING</b>	
<ul style="list-style-type: none"> <li>• acceptable, non-stigmatising</li> </ul>		<ul style="list-style-type: none"> <li>• providing support too much for wardens</li> <li>• other residents intolerant</li> </ul>
<b>ALL OF ABOVE POINTS</b>	<b>CARE HOUSING</b>	<b>NONE OF POINTS ABOVE OR BELOW</b>
<ul style="list-style-type: none"> <li>• may need if ill</li> </ul>	<b>HOSPITAL</b>	<ul style="list-style-type: none"> <li>• poor physical environment (lack of privacy and dignity)</li> <li>• depersonalising</li> <li>• vegetate because of imposed dependence and inactivity</li> <li>• disruption and upset from other residents</li> </ul>
<ul style="list-style-type: none"> <li>• may need nursing care</li> </ul>	<b>NURSING HOME</b>	<ul style="list-style-type: none"> <li>• same as hospital but less extreme</li> </ul>
<ul style="list-style-type: none"> <li>• most direct alternative - no advantages</li> </ul>	<b>RESIDENTIAL HOME</b>	<ul style="list-style-type: none"> <li>• same as hospital but less extreme</li> </ul>

The residents' perspective was obtained indirectly through reports by staff and kin. To summarise what has been learnt, it is clear that the move did not take place on their initiative and that they rarely agreed that they needed support for which they had to move. They were as passive as the literature suggests has been the case in moves to residential care (see Sinclair, 2.5.1). Residents moving from community housing had to forego private amenities to receive the support they needed, though people moving from institutional care might have moved to improved facilities. Whereas residents had typically previously lived with kin and latterly on their own, they moved to a communal form of living with non-kin whom they had not chosen to live with. Although kin and staff packaged the move as to another house, it seems residents did not necessarily perceive it as such.

This chapter has provided a framework for the more detailed examination of care housing presented in the next two chapters. The pluralist evaluation has shown a strong loyalty to the social model of care from all respondents, but suggests that the progression of dementia is one of the most difficult issues in its operation. This is the concern of Chapter Five. The way in which the case studies were able to promote homeliness, and how residents lived in the houses, is dealt with in Chapter Six. The respondents suggested that while other residents could be a problem in alternative settings, company and stimulation were important features of care housing. This is investigated in Chapter Seven.



## **CHAPTER FIVE**

### **RESPONDING TO CHANGE: MOVES IN AND OUT OF CARE HOUSING**

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Chapter Five is concerned with the question of how care houses could and should deal with the progression of dementia and accompanying physical frailty. The first section of this chapter (5.1) presents data about Scottish care housing residents and provides more details of the case study residents, including dependency assessments. Section 5.2 uses staff and kin interview data to consider how residents 'settled in' to the care houses, and changes reported after the move. Section 5.3 shows how the commitment to providing a home for life was not always realised in practice. These findings summarised and discussed in section 5.4.

## **5.1 Residents of Scottish care houses**

### **5.1.1 National survey of Scottish care housing residents**

The national survey by postal questionnaire (see 3.6) included everyone who had moved into seven care houses in six different locations by the end of October 1994. All the houses were open by January 1992, but each had been operational for a different length of time. The seven units together could accommodate 62 residents. Since the units opened, 127 residents had moved in. By the end of October 1994, 25 residents had died and 40 had moved out. Of the 62 people resident at 31.10.94, fifty three (86%) people then resident were over 75, and 26 (42%) were over 85. The mean age of people then resident was 83. For the 65 ex-residents, the mean age when they died or moved out was 82. Of the total of 127 residents, one hundred (79%) were female. Over half of the males had moved to one unit (Heartfield): if this is excluded, 88% of all who had moved in were female.

Health services had been involved in or solely responsible for 90 (73%) of 124 referrals for whom data are available. This high reported involvement of psychogeriatric services occurred because a diagnosis of dementia was a prerequisite to move to care housing. Initially psychiatrists had been key-players in the referral and assessment process, but this had changed since April 1993.

**Table 5.1.1/1 Where care housing residents moved from**

<b>Moved from:</b>	<b>Number (%):</b>
community housing	66 (52%)
hospital	50 (39%)
care homes	11 (9%)
<i>Total</i>	<i>127</i>



Of the residents coming from hospital, 32 (25% of the total) had come from long stay care, and 18 (14%) from assessment units. Of the forty people who had moved out, seven had moved following assessment (between four to 8 weeks) and did not become full residents of care housing. Four of these seven people moved to psychogeriatric long stay care, one to a residential home and two to acute hospital. Table 5.1.1/2 shows where the remaining 33 moved to.

**Table 5.1.1/2 Where residents moved to, if they moved**

<b>Moved to:</b>	<b>Number(%):</b>
<b>Hospital:</b>	
Acute medical	4
Psychogeriatric assessment	5
Geriatric long stay	7
Psychogeriatric long stay	11
<b>Total</b>	<b>27 (82%)</b>
<b>Nursing home</b>	<b>4 (12 %)</b>
<b>Other (community housing)</b>	<b>2 (6%)</b>
<b>Total</b>	<b>33 (100%)</b>

The two residents who had moved to community housing had either moved to a relative's house or sheltered housing.

In summary, just over half (52%) of the 127 people who had moved into care housing by October 1994 had moved in from community housing, the remainder coming from care homes and hospitals. Of the 33 who moved out after a period of residence, 27 moved to hospital where it can be assumed they stayed until they died. Section 5.1.2 shows that over half of these (16) were from the three case studies, but these were the units that had been open the longest. These data therefore suggest that the case studies reflected a wider pattern of not being able to provide a home for life for all residents.

### **5.1.2 Residents of the case studies**

This section applies to the residents of the case studies only, about whom more detailed information was collected. By the end of October 1994, 67 people had moved

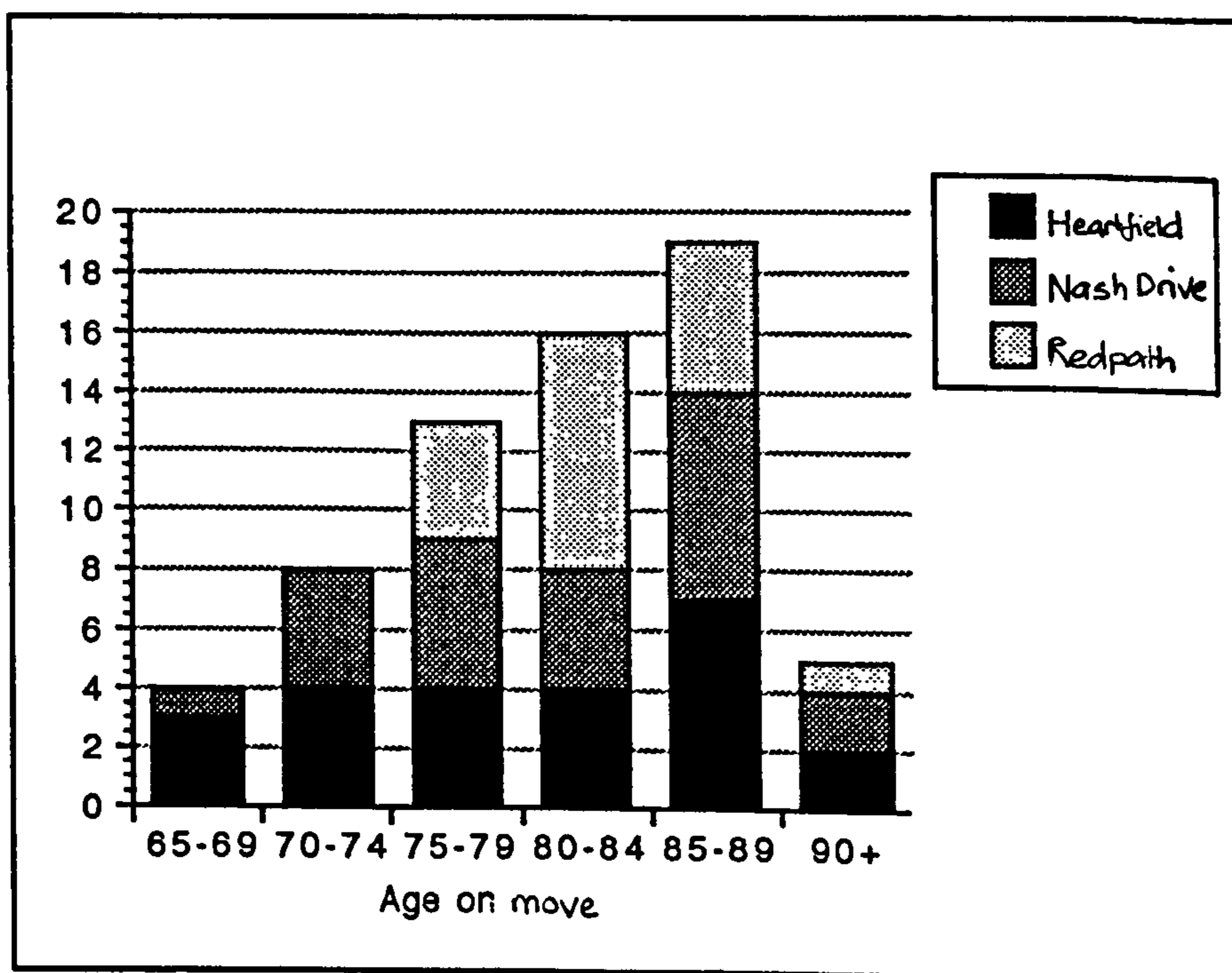
to the three case studies, and there were 39 ex-residents. Eighteen people had moved to Redpath, which by 31.10.94 had been open for 4 years and 3 months and had the capacity for eight residents. Heartfield had been open for a month longer and also had eight places, but here 26 people had moved in. At Nash Drive, where there were twelve residents, 23 people had moved in over a period of 2 years and 10 months.

*Age of residents*

Table 5.1.2/1 shows that the modal age when people moved into care housing was to be in the late eighties. There were four people who moved in their sixties, who presumably had early onset dementia.

**Table 5.1.2/1 Age at moving in to care housing.**

N = 65 (2 missing cases)



The mean age of moving in was 73.7 years for men and 80.5 years for women. The overall mean age was 81.0 years. At Heartfield the mean was 80.1 (range 65-93 or 28 years), at Nash Drive, 80.6 (range 68 - 90 or 22 years), and at Redpath, 82.7 (range 75-90 or 15 years).

*Gender*

Altogether 48 females and 19 males had moved to the case studies, details are shown in Table 5.1.2/2 overpage.



**Table 5.1.2/2 Gender of residents who had moved to the case studies**

Unit	female	male
Redpath	17	1
Nash Drive	20	3
Heartfield	11	15

The pattern at Heartfield was unique, where over half of those who had moved in were male. Sometimes at Heartfield, preference had been given to male applicants when a vacancy fell in a shared room, if it was already occupied by a male.

#### *Where residents had moved from*

Altogether, 43 (64%) had moved in from community housing, 17 (25%) had moved from hospital, and 7 (10%) had moved from care homes. There were differences between the units in the proportions of people moving from hospital or housing. Uniquely, all Redpath's residents moved directly from community housing (see section 4.2). Differences in where people moved from could have been due to the varied effectiveness of community support, the availability of alternatives in each area and the pressure from Health Boards wanting to use care houses for resettlement. The only two people who had moved from nursing homes lived in Nash Drive, which was explained by a shortage of residential home places in this area, leading to a temporary and inappropriate move.

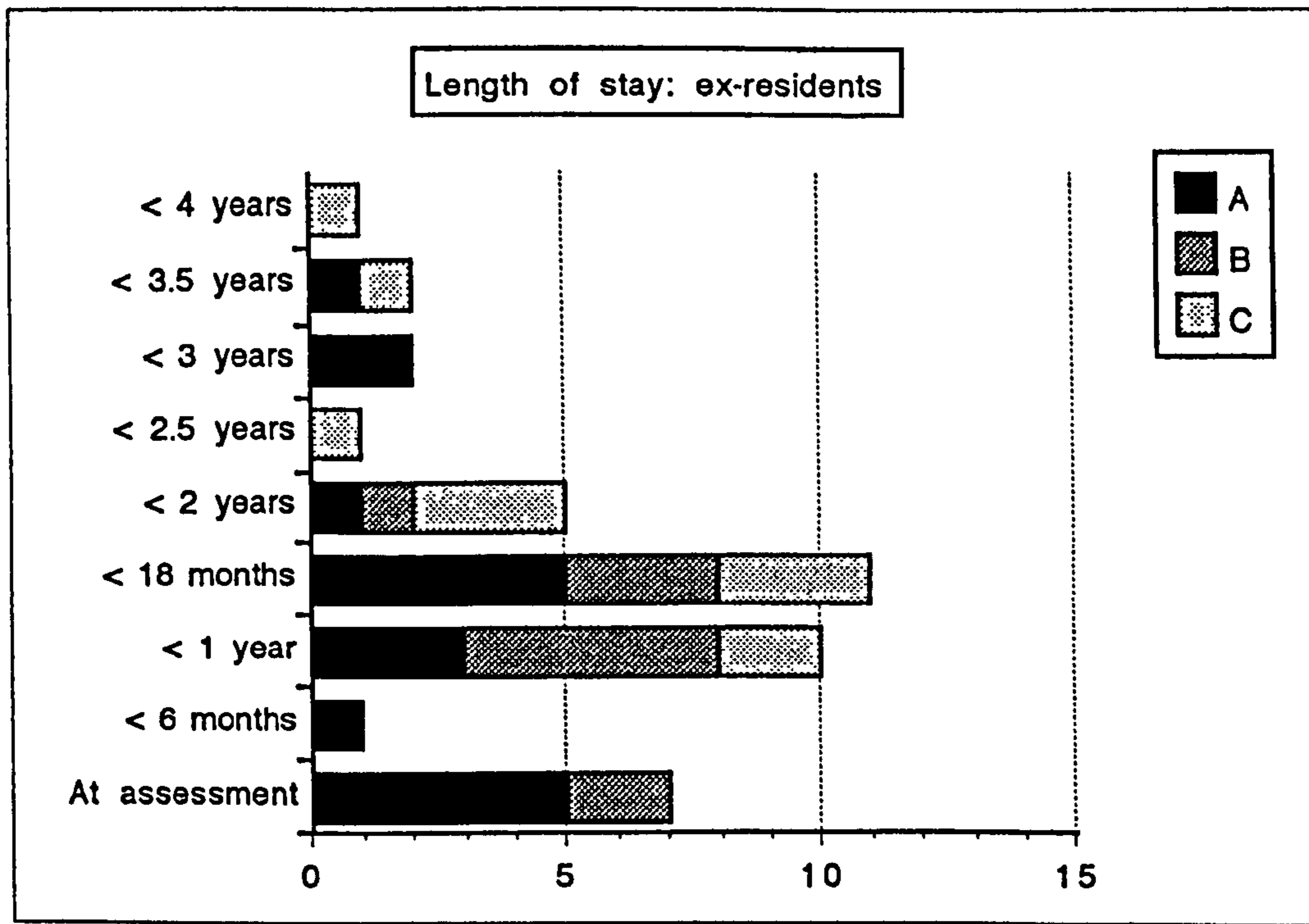
During the study period more than half of Heartfield's residents came from community housing. The pattern of where the remainder moved from changed from being predominantly moves from hospital to predominantly moves from residential care. While at Nash Drive initially a minority of residents had come from community housing, by the end of the study period, this had risen to become the majority (eight of 12). Initially, when Nash Drive opened, residents had been taken from the long stay settings run by its funding agencies, but this cohort was gradually being replaced by residents from community housing.

#### *Career in care housing*

As noted, seven people moved to other forms of long stay care following assessment and did not become residents. Five of these were from Heartfield. Of the 32 who had a period of occupancy, twelve had died as residents - six of these in the house itself. Altogether twenty had moved out: sixteen to hospital, three to a nursing home, one to a relative's home. The person who moved to a relative's home did not have dementia but moved on the death of his spouse who did have dementia. Interview data suggested that this was unlikely to be repeated, not because it was an unsatisfactory

arrangement, but because the managing agencies argued this was a scarce resource which should only be given to those who needed the support offered, that is, having dementia. This person is excluded from the following calculations on length of stay.

**Table 5.1.2/3 Length of stay of ex-residents**



For the 31 ex-residents, the mean length of stay was 17 months but the picture differed at each unit: 18.9 months at Redpath, 12.1 months at Nash Drive, and 10.1 months at Heartfield. The mean figure for Heartfield disguises the fact that the length of stay was bimodal, with 6 of the residents having stayed for under 20 months, and 3 of the residents having stayed for 34 or more months.

The mean length of stay for the 20 ex-residents who had moved from community housing was 19 months, with a range of 7 to 37 months. For the 11 who had moved from care homes or hospitals, including assessment wards, the mean length of stay was 12.9 months, with a range of 3 to 22 months. The mean length of stay for the 19 ex-residents who had moved out was 18.9 months, and for the 12 who had died as residents, 14 months.

At each house there were people still resident at October 1994 who had moved in when the houses opened. In Heartfield, two individuals had moved in as the unit opened over four years previously, but three quarters (6) had been resident for under a year. In Nash Drive and Redpath there was a more evenly spread distribution of length of stay: in Nash Drive half (6) of the residents had lived there for under a year, and in Redpath, only a quarter (2) had lived there for under a year.



## *Social history*

These data were collected only for the 28 people who were resident during the observation. Twenty one (75%) were widowed, and 4 (14%) were single. Two (7%) were still married (both male), and one was divorced. The male occupations included sales, working in an engineering company, butcher, miner, farm-work, and school maintenance. Eight females had been housewives; four had worked in catering and one as a publican; three had worked in factories. Other occupations included laundry work; nursery gardening; accounts; service and shop work. One person had had education after leaving secondary school: this was nurse training. Everyone living in the case studies during the observation period was white British, and all but two were regarded as Scottish. One was English and one Irish. Only one person who had ever moved in was from an ethnic minority. This person moved elsewhere following assessment.

In summary, residents at Redpath were on average older when they moved in, with the narrowest age range, were predominantly female and, unlike the other units, had all moved in from community housing. Heartfield had more male residents than the other units and the widest age range. Nash Drive's residents had the youngest mean age on moving in. The mean length of stay for ex-residents was 17 months, but Redpath's residents stayed on average for over 5 months longer than at Heartfield and Nash Drive, despite tending to be older when they moved in. People who moved from community housing stayed about six months longer than those who had moved from any form of institutional care.

### **5.1.3 Dependency of case study residents**

This section reports findings obtained by using the Revised Elderly Person's Disability Scale (REPDS), which was used to assess whether dependency of resident groups matched stated entry criteria. The first assessment was made at the beginning of data collection in winter 1991 (Time 1) and the second assessment at the conclusion of the data collection period in summer 1994 (Time 2). On both occasions, 28 residents at three case studies were assessed which meant that dependency of resident groups could be compared. Eleven individuals were assessed on both occasions and changes in their assessments are noted.

The REPDS sub-scale scores of physical problems, self-help problems, confusion, behavioural problems, problems with sociability and nursing dependency are presented first, which give an indication of severity. Table 5.1.3/1 shows in which category the median score at each case study fell at Time 2 according to three ranges of severity (mild, moderate, and severe) as explained in section 3.5.

**Table 5.1.3/1 REPDS sub-scales: severity of median scores at Time 2**

<b>REPDS sub-scale</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>
<b>Confusion</b>		Redpath Nash Drive Heartfield	
<b>Physical Problems</b>	Redpath Nash Drive Heartfield		
<b>Self-help Problems</b>	Redpath	Nash Drive Heartfield	
<b>Behaviour Problems</b>	Redpath Nash Drive Heartfield		
<b>Sociability Problems</b>	Redpath Heartfield	Nash Drive	
<b>Nursing Dependency</b>	Redpath Nash Drive Heartfield		

The table above shows that according to the REPDS assessment, at each care house, median scores were mild for nursing dependency, behaviour and physical problems, but confusion fell into the moderate range. No median score fell into the severe range for any sub-scale at Time 2. Unlike the other units where the median score was in the mild range, problems with sociability were moderate at Nash Drive. Both Heartfield and Nash Drive had a moderate median score for problems with self-help.

Possibly the term 'mild' is misleading, since the problems were substantial enough for residents to require 24-hour support. However, these data cannot be compared to norms for other settings. Nash Drive specified that it provided accommodation for people moderately to severely affected by dementia, but these data does not suggest they were more dependent than other resident groups except for problems with sociability.

Table 5.1.3/2 gives the median scores and inter-quartile ranges at each care house and as a total, at Time 1 and Time 2. The data presented here show that the median score for confusion at Nash Drive at Time 1 fell in the severe range, and though



this had dropped by Time 2, it was still the highest. There was an increased range at Nash Drive at Time 2 which was explained by a resident who did not have a diagnosis of dementia but who had psychiatric problems and, by agreement with the managing agencies, was accommodated in Nash Drive.

Readers are reminded that the three severity ranges are determined according to how many items are in each sub-scale. To help read the table, the range for each sub-scale is noted under the sub-scale title. For example, confusion which has eight questions, is rated mild if the median is 8 or below, moderate between 9 and 16, and severe if 17 or above. The median is given first, and the inter-quartile range below in brackets.

**Table 5.1.3/2 REPDS sub-scale scores at Time 1 and Time 2**

	<b>Confusion</b> 0 - 8 9 - 16 17 - 24	<b>Physical Problems</b> 0 - 7 8 - 14 15 - 21	<b>Self Help</b> 0 - 8 9 - 16 17 - 24	<b>Behaviour Problems</b> 0 - 7 8 - 14 15 - 21	<b>Sociability Problems</b> 0 - 7 8 - 14 15 - 21	<b>Nursing Dependency</b> 0 - 9 10 - 18 19 - 27
<b>Redpath</b>	12.5	1.0	4.0	4.0	6.0	6.5
<b>Time 1</b>	(8.5 - 15.3)	(0.0 - 3.3)	(3.8 - 5.0)	(2.8 - 5.0)	(5.3 - 8.0)	(6.0 - 7.3)
<b>Time 2</b>	12.5 (10.5 - 13.8)	4.5 (3.0 - 6.3)	7.5 (6.0 - 10.5)	3.5 (2.0 - 4.30)	7.0 (5.0 - 8.5)	6.0 (5.0 - 7.5)
<b>Nash Drive</b>	17.5	2.0	14.5	8	5.5	8.0
<b>Time 1</b>	(15 - 19.3)	(0.8 - 5.3)	(12.3 - 17.3)	(4.0 - 10.0)	(3.8 - 8.3)	(6.0 - 11.0)
<b>Time 2</b>	15.5 (10.0 - 19.0)	3.0 (0.8 - 6.0)	13.5 (11.5 - 16.0)	4.5 (2.0 - 7.0)	11.5 (9.0 - 13.0)	8.0 (7.0 - 9.5)
<b>Heartfield</b>	12.0	1.5	10.5	3.0	8.5	6.5
<b>Time 1</b>	(9.0 - 14.0)	(1.4 - 2.5)	(7.8 - 14.0)	(1.8 - 5.3)	(3.5 - 14.8)	(6.0 - 9.3)
<b>Time 2</b>	12.0 (9.5 - 15.0)	5.0 (3.8 - 6.3)	14.0 (9.5 - 17)	4.0 (1.8 - 5.3)	7.0 (4.0 - 10.3)	9.0 (8.5 - 10.0)
<b>Total</b>	14.5	2.5	10.0	4.0	6.0	7.0
<b>Time 1</b>	(11.8 - 17.3)	(0.8 - 4.3)	(4.8 - 14.3)	(2.3 - 8.0)	(3.8 - 9.0)	(6.0 - 10.0)
<b>Time 2</b>	13.0 (10.0 - 17.0)	4.0 (1.8 - 6.3)	12.5 (7.8 - 15.3)	4.0 (2.0 - 6.0)	9.0 (6.0 - 12.0)	8.0 (6.0 - 10.0)

Table 5.1.3/2 shows that, given the maximum possible range, the differences between the units and between Time 1 and Time 2 at each unit were relatively small. The most marked change over time was an increase in sociability problems at Nash Drive, which had a median score of 5.5 at Time 1 (mild) and of 11.5 at Time 2 (moderate).

The sub-scale score for physical problems increased at each unit between Time 1 and Time 2, but there was no consistent trend in the other sub-scales. At Redpath, the most marked changes were an increase in self-help and physical problems but the median scores did not move out of the mild range. At Nash Drive, while the staff reported more problems with sociability, there were fewer behaviour problems reported. At Heartfield, more problems were reported on all sub-scales except sociability.

Examination of the individual questions suggested that increased physical problems were mainly caused by residents' decreased mobility. At Time 1, six of the 28 residents had minor or moderate restriction of movement or weakness, but by Time 2, this number had risen to 18. This was reflected in the assistance needed when walking: at Time 1, three of 28 residents needed assistance but this had risen to twelve by Time 2. Despite this, the entry requirement that residents would be mobile, whether using aids or not, remained true for all residents during the data collection period. Though problems had increased, this was not to the point that any resident was chair-fast or bedfast, or needed more than one person to assist them with walking.

At Time 1, five residents rarely or never went out of their living area, but this applied to nine people at Time 2. The nine who rarely or never went out at Time 2 included two individuals who were reported to have no problems with limb disability. There were increased problems for the activities of daily living, eating, bathing and dressing. At Time 1, twenty two of 28 residents required no assistance with eating but this dropped to eleven at Time 2, by which time twelve rather than six required full assistance with bathing, and four rather than one required full assistance with dressing. Problems with urinary and faecal incontinence had also risen: by Time 2 fourteen rather than eleven had problems with urinary incontinence, and twenty rather than fifteen had problems with faecal incontinence.

These shifts towards increasing physical problems may both have been due to a cohort effect as residents aged, and due to residents being more dependent than formerly at the point they moved in. Most physical problems were reported at Heartfield at Time 2. Here all residents required at least some assistance with dressing by Time 2, and only one resident of eight had no problems with urinary incontinence, and less than half (three) had no problems with faecal incontinence. By comparison, at Redpath at Time 2, six of eight residents required no help with dressing, five had no problems with urinary incontinence and seven had no problems with faecal incontinence. Redpath's resident group had the lowest self help sub-scale median scores.



At Time 2, fifteen residents, representing all units, were reported to disturb others to varying degrees, by being noisy, interfering or threatening. While five of these fifteen lived at Redpath, this was the only unit not to report physical harm to others as characteristic of any resident. This raises the possibility that "disturbance" was interpreted differently, as suggested by Patel and Hope (1993, see 2.1.1).

### *Individual changes*

Table 5.1.3/3 shows the percentage scores of eleven individuals on each sub-scale at Time 1 and Time 2. The expectation was that these residents would have more problems reported at the second assessment than at the first because of the progression of dementia and physical frailty associated with ageing. Each of these eleven residents had a different score at Time 2 in at least 4 of 6 sub-scale totals, but not all changes were negative. In each sub-scale between one and three residents were reported to have fewer problems. Two thirds (41 of 62) of these changes represented a shift of under 20% of the total possible score. The most consistent shift was in the physical problems and self help sub-scales where all changes over 20% were towards having more problems. While seven individuals had shifts of over 20% towards having more problems with sociability, only one individual had an equivalent shift in behavioural problems. Shifts towards having fewer problems demand explanation, and this was most apparent in the confusion sub-scale. Possible explanations are that this sub-scale has poor test re-test reliability, that performance testing was not done adequately by staff, or that residents had become more familiar with the unit and people's names over time.

Table 5.1.3/3 Eleven individuals' percentage scores, REPDs sub-scales at Time 1 and Time 2

Resident	Confusion			Physical Problems			Self-Help Problems			Behaviour Problems			Sociability Problems			Nursing Dependency		
	Time 1	Time 2	% Change	Time 1	Time 2	% Change	Time 1	Time 2	% Change	Time 1	Time 2	% Change	Time 1	Time 2	% Change	Time 1	Time 2	% Change
R10	83	83	0	4	29	25	87	100	13	14	19	5	80	48	-32	40	44	4
R29	58	21	-37	23	10	13	58	29	-29	9	5	-4	19	5	-14	22	7	-15
R24	4	46	42	42	71	29	41	71	30	4	5	1	4	38	34	22	33	11
R11	50	79	29	0	0	0	41	54	13	47	52	5	4	52	48	14	29	15
R4	91	95	4	23	28	5	75	87	12	4	14	10	38	61	23	44	48	4
R15	83	37	-46	0	19	19	58	62	4	8	33	25	23	47	24	29	40	11
R6	62	83	21	9	28	19	54	75	11	47	28	-19	19	57	38	40	59	19
R28	58	75	17	23	38	15	33	66	33	4	4	0	57	61	4	22	29	7
R12	58	*	*	19	10	-9	12	41	29	23	19	-4	38	71	33	25	18	-7
R9	29	*	*	4	7	3	16	33	17	9	14	5	14	38	24	22	22	0
R23	50	54	4	0	14	14	16	25	9	9	9	0	9	19	10	22	22	0



## **5.2 Settling in: perceived changes after the move**

The dependency assessment data presented in 5.1.3 suggested that over time, physical problems for both individuals and resident groups increased but the patterns for confusion and problems with behaviour and sociability were less consistent. At interview, staff and kin asserted that positive changes also occurred following the move, a finding which is reported and discussed in this section.

### **5.2.1 Intercepting decline: perceptions of dementia's progression**

The residents that kin referred to had lived in care housing for between one and two years at the time of the interviews. It is likely that, in the process of moving to care housing, kin's perception of the situation was influenced by contact with the staff. Kin described an increase in their relatives' dependency in the period preceding the move (see 4.4) and accepted that dementia would worsen. Despite this, more than half referred to positive physical changes (8), and to improvement in emotional state (6). Less than half mentioned illnesses or accidents since the move (4) or more disturbed behaviour (3). Surprisingly, then, more positive than negative changes were mentioned. It seemed that kin expected decline, in physical health or with the progression of dementia, but remarked upon its interruption, as the following quote suggests.

**K2: I think he's just following a line of elderly people do, they do get a bit frailer as they get into their nineties, don't they. I can see him getting very frail but he was doing that anyway, so its just a progression of what was happening before. At least he's doing it in better surroundings, I think the quality of life is better ... (K2 change 45/46)**

The staff asserted that the physical care they gave and the relationships that developed made a difference to residents. There was an accent on improving quality of life, not just maintaining it or managing deterioration. This therapeutic optimism was strongest at Heartfield, but evident from staff at each care house. Only one dissenting voice thought that in providing care to people with dementia you were fighting a losing battle. More typical was the following reply:

**S16: A plus is that their general way of life and living conditions have been greatly improved by coming into somewhere set up with the precise purpose of looking after dementia. (S16 hopes 2)**

The data analysis separated changes that staff thought were a result of the move (effects) and changes held to be independent of the move. Changes were then categorised as either positive or negative. Almost all of the effects that staff described were positive, and most of the independent changes were negative. Staff in the smaller units pointed out more positive effects than negative changes, but staff at Nash Drive



described more negative changes than positive effects. It seemed possible that staff at Nash Drive were less assertively optimistic about what their care could achieve.

### 5.2.2 Settling in

Both staff and kin referred to a process of 'settling in' when residents began to experience the benefits of the move. Settling in consisted of psychological adjustment and starting to use the care house as their own home and to take part in its daily activities. Being cared for had psychological as well as physical advantages. If all went well, residents could start to look healthier and neater, be more outgoing, and be less anxious and insecure. One interviewee summed the process up as 'becoming a person again' (S8 change 7). Staff who mentioned the time taken to settle in thought it took 3 to 6 months, though they also noted daily improvements. Kin referred to improved general appearance, better nutrition and increased contentment. Benefits were also described in terms of what you did not see, for example someone who packed their bags less often than they had when they moved in, the absence of marked deterioration, or less anxiety and agitation than, speculatively, would be apparent in other settings.

These positive effects were attributed to good quality of care which offered security and support and ensured a good quality of physical care, possibly with a review of medication. Stimulation and encouragement to be active and to participate in self-care and activities and the company of staff and other residents was held important (see 4.5). Residents were not portrayed as distancing themselves following the move (compare with Nay, 1995, see 2.5.2) but rather as making a social re-entry. A member of staff described how she thought residents improved:

S25: There's a big change in a lot of residents who come here, because they have stimulation every day, we are keeping them active. They are not just staring out of the window as they may be at home. They have friends and staff here to talk to, they are encouraged to go to the shops, we try to get them back into the community as much as possible. Maybe they have been sitting at home before, between nine and five, waiting for their family to get back, very bored.

KF: You said big changes?

S25: Like to be going out shopping. If its one to one you get on great. In the kitchen they get back to their old skills, like making jam and baking, that they haven't done for a while. Their families have been frightened to let them do this, they may forget there is something in the oven. // This applies to a lot of them, say they haven't done something for years, then you give it a try and they can, and they are chuffed, recipes come out. [S25 change 16]

Staff referred to the feelings engendered both by the move and the process of dementia. Anxiety was depicted as a constant companion, worse for some residents than others, but helped by the knowledge that support was available and being reassured by staff. Being withdrawn was seen as a feature of depressed loneliness that could lift on moving to care housing, when some people started to communicate more. Some staff and kin saw withdrawal as a feature of the progression of dementia when



people no longer wanted to mix with others; one person was described as tormented by dementia, which could change peoples' nature and behaviour.

Residents did not settle in equally well. Not having wanted to move to the care house, reportedly they could grieve for their own home. Settling in well could depend on accepting that the care house was the right kind of accommodation to move to, which required a degree of insight to their need for support. Personality also could help people fit in: staff suggested that being cheerful and sociable helped. As one put it, if you were unsociable, it would not be your ideal place (S28 suit 20). According to these accounts, being settled in care housing was not necessarily associated with whether the resident had wanted to move or not. One person who had resisted and refused the move was said to have settled remarkably well and never to wish to return home, while another (described in 4.4.2), who had earlier decided she would move to care if necessary, was unsettled once she had moved and often wanted to go home. Success stories were told about people moving in from both community housing and hospital.

### **5.2.3 Success stories**

At each house, success stories celebrated residents who had notable improvements in mood, participation and conversation. One woman had moved in from sheltered housing when the house opened, at the age of 90. She had lived in care housing for four years by the time of interviews. Staff enjoyed this woman's current outspokenness, repeatedly saying that she had 'come out of herself' and was 'the life and soul' of the house.

S15: We have had one lady straight from home, she was very depressed, crying. After three months, she settled in well, she became more content, and ate a lot more. She had lost the will to live - she would just sit and throw cigarettes into the fire. And she is really contented here. She sees us as an extended family and speaks her mind - she tells her opinions. [S15 change 14]

Another woman had moved in from residential care who otherwise would have had to move to hospital. Staff said she had made remarkable improvements and this is consistent with information given by kin at interview. This respondent had worked in the residential care home and was able to compare her in both settings.

S6: [In residential care] she was in a unit of eight but the others did not have dementia. The others wouldn't let her out of her chair, and would get angry with you if we did not put her to bed at eight. Because there were so many residents, we could not toilet her as often as needed. There's a big difference in her - her family have noticed too. I never heard her speak while working there for six months.

KF: What difference do you see?

S6: Here we put her on a toilet programme, with pads underneath, but not bulky ones. She seldom is incontinent now, she chatters away. I don't understand what she says but at least she is communicating. Lately you will get good answers to questions, other times you can't work it out. Her family say they cannot get a word in sometimes - she talks so much! (S6 change 1)



Several kin (including all those describing a move from hospital) described dramatic and positive changes. Section 4.4 used lengthy quotes from a family who were dismayed by the conditions in hospital. The resident was no longer distressed when the family left after a visit, which they felt was an important change. Further:

K7: She was a totally different person, she had not been eating well at home, and even in [the hospital] she had not been eating a lot, but within a few months at [the care house] she had started to put weight on, eating very well. Her skin had improved, her looks had improved - she had her hair done which made her look a lot better. (K7 change 30)

A resident moving from hospital was said to be more mobile than previously, which was helped by activities promoted by staff. In hospital, reportedly, she had been taken everywhere in a wheelchair. This activity helped her recover from a broken femur. Another respondent also attributed physical and mental improvements to the staff's good care.

K6: I am delighted to let them look after him. As I see it, he is well looked after, and brought into conversation, questioned about things, and bringing him forward. He remembers some things now, that he did not remember before. Like from before the war, which he did not remember before. They have brought him forward. I think they have done him a lot of good. (K6 change 8)

Describing someone who had moved from sheltered housing, one kin noted a 'tremendous improvement', the resident becoming more content and less possessive:

K5: The way she looked: she was very thin, she didn't have colour - I would say she was heading downhill fast, when she came in here, it was a significant change.

KF: How has she changed?

K5: Her colour is better, fatter - she has always been thin, but she looks ten times better than before she came in. (K5 Change 13)

According to another respondent (K9), the staff's patience and humour had helped give a resident much better quality of life than she had had when she lived on her own. Previously, this woman's anxiety had shown in her face ('her eyes all screwed up and tense') but now she was more content. She only occasionally worried, for example, about not having paid her pension. She seemed more independent, and rather than insist that kin stayed when they visited, would be worried that she was missing something going on in the unit. The staff had managed to persuade her to have a bath regularly which she had previously resisted, so much so that she even seemed to enjoy it, and also changed her clothes every day. Having her hair done regularly was interpreted as a sign of being cared for. Summarising the changes, this relative said:

K9: She just looks so much better, obviously she is getting nourishment that she didn't have and peace of mind because she knows that she is never on her own and she never has to be frightened. (K9 change 61)



Twenty four hour support ensured residents had regular meals. However, this could be too much of a good thing. This relative was not the only one to be concerned about weight gain.

K12: After going into [the care house] she has a good breakfast and cups of tea in between and have their lunches and then again they make cups of tea in between so her weight has gone up. It's quite worrying, a bit, because she's gained three stone and I think that's a lot in a year. (K12 change 19)

#### **5.2.4 Negative changes**

After the settling in period which brought benefits, staff suggested that typically, perhaps in the second year, age and dementia took its toll. Then staff had to provide more physical care to residents. Staff reported that the resident groups as a whole had become more physically and mentally frail which, especially at Heartfield, was said to put more demands on staff. This impression was confirmed by the dependency assessment data reported in 5.1.3. An increase in dependence was specifically reported in residents' inability to clean their rooms any longer, fewer people being able to go out, and the use of an ambulift. Despite acknowledging a cohort effect, a number of staff (7) noted different individual pathways. While some people had noticeably lost skills and become more dependent, others had retained the same level of dependency.

Reported mental changes included increased agitation, aggression, irritability, and becoming withdrawn and disinclined to mix with others. Speech and short-term memory worsened, and skills in self care and participation in household activities declined. Residents became less mobile, less continent and perhaps needed catheters, they were more liable to fall and developed illnesses such as chest infections, strokes and heart failure. Behavioural problems, such as irritability and being withdrawn or aggressive, were attributed to the progression of dementia rather than the way that staff managed these problems.

While kin assumed that residents could no longer sustain their hobbies and that their capacity for activity was declining, some (e.g. K5, K7) said explicitly that the setting could influence the course of dementia, and drew the same conclusion as staff - that deterioration in care housing residents was due to the dementia, rather than the care given, but this might have been slower than it would have been elsewhere.

Kin particularly noticed when speech became less clear or the resident could remember less about their shared past. This was a continuation of the process described in the lead up to the move, where residents were seen to become less like their former selves. They described residents becoming more remote and withdrawn, for example:

K11: She's quieter, very quiet, sits in her shell and doesn't want to be bothered really. (K11 change 42)

A dramatic demonstration of withdrawal occurred when a resident, to her kin's distress, had refused to write Christmas cards and even to open her presents. One family was particularly concerned about behavioural changes, and unhappy about the use of sedation (see 4.4.3)

In summary, respondents attributed positive changes to the good quality of care in care housing, and considered negative changes inevitable. There appeared to be a settling in stage when the positive changes began to be evident but then, individually and collectively, respondents noted more problems arising from dementia and physical frailty.

### **5.3 Providing a home for life**

While care houses wanted to offer a home for life, this was not promised (see 4.1.1) and residents did not have tenancy status. Entry criteria were set out but it seemed more difficult for care houses, especially in their early stages, to define when someone may be asked to leave. The pluralist evaluation demonstrated that the progression of dementia was a significant concern for each group of respondents, albeit for different reasons (see 4.6.2). This section considers the commitment of staff and kin to the aim of providing a home for life and considers, from the available data, for whom this was possible and who had to move out.

#### **5.3.1 Commitment to the ideal**

Unanimously, kin believed the care studies were the right place for their relative at that point and hoped that there would be no need for another move. Most kin, but not all, had thought of the possibility that care housing might not prove to be a home for life, under certain circumstances. One respondent was puzzled and slightly alarmed, by the question about what he hoped for in the future. This quote shows him thinking through this problem.

**K11: Well that is a difficult question, what is her future? At 85 years of age what is her future? I can't see anything else for her, I don't think you could disturb her environment now, she's in that environment and she's been disturbed once, and as far as I was concerned it was for the better, but to disturb her again, I can't say it would be for the better so it would have to be for the worst and I don't see why she should ... if it's not going to improve her quality of life, so I can't see anything other than [the care house] (K11 future 7)**

Being 'at home' was sometimes seen as implying a right to stay there.



K2: The way I see it, is that the residents are there until they are either taken ill or they die, that that is their home, that's how they tell you to look on it, that that's their home, so I take it that - I've never asked that question, if there was any need for them to be moved.  
(K2 future 10)

Becoming ill, most kin realised, could change things, but interviewees were unsure at what stage residents could get too much for the unit to cope with. Kin at the longer established units had seen residents come and go, and referred to this. Some expressed a hope that their relative would die from a quick, acute illness such as a stroke, rather than gradually decline and have to move. Kin knew they could not manage to provide support themselves and saw any alternative as inferior, especially hospitals where residents would be most likely to go. A move to hospital was believed potentially to hasten deterioration. Kin clearly trusted the staff to try to continue to provide support and some referred to occasions staff had taken pains to nurse their relative through a short-term illness.

Staff interviews also suggested commitment to care housing being a home for life. They emphasised that they did everything in their power to make sure people could stay, for example to be nursed when they were dying, and were satisfied when they had succeeded in doing so. Staff referred to attachment to residents. Having mentioned being upset when someone left or died, some also mentioned the need to be detached, and keeping things 'in perspective'. From the interviews, there was also a sense that the resolve to provide a home for life had been tempered by experience. Some began to argue that it was unfair to the individual and the group if staff attempted to continue to support anyone whose needs were significantly greater than those of other residents and whose support stretched the capacity of the staff.

According to interviewees from each staff group, it was inappropriate to introduce people to care housing who had substantially different degrees of disability to other residents. It was said to be best if residents 'were on a par'. At Nash Drive, staff were concerned that an able resident would not get enough stimulation. At the smaller units staff believed that residents adjusted more easily and were better accepted if the dementia was not advanced. Ideally people moved to the smaller units when they were mild or moderately confused and could stay for a few years before they died.

At Redpath, senior staff had been able to control who moved in and residents had met these criteria, but at Heartfield this had not been possible with the result that several people had had to move out, and some current residents were not considered to suit care housing because they were physically frail or had behavioural problems.

Residents had to live with each other and behavioural problems were the most threatening to group harmony. Physical frailty could also absorb disproportionate amounts of staff time and restrict what other residents could do. All staff agreed that nursing care was beyond what they could offer but staff at Heartfield supported a group of residents who collectively strained the equipment and design of the domestic setting.



Staff groups disagreed over whether care housing suited people moving from institutional care. Staff at Nash Drive suggested that they fitted in better because they had already adjusted to life in care and people coming directly from home were less likely to settle. Staff at Heartfield thought that it was a disadvantage if people had got used to institutional care, as they reportedly found it harder to adjust to living in small-scale groups and to take on more independence. However, at Heartfield, someone who had moved from community housing was said not to have settled because he was too used to being looked after by his wife and did not take to the idea of 'independent living'.

In short, in considering who suited care housing, staff took both individual characteristics and contextual issues into account. Residents, they believed, had to be disabled enough to need care but not at a substantially different level from other residents. There was inconsistency about whether it made any difference where they moved from. Success stories (5.2.3) were told of people moving from each setting. The balance had continually to be weighed between individual needs for support and their potential to benefit, and the interests and capacity of the other residents and staff.

### **5.3.2 The actuality: who had moved and who had stayed**

Despite the aims and aspirations, more people had moved out than had died as residents. The 39 people who moved out of the case studies are examples of people care housing was unable to support. Over four fifths moved to hospital, mainly to geriatric and psychiatric care. If people moved it was to receive long term nursing care, as a result of acute medical incidents or behavioural, especially aggressive, problems. If they died as residents, they tended to have short terminal illnesses that did not require specialist nursing care. Each care house had supported a dying resident, and also had residents who had moved out. Nash Drive had only required people to move out because of physical problems but the smaller units had experienced behavioural problems they could not support.

#### *Moves following assessment*

When someone moved in, there was an assessment period of between four and eight weeks, which was intended to be a period of mutual appraisal as to whether the prospective resident and the care house suited each other. Seven residents had moved following assessment. Staff indicated that this was for a variety of reasons, some comments suggesting that particular residents would have had difficulty fitting in anywhere, and by implication were unsuitable for group-living. The main reason cited was an inappropriate level of dependency. Five at Heartfield had moved to somewhere



providing more intensive care and two people at Nash Drive had been judged not to need the level of support care housing could offer.

### *People who died as residents*

The six residents who had died in the units had either died suddenly or had short terminal illnesses which did not demand intensive or long term nursing care. Staff had worked together to make sure that the dying resident was not left alone, and had brought in Macmillan or Marie Curie nurses who had helped enable support to continue. A woman who had a stroke was cared for with the help of the district nursing service and also a large supportive family who were able to be with the resident and make arrangements after the death. Staff at Nash Drive had provided care for someone who was bed-bound for a week without the help of community nursing services. Staff thought it was preferable for someone to die in the care house than to move.

S27: She died in here. In the last stages she was in bed all the time, we had to do everything. We felt though that if she had gone to hospital, she would not have got the care and attention she needed. Also there were tenants coming in to see her.  
(S27 home for life 13)

Staff satisfaction in being able to support someone till their death was evident.

S19: I was so pleased that [the resident] could stay, you get very attached ... everyone made an effort to keep her. We know what would have happened if she had gone to hospital - she would not have had the personal care, nor someone with her all the time, and she was in her own bed and her own nighty. (S19 home for life 3)

A woman died while getting dressed in her room one morning. This was unexpected and staff were distressed to find her later. They debated whether they had the right to enter people's rooms to check that all was well. Six people had died in hospital but had still been residents of the care house. They had broken a femur, died following surgery, or had a stroke requiring nursing care.

### *Moves to hospital*

Three residents had moved to acute medical wards, five to geriatric long stay wards, four to psychogeriatric assessment wards, and four to psychogeriatric long stay wards. Three had moved to nursing homes. The reasons given were not always consistent with the place people moved to and perhaps depended on local provision. Sometimes the initial move from the care house was followed by further moves, known to staff who had kept in touch with the resident.

### *Moves for medical and nursing care*

Residents who had had to leave had developed cancer, stroke, chest infection or poor mobility following a broken femur. Being unable to walk without support and falling down seemed important factors. Some staff brought up the issue of whether they should use nursing equipment, such as cot-sides, urinal bottles and adjustable beds, but these were not provided. An example was given of someone who had become increasingly dependent over an extended period, and was making substantial demands on staff time.

S4: She couldn't manage her meals and cutlery. The other tenants were cruel, we ended up taking her to the staff table to protect her. At the end she was neither getting anything out of nor contributing to the care house. (S4 home for life 7)

Another example was given of a resident who became increasingly confused and agitated, and could not walk well after breaking her leg.

S9: For example, (this resident) had made this her home for three years. She was happy, it had made a big difference to her. She fractured her femur. Her dementia was worsening ... and she was very confused and agitated. When she came back to the unit there were behaviour problems, she also needed nursing care. This upset her, her family, and staff and management because we always set out to provide a home for life, especially for someone who is well established in the place. This is a drawback - they lose hope, kind of give up, they thought they would be here to the end of their life. (S9 home for life 28)

After leaving the house, this resident moved between hospitals and wards several times and was visited by her former key-worker who believed that this woman, being in distress and pain, lost heart and had eventually given up, refusing to eat or drink.

### *Moves because of behavioural problems*

Each staff group had experience of behaviour they had found difficult to accommodate, but Heartfield's staff had had most experience of violent and aggressive behaviour. People who had been prone to verbally and physically abusive outbursts had moved out of care housing to hospital. One example was of a man who moved from home and lived in care housing for seven months. During this time he began to tear at the wall paper and furniture, which staff had managed, but then his behaviour became increasingly aggressive and he moved eventually into psychogeriatric long stay care. In another unit a woman had lived there for eighteen months before moving to a nursing home. The problems are described in the next two quotes. Staff had resisted using sedative medication and also were not prepared to change their policy about unlocked doors.



S27: (This resident) would not stop leaving the building, the door is open, but she would not come back. Sometimes, the police brought her back after hours away. We could not cope, when there were only two staff on duty at the weekend for example, and if her family were not there, she was out on her own. She used to get agitated and aggressive too, because she felt closed in. (S27 home for life 12)

S16: One was aggressive before she left which was hard for everyone: she would give the tenants a mouthful ... we could not keep the doors locked, and she was always leaving, she had no road sense, and she got lost. We would have to ask if we could go with her... she ended up in a nursing home with a locked ward. Other staff have been to visit her and say she is more contented there. It just did not work out for her here at that stage. (S16 home for life )

Wandering inside the unit had been accommodated at both Heartfield and Nash Drive, though it reportedly irritated other residents and showed up Heartfield's confined space. Staff did not necessarily think that problem behaviour would improve in hospital, they sometimes commented that particular residents would have found it difficult to fit in anywhere. Staff had found aggressive behaviour unacceptable, both for their own sake and that of the residents. Observation suggested that behavioural norms were different in each house and that different units had different capacity for and responses to aggressive and other behavioural problems.

In Heartfield, living in a confined space with shared bedrooms posed extra demands and this may have been a factor provoking aggression. Staff at Heartfield accepted locked doors as necessary for security from theft and vandalism and also for residents' safety in case they wandered on to the busy road outside. All Heartfield's residents who had moved out because of behavioural problems were male. Night staff seemed particularly vulnerable and reported most incidents where they were worried by situations that were hard to control, as the following quote illustrates.

S21: One man became violent. Where it is putting other residents at risk, it has to be looked at. That is the main thing, staff can cope with most situations, but violence has to be reviewed. An example was a gentleman who could not walk, but with a temper tantrum he got the strength to run, and chased me down the hall at great speed. I got a fright - and I have had a lot of experience with dementia sufferers. He tried to stab another resident with a fork... he was obviously upsetting other residents, and striking out at staff a lot at the end. (S21 suit 19)

Only senior staff, who provided least direct care, had had any professional training which might equip them to deal with behavioural problems using psychological approaches. Whilst care staff had developed skills in promoting good relationships between residents (see 7.4.6) they did not have professional training or support with which to approach the most difficult behavioural problems. The level of knowledge about the dementing process was, for care staff, basic and when they were talking about aggressive behaviour, they did not always speak with the confidence of understanding its possible causes and approaches to its management.



## 5.4 Summary and discussion

Chapter Five has been concerned with how care houses dealt with the progression of dementia and accompanying physical frailty, and has established that residents' support needs at least met the case studies' entry criteria. This chapter examined changes in residents as recorded by REPDS assessments at the beginning and end of data collection, as well as reported by kin and staff at interview. Data about residents who moved on, and why, have been presented.

This chapter has confirmed the picture which was developing in Chapter Four, that according to a notional continuum of care, care houses were an alternative to residential care. Dealing with the progression of dementia and increasing physical frailty was difficult for the case studies. Of 65 former residents of Scottish care houses at the end of October 1994, over 60% had had to move out, almost all to hospital care.

Nash Drive aimed to accommodate people with more advanced dementia at the point they moved in than the two smaller units. The resident group at Nash Drive had more problems with confusion according to REPDS, but did not have as many physical problems as reported at Heartfield. The differences between the resident groups would seem however to be small given the possible range of scores. This also applied to changes over time.

The literature review (see 2.2.3) suggested that care housing residents would be predominantly female, most being at least over the age of 75, most likely to be unmarried or widowed and to have lived alone before entering care, more likely to have rented houses than be owner occupiers, and (for men at least) to be more likely to come from social classes three and four. The limited evidence confirmed this picture of case study residents but there were differences between the groups that, though not necessarily of wider significance, could influence the character of groups at each house. Most notably, while just over half of Heartfield's residents had been male, it was exceptional for men to move to either of the other two case studies.

Just over half of all residents moving to Scottish care houses had moved from community housing, the remainder from care homes and hospitals. In the case studies, residents moving from community housing stayed about six months longer than people moving in from elsewhere. It is difficult to compare this finding with other care housing developments (see 2.5.6), but the length of stay appears to be shorter than would be expected for *domus* or *cantou* residents, presumably because so many residents moved out. However, there are no comparable data to compare how disabled the people moving in to these different settings were.

All of Redpath's residents had moved from community housing; here residents were on average older when they moved in and this unit had the narrowest age range. At Redpath, staff had been able to select residents most carefully according to the principle that people should move in before their dementia was advanced as this helped



them settle and benefit from care housing. Redpath had the best support from psychogeriatric services (see 4.6). Annerstedt (1993, see 2.5.3) suggested that the quality of care in Swedish *gruppboenden* depended at least in part upon the selection of a well-diagnosed, homogeneous group of residents. Unlike the Swedish researchers in Malmö-Lund, the staff interviewed were reluctant to cast suitability in clinical terms but instead referred to previous experience and personal characteristics and preferences to describe suitability. Such social factors were not explicitly acknowledged in the stated entry criteria.

This chapter has reported two different assessments of change, firstly from REPDS and secondly according to staff and kin. Section 3.5 noted concern about the trustworthiness of REPDS and its limited relevance to settings committed to household care. Examining the changes following the move retrospectively, and through parties who had reason to hope that the move was beneficial, was far from ideal. I approached these interviews expecting that 'change' would primarily represent a pattern of decline, and did not expect such strongly expressed and frequent reports of positive effects. The effects described were against an acknowledged background of substantial deterioration in physical and mental health, but the descriptions formed patterns and were consistent when more than one informant described a resident. Both interview and REPDS data suggested that physical problems of both individual residents and groups increased more consistently than behavioural or social problems. The qualitative reports were consistent with the REPDS data in terms of negative changes. While both data-sets suggested that increased dependency was the order of the day, positive changes were noted in the qualitative data that REPDS could not address. The positive effects asserted by kin and staff were indirect, subjective appraisals of well-being and consisted of subtle changes which may require knowledge of the individual to recognise.

Section 4.4 showed that moves to the care houses typically came at a point of crisis, with the decision taken out of the hands of the people with dementia who rarely recognised the need for it. These circumstances make it surprising that the move was still reported to benefit residents (see Schulz and Brenner, 1977, 2.5.2) but the consensus of qualitative assessment was undoubtedly that a move to care housing, for some residents at least, was followed by improved physical health and mental well-being. This was reportedly evident in general appearance, improved communication, and ability to care for oneself and to participate in household activities. Respondents were sure that the move to care housing was beneficial and a move out to hospital would be harmful to residents.

Respondents may have uncritically attributed positive changes to care housing and negative changes to an inevitable progression. These data were however consistent in the kind of changes reported, manifest in residents' appearance and behaviour and attributed to their improved confidence following relocation to a setting where they lived socially and according to a normal daily pattern. These reports allow for the possibility



of rementia described by other researchers (see 2.1 and 2.5.5) and implicitly suggested that the pathway was the same as the positive approach described by Holden and Woods (1995, see 2.1.3).

The respondents' reports were also consistent with the suggestion (Annerstedt, 1995; Ritchie *et al.*, 1993, Dean *et al.*, 1993) that benefits may level off over time. People cited as particularly benefiting moved in from different settings. Who may benefit and how from relocation, and the implications of cognitive impairment in this are poorly understood (see 2.5.2) and requires investigation of environmental discrepancy as proposed by Lieberman (1991). A very important problem is the difficulty of investigating the perspective of those most severely affected by dementia.

The problems that were *not* reported nor observed by myself are also interesting. Observation suggested that behavioural problems were less severe than I observed in hospitals. No care housing resident was withdrawn and passive. No sexual disinhibition was reported. Interpreting dependency data is very difficult with any instrument that focuses on individual ability rather than interaction with social environment (Wilkin, 1990). Differences between the units, in self-help especially, may have been influenced by how actively staff promoted independence and the physical design. Staff also suggested that differences between individuals resulted from previous experience of care, as they believed dependency was induced in hospital. Differences - if they really existed - with hospital populations may be a product of referral patterns as well as interaction with social environment.

Exclusion of people on the basis of the type of support required is an inevitable consequence of linking support to accommodation (Clapham and Smith, 1990). Staff were satisfied if they had supported someone until they died and this is certainly what kin interviewed hoped for. Staff did not assert that residents who moved out had gone to ideal settings but instead that the only possible option had been taken. While it was thought regrettable for the individual, particularly if it meant going to hospital, the move was justified from the perspective of other residents and staff. When the units opened, the aim of providing a home for life was asserted more confidently than at the end of the data collection period, when staff and managing agencies explained that it sometimes proved necessary for people to move out. Residents who needed longer term medical or nursing care and who developed behaviour experienced by others as disruptive were more than likely to move on. Apart from the degree and nature of disability and the preparedness of staff to use physical or chemical restraint, other factors which may have affected whether someone moved was the flexibility of staff groups in providing intensive support. Hypothetically, attachment staff had to particular residents might influence them to sustain greater levels of support. The nature of the accommodation, the unit's location, access to community and specialist services could have been influential, as perhaps was the availability of family support. Moving because of behavioural problems was most common in the unit where there were most male



residents, where rooms were shared and there was limited communal space, and staff had least control over who moved in.

Care staff had little or no professional training to work with aggressive behaviour and could feel vulnerable and out of their depth when it was experienced. It is paradoxical that in specialist units for dementia, behavioural problems particularly challenged the limits of care housing.

## CHAPTER SIX

### HOMELINESS AND HOUSEHOLD CARE

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## **Introduction**

Chapter Six considers different aspects of care housing as 'home' for its residents. Section 4.4 showed that respondents thought its homeliness was a very important feature of care housing which was perceived as the 'next best thing' to one's own, ideal, home. To interviewees, important aspects of homeliness included living in a familiar locality, being able to choose whether to spend time alone or in company, being able to go where you wanted in the home, and to have your own things with you. Staff interviews suggested five main ways that a homely setting could be recreated. Firstly a 'domestic style' physical environment was needed. Secondly, staff promoted well-being by encouraging residents to participate in the life of the household, to go out and to socialise as they wished, to exercise choice and independence, and to keep to a daily pattern of their choice. Thirdly, kin should be made welcome and able to sustain their relationships with residents. Fourthly, staff promoted group interactions and activities. A fifth aspect, the use of community facilities, relationships with neighbours and other events taking place outwith the care house, was not explored in this study. Staff recognised some things that were outwith their control, including the constraint of limited resources, people's personality and biography, the nature of relationships with kin, and the impact of the dementing process.

Section 6.1 is concerned with whether residents felt 'at home' or not. Staff described at interview the ways that they promoted residents' well-being and put the ethos into practice, which is the subject of 6.2. The quantifiable data obtained from observation about activities and well-being are summarised in 6.3 and referred to in 6.4 that deals with the daily pattern that had developed, the use of different rooms in the care house, the ways that residents spent their time and the well-being experienced. Section 6.5 is concerned with household care and 6.6 with how residents kept in touch with family and friends. The findings are summarised and discussed in section 6.7.

### **6.1 Feeling at home: residents' experiences**

Section 4.4 suggested that both residents and kin differed in the degree to which they had accepted the move. It became clear that residents themselves did not make the decision to move, and nor did they necessarily accept that they needed support. In assessing residents' contentment, interviewees pointed to signs of diminished anxiety rather than positive acceptance. Section 5.2 noted that a stage of settling in was identified by kin and staff. Positive effects of the move were reported with some particular success stories. Here, the extent to which people with dementia could, or found it difficult to, accept care housing as home is examined.



### 6.1.1 Continuity in location and type of accommodation

The residents (28) included in observation came from within the catchment areas defined by entry criteria, though two had moved within recent years to be near relatives. Kin interviews (12) showed that their relatives had been born in the same part of Scotland as they were currently living in, perhaps outwith the catchment area but in a neighbouring part of the city or village. Residents were not necessarily familiar with the actual street the care house was in. They may have moved between parts of the city or between villages, most recently to live closer to relatives, on being widowed. Most but not all were thought to be living in the area of their choice: two had expressed regret about leaving the places they had spent their married life. People in the city had experienced substantial changes in the locality during their lives; tenement flats were a favoured, perhaps idealised, form of living. Most had lived alone before moving into care, typically in a rented single person's flat.

### 6.1.2 Perceptions and acceptance

Kin found it helpful to be able to present the place that residents were moving to as housing (see 4.5). Several used the term 'patients' in interviews which did rather confuse this message. Respondents got into linguistic tangles: one respondent could not bring herself to use the word 'home' to prepare a prospective resident for the move for fear of the response. Interviewees stressed that care housing was not '*A Home*' but more like a family home. The homely ideal, appropriated by nursing and residential homes to describe their provision inaccurately, led to these tangles.

A number of factors were reported in interview to make it difficult for residents to accept they were at home. Adjustment was difficult both because the new external environment was unfamiliar, and also because residents hoped and expected to see somewhere from their past lives. The disorientation brought about by dementia made it hard for people to link their past to their present and it became progressively more difficult to recognise where they stayed as where they should be, or as 'home'. This quote illustrates some of the complexity of the question staff were asked.

KF: Do you think residents see this as their home?

S10: Yes, definitely. R17 keeps saying: "This is my house, when are you going home?" // She will see all these people and asks: "How are we feeding all these people?" If they are making too much noise, she will look around and say: "Get them out, this is my house". With R25 [a resident with whom she clashed] it is difficult. It depends on where they are in their life, if they are at the present time, it is their home, and they accept it, but if, the likes of R24 - she wakes up, and looks around and says she doesn't know what she is doing here: "When are my family coming to pick me up?" [S10 group 93]

Kin took it for granted that at times residents would be unsettled, wherever they lived. Residents asked after people who had died as though they still lived, wished to



return to households that did not exist, and wanted to fulfil obligations, such as cooking for their family, which no longer held.

K2: ...He will sometimes ask who he's going to stay with, that's a normal thing, because the next question normally is "I'll go and see my father". I've heard the other patients in [care housing] say the same thing: "My mother and father's waiting on me". Well, that seems to be something that happens...or he'll say: "Nobody from [the street where he lived in earlier years] has been down to see me, your mother's never came to see me". Well, these are all just things that are flashing through his mind I would take it.  
(K2 home 56)

Feeling unsettled and insecure about where they lived in likelihood pre-dated the move to care housing. One woman (R15, see 4.4.2) had temporarily lived with her daughter, but this did not work out partly because she repeatedly asked where she was. She returned to the house where she had lived for a number of years, but it grew strange to her as she became increasingly confused and mistook it for somewhere else. One resident, out for a car-ride, would recognise the area she had lived in as a young married woman, and speak as if she were going 'home', but pass by the flats where she had lived in later years without comment.

Collectively, residents could reinforce to each other the idea that they were trapped and should leave. Possibly this was most acute when a cohort of residents moved in together. Kin had overheard conversations between residents where they commiserated with each other for having been betrayed by their children and put out of their house. Sometimes, small groups of residents would agitatedly talk and prepare to go 'home'.

Although one resident (R15, see above) had made it clear she wished to move to care if necessary, in her kin's opinion this occurred because she had picked the line up as a way of making conversation. Whilst complaining, she made no move to go and appeared perfectly settled in her chair. Another resident, who had threatened to jump in the river should she be moved to a home, was overheard to say to other residents that they should remember they all lived here now and should not try to go home. On other occasions, however, she herself said she was going home and would not stay any longer. There were differences both between individuals, but also fluctuations in how much anyone felt at home.

K11: She has her ups and downs, the staff tell me some days she's wanting home, but then all the residents do. (K11 home 41)

With such ambivalence and intermittent strong desire to return 'home', respondents could not say exactly how residents perceived care housing, and whether it could ever really be accepted as 'home' to residents. Staff believed they had a role in helping residents accept their present circumstances and accepted that they would need to remind and encourage them to think of it as home. Asked if there was anything



making it difficult to make it home-like for the people who lived in care housing, one staff member responded:

S11: That's a hard question. You can only do your best: their memories go back and they remember their own home, and think it is still there, and you say this is your home now. I have asked one or two if they like it here, and they say yes, but will still go back and tell you that their home is somewhere else. We try to make it - tell them that it is their home, that they can have a cup of tea and biscuit as they want, that they can do as they would in their own home, things they can't do, that's where we come in and do it for them. They have their own thoughts but we do not know what they are thinking - I can't see it. A hard question. (S11 home 19)

Staff did not necessarily expect residents to agree that where they were was right for them just now, as their experience was that residents did not always recognise their own needs for support. A successful adjustment was cited as when one resident said 'It's not my home, but I am happy to be here.' Some staff thought they should not insist that care housing was home, nor attempt to replace it, but rather respect residents' views on this.

KF: Is there anything that makes it difficult to make it home-like for the people who live here?  
S24: The fact is that as much as we try it is not their familiar environment and there is another eleven here.

KF: Can you give an example of this?

S24: For example, one lady who says why are all these people in my house - she does not believe you that is communal, she asks: "How would you like it if it was your house?" What can you say? (S24 group 68)

Staff noted that for those who settled in well, demands to go 'home' became less frequent. Residents began to move around as though they lived there and act of their own accord.

S28: For some, yes, it is as their own home, but others usually come down and say: "Is it OK if I have bath?" Which you would not do in your own home. (S28 home 24)

The difficulty of accepting care housing as home was not just related to dementia. The presence of strangers (co-residents, staff, and other visitors) further undermined the extent to which residents could feel at home. How they interpreted their surroundings presumably depended, at least in part, on what they saw. Sometimes residents thought of care housing as a hotel, others as a nursing home. If they had moved from hospital, they might think of staff as nurses. One woman believed that she lived in her son's house, and worried about how the mortgage was being paid. Someone else thought that she had come for a holiday, and perhaps this was how her relatives had described the move, presenting it as a 'rest'. Another, also reportedly told this by kin, believed she had moved to care housing temporarily while she was ill.

Residents' attitudes may have been determined not just by the circumstances leading up to the move, but also by their personal relationships with kin. The resident who frequently returned to her daughter's home did not accuse her daughter directly, but



repeated her name when she angrily said that she had been turned out of her home. Her daughter was distressed by this and unsure how the resident saw the care house. Asked about how she saw the place, the couple interviewed said:

K3: The place, I would say yes, my mother just takes it as some place to live, she doesn't associate it with being her home, in a sense

K3's spouse: I would disagree with that, she says countless times to me: It's a lovely wee flat this

K3: Yes, she likes it but she's always looking for something else. (K3 home 75)

One resident was said to realise that she had had no option which perhaps helped her settle in well; others may have wished that alternatives had been possible and might have been unwilling to accept either that they could not live alone, or that they could not live with their relatives. Sometimes residents appraised the situation accurately, and correctly recognised staff as people who worked there, and might remind them of this:

S21: In the past [a particular resident] has been known to say to staff - "Can I have a cup of tea?" Then she will say to [another resident]: "That's the servant". Saying it for the staff to hear: "Remember your place! You work here!" (S21 home 40)

For anyone in later life there may have been some places where one felt more at home than others: one relative tearfully described her memory of a previous family home. This was equally unattainable for both the resident and the relative. In saying that care housing was 'the next best thing', respondents acknowledged its discrepancy from the ideal of home. One respondent summed up the situation like this:

K7: She does not actually say: "I'm happy here" and I suppose that if she were well, she would want to be in her own home. (K7 home 28)

'Home', as an ideal, was often seen as being shared with family:

S14: Home is where they came from, not sharing a building with others but sharing with those who are closest to them. (S14 home 15)

Home, it appeared was an ideal of a comfortable place, where you can live to the end of your life; where you can choose whom you live with to be those closest to you, which is, by definition, private, and where you can please yourself.

## **6.2 Making a home: the staff's strategies**

This section considers the role of staff in promoting residents' well-being and activity, setting out the ideal, and fleshing out the ways that staff thought that, through household care, they should respect independence, individuality, choice and privacy.



The staff had to judge how to react to each situation, which required considerable skill and mutual support.

The preceding chapters have shown that staff and kin believed that the nature of staff interaction was important to residents' well-being, and this assertion is supported by theorists (e.g. Kitwood and Bredin, 1993). A homely setting was supposed to be a hall-mark of the care houses and household care was the therapeutic principle stressed in operational policies, through which independence, choice, privacy, individuality and dignity could be enhanced. Staff were expected to respect the house as the residents' home and domestic routines were intended to reflect the normal rhythm of home life. A theme evident in staff interviews was their discussion of how best to recreate home for the residents. They needed to be inventive, finding strategies to suit each individual. They agreed that they should act in ways that supported residents' self esteem, meaning that if they intervened, this should be done with tact, using discretion and humour. They tried to frame choice in ways that helped residents articulate what they wanted. The support offered was supposed to build on residents' existing skills and be consistent with their preferences and habits. Their support should be as unobtrusive as possible, which meant the more successful they were, the less conspicuous was their own role and skills.

Since residents had dementia, staff could not necessarily get information directly about individual histories, needs and preferences. If kin had little contact and staff who had previously provided care had not passed on information, staff could feel at a loss. In determining standards to work to, staff had to gauge resident's views, which could be different to those of other residents, to their families, and to staff members' own personal views. Staff needed to balance the support given to individuals with the needs of the group, define acceptable risk when residents themselves might not recognise their needs or dangers, determine whose standards to refer to, decide when to re-orientate and when not to disturb residents, when to push residents who were reluctant and when to intervene or to stand back. Staff had to agree collectively what the limits of their responsibility were: it seemed that the more responsible that staff felt for residents' care and safety, the more they had to use their power. The managerial staff were vital in helping staff work through such questions and to support them in offering independence and choice to residents.

Staff, especially at Heartfield, repeatedly asserted that they treated residents as 'people', that they remembered 'the person' and that this was how their care was different to institutions. Staff believed that a small unit and intensity of contact made this easier.

S22: You have to be in the place day after day to get to know what pleases them, makes them happy or sad, constantly being with them you find out these things.  
(S22 well-being 9)



Referring to one of the residents most severely affected by dementia, a staff member implied that I should be careful in jumping to conclusions about the care offered.

S10: For example, a social worker came round, and said that R10 was capable of doing something, when we knew him. You can't judge, by looking. The social worker thought R10 should be doing something, a complete stranger can say that, but they don't know the individuals. We are still finding things out about people who have been in here for years. [S10 activities 44]

Staff linked expressing individuality to being able to make choices. One argument was that choice in the smaller daily decisions became increasingly important as people with dementia lost skills and that these choices contributed to their independence. What was the nature of choices that residents could make? This was the response of one project manager.

S4: It's like you and I can make, there is no difference. If they do not want an egg sandwich, they can have egg or cheese, or if (they do not want to) listen to music, they can choose to go to their flat, or if they want to lie in bed, they can. Normal choices, have a biscuit or cake - normal. (S4 well-being 6)

Another respondent acknowledged the abnormality of living in care housing and having dementia and that, for example, staff might encourage people to keep within normal waking hours or keep to widely accepted meal-times. There were some differences between houses in the details of offering choice: were decisions about menus, for example, made daily, weekly, or planned further in advance? Promoting independence meant neither choosing on behalf of residents, nor doing what they were capable of doing themselves.

S21: I don't think they want to feel that everything is done, they want to feel independent. For instance, [a male resident] was at the end, quite severely demented, but he was active at night, and said "I'm starving". I said what would he like, he said that he would like a piece, and then said to me: "For God's sake, I can make a piece and jam for myself!" and he did it. Make it their choice. They don't want to be made to feel incapable. (S21 activities 43)

Staff noted skills could be gained as well as lost. Examples included regaining continence, learning the way round the house, or regaining confidence to bake. Keeping independent was seen as a right to which everyone should aspire and this carried a sense of obligation. Residents were, it seems, sometimes reminded that 'If you don't use it, you lose it!' and staff frequently said that residents were 'encouraged to do as much as possible' for themselves. It then became difficult to accept if residents chose to do less for themselves than they could actually manage. Staff had to train their own responses as well as those of residents. One interviewee thought that her previous work in a nursing home meant that she was apt to offer help too quickly, and accepted



reminders from other staff not to jump in. Another, describing herself as a 'fit young lassie', found it difficult to watch an older person struggle with a task. Residents could try to persuade staff to do things, even reminding staff that they were paid to look after them. Staff had to balance concern to promote independence with offering choice and were caught either way. One overheard response to a resident was the ironic comment: 'What did your last slave die of?' suggesting that a demand was unreasonable. As staff themselves were shaped by their own expectations, they thought that residents could have been influenced by the attitude and actions of previous carers. Someone living at home had had relatives who were thought to have done too much for the resident, while someone moving from an institution was said to have lost skills because nursing staff had not taken time to encourage independence.

A common view was that, in reality, residents were very dependent on staff, and though all staff accepted the obligation to promote independence, from this point of view the realms in which they could do this seemed trivial. A more determinedly optimistic view was that staff should assist residents with what they normally did, but they had to adjust to increasing frailty. An example given was that if a resident was having difficulty washing up dishes, the task of staff was to point out where the detergent was. Where staff were in touch with individuals' histories, they appeared more easily to see the struggle to maintain independence as meaningful.

There was another balance to be made between what residents might want to do and their safety. 'Acceptable risk' referred to the level of risk to be expected in daily life. If residents wanted to do something beyond this, staff used 'informed risk', meaning that they warned residents of what could happen. An acceptable level of risk had to be mutually agreed, and kin might have their own views. This could be tested if residents wanted to go out on their own. In practice this rarely happened, and if it did, staff were anxious on their behalf. Staff actively observed where residents were and had various alarms to help monitor this. When residents wanted to go out on their own, staff had to work out how to manage this. Ideally staff accompanied residents who might well otherwise get lost, and would shadow them if their company was rejected.

While kin valued the chances that residents had to leave the house with staff, they preferred that residents should be restricted in leaving on their own. Some kin mentioned specifically that it was appropriate for staff to restrict residents. One interviewee, whose relative frequently appeared at their home on her own, was asked what she thought staff should do.

K3: I don't think she should get out on her own, because she's got no sense of direction. She's been lucky every time that she's come down here that someone's seen her and she's got back, but she could get out and walk away because she just doesn't know where she is, she's lost the direction of where she is. I know the home cannot watch her all the time and I don't blame them, I know that she's devious for getting out, if she wants to do it, she'll do it. I'm always glad when I hear that she's not got out, it's too big a responsibility ... The last time she got out, we went up to visit her on the Monday and she escaped, I always say she's



escaped, she had got out. We waited a wee while, and got her on the road with one of the neighbours who was out walking the dog, trying to persuade her to come back.  
(K3 staff regime 109)

Senior staff argued that ultimately families had to accept that if residents were not heavily restricted, as in psychiatric hospital, there would always be a level of risk. Whether a decision made by staff was right or wrong depended on the context, which could change rapidly. It depended on the weather, the season and the residents' capabilities. In the case above, the resident had begun to take unwise actions, going out without a coat, and usually got lost. Cooking was another potential risk: senior staff insisted that residents had a right to be in the kitchen and should be as independent as possible while working there.

Privacy was mainly interpreted as residents' rights within their own rooms. Residents had been offered and given keys when the care houses opened, though staff kept a master key. Some residents, especially in one house, used their own key, but reportedly elsewhere it had been an impractical arrangement and residents had asked staff to look after the keys. After someone who died while getting dressed, one staff group decided that exceptionally they would enter if there were no response after repeated knocks but not all were comfortable with this. This staff member was unsure how to respond to 'the theory of the place'.

KF: The theory of the place?

S28: Not going into tenants' flats uninvited because it's their own home, but in extreme if they normally get up at eight but not have appeared by twelve.

KF: Has this happened?

S28: Yes, I rang the door bell, I listened at the door, no movement, so eventually - usually [this resident] was always up. I thought if I was a neighbour, I would want to check. Eventually at 1.00 p.m., I chapped the door and asked if he was ok. He said: "Yes but I cannot turn." Over in bed he meant, he had just woken up, had just had a long lie. Then it is difficult to know if you are doing the right thing - don't want to invade privacy, nor let them lie there distressed or injured. Sometimes you know it is a really good theory, but you are stumped, and not sure what to do, common sense may tell you in this situation (to do something against the theory). Obviously you put tenants first. (S28 well-being 27)

Privacy was helped by having your own bathroom but endangered by sharing rooms, especially at night. If staff were helping one of the room-mates, this could disturb the other. Night staff also had to decide if it was justifiable to wake residents who were habitually incontinent. Privacy included protection from other residents, but when people with dementia wandered into the wrong room, possibly going to sleep in the wrong bed, staff had to find a way of discouraging this, which could amount to insistence that the disoriented resident moved. Another dilemma was if a resident, prone to incontinence, needed a WC urgently. It could be tempting to use the nearest WC, even if it was in someone else's room. Privacy, a few staff stated, should be extended to the confidentiality they observed in contact with relatives, or, more subtly, to whether



residents who were sitting peacefully and resting in shared areas should be approached or expected to share a box of chocolates.

Dementia was seen potentially to undermine self-esteem. Staff disapproved of infantilising, patronising or condescending approaches and, ideally, worked unobtrusively and tactfully. For example, if a resident had made their own bed, staff might return to the room later to check it was dry.

S10: It's encouraging them, and praising them up when they say can't do. If you are helping, you do it at a discreet distance, make them feel they are doing something. If you are laying out clothes, you put them out in the right order, if they are having difficulty with buttons, you let them try. You talk all the time, you never get anyone washed and dressed without standing, and not saying anything. I wouldn't like it myself, you encourage them all the time to do things, and do things for other people. (S10 well-being 41)

How should staff explain why residents had moved to care housing? Staff varied: some saw it as tactless and hurtful to mention the word 'dementia' directly, and referred instead to 'poor memories'. Others acknowledged explicitly that all the residents had dementia.

Staff and kin thought residents should be as active as possible to enhance their independence. Activity was principally framed by household care, but also included leisure.

KF: For residents, what are the main activities they take part in, living here?

S25: The household activities, they like to do their bits and pieces in their own flat, generally tidying up, and we try to encourage them around the care house, show them for example tasks in the kitchen - the day to day running that you do in your own house, rising, bathing, do a bit of laundry, helping with meals and possibly going out in the afternoon for a walk, and preparing meals, and at night, sometimes we have an activity - for example, playing bingo, dominoes. (S25 activities 1)

In Heartfield, where there was least equipment, the emphasis was on informal and spontaneous activities. At another house where staff had access to more resources such as games and reminiscence packs, senior staff commented that their experience had shown that planned activities were generally less successful than when they 'went with the flow'. Care staff had to judge what would be well received.

S23: To sum up: if I were producing a guide, I would say never feel under pressure to do activities with people with dementia. It got to the point where we did feel under pressure. Residents are not looking to you always to perform, whereas they might in part IV - it's important to remember that. They can sit and do nothing all day, but this is not neglect, it is just the way it is. (S23 activities 40)

Staff valued spontaneous activities, built on the interests and ability of individuals or small groups, for example supporting men who enjoyed using mechanical tools, or women who were skilled in the laundry. Singing and music came out clearly as an important and successful activity in each care house. Staff wanted gardens where



residents could grow or simply enjoy flowers and, at each unit, wished for a minibus as they valued opportunities for residents to get out and for kin to be involved.

At Redpath, where household care was perhaps most successfully implemented (see 6.4), staff were most satisfied that they were helping residents appropriately. Elsewhere, staff wanted to increase residents' involvement. There was a potential difficulty if residents had been inactive at home and preferred this state. A minority view held that it was their right to choose this: perhaps they had earned a right to rest. This attitude, it was often reported, was shared by at least some of the residents.

This section has distilled all the staff interviews, but a certain qualitative difference between the houses were evident. Redpath's staff were the most diligent in checking what was normal for life at home and trying to put this into practice. Heartfield's staff were assertive that individuality and personhood should be nurtured and more likely to point to things that residents could enjoy and try to create fun. At Heartfield, some respondents noted that as a staff group they had occasionally been criticised by visitors for being too relaxed, as if they were not professional enough. They rejected this criticism on the grounds that their job demanded that they shared the residents' home with them and a formalised approach would therefore be inappropriate.

### **Contact between kin, residents and staff**

The presence of dementia meant that kin acted as a link between residents and their former social network and events in their past lives. Practical care could be delegated, but nurturing this link could not. Staff believed that ideally kin should continue to be involved in the lives of residents, and that this could benefit all concerned. Kin could help make care more personalised and provide the biography that helped staff get to know residents. As one staff member had experienced, there may, however, be skeletons in the cupboard about which it was inappropriate to pry. Given that residents often asked about their family, staff welcomed regular family contact as a means of reassuring and orienting residents, and as something that improved their well-being. A good relationship between residents, family and friends was defined as follows.

S28: A good relationship is when relatives and friends come in and understand what is going wrong, that they are not what used to be and need a bit more. For the relatives' part, they have to be a lot more patient - but if they are used to go shopping every week, or getting the pension, then if they keep up doing that, going for pension, that's a good relationship. Some people have never had good relations with their family and you can tell that, they may shout at each other. (S28 kontakt 16)

The ethos instilled in the staff was that they should respect family relationships and preferences, although they saw themselves as primarily available for the residents. Recognising that they could not be a substitute for family, some pointed out they could never compensate for poor relationships in the past. A question was raised about the

limits to what staff could provide. Was it up to the family to give support over and above what employed carers could provide?

Staff tried to promote good family contact between themselves and residents, and their families. Reassurance that the move was legitimate and beneficial to the resident was intended to allay guilt feelings. Kin, staff felt, should be able to continue providing the same type of care as they had before the move and be made welcome by staff who were approachable and open. It was intended that kin should use the unit as though it was the residents' own home, meaning unrestricted use of the shared rooms and no set visiting hours. Kin might be helped to adjust to residents' behaviour which was perhaps found embarrassing, or to understand what residents were saying. Staff might also try to persuade kin that they should offer support in ways that promoted independence.

### **6.3 Observation: residents' activities and well-being**

This section summarises the observation data obtained from Nash Drive, Redpath, and a hospital ward, using the modified Dementia Care Mapping method explained in section 3.8. These data are referred to in the following sections and in Chapter Seven.

#### **6.3.1 Activity codes**

The definitions of DCM activity codes are as set out in Box 6.3.1/1. The frequency of observed activities is shown on Table 6.3.1/1 below. No record was made for 29 % of the total time frames because the resident was not observable, possibly being out of the unit or in their flat. Of the activity codes shown in Table 6.3.1/1, sixteen were observed of a possible 20 (C, H, J, and R were not observed). In the observation, records of the activity code A (interaction) included some interactions that could have been coded S (relating to sexual expression or flirtation). Codes 'E', 'G', and 'I' are counted together (EGI) in the following table as these were found to all relate to leisure activities initiated by staff. The term 'RTF%' is used to indicate that the preceding figure is a percentage of the number of recorded time frames.



**Box 6.3.1/1 DCM activity codes and their definition.**

B	Being socially involved but passively
F	Eating, drinking
A	Interacting with others, verbally or otherwise
N	Sleeping, dozing
K	Walking, standing, moving in a wheelchair
E	Engaging in an expressive or creative activity
G	Participating in a game
I	Using intellectual abilities
L	Performing work or pseudowork
P	Receiving practical, physical, or personal care
M	Engaging with media
O	Independently engaging in self care
X	Episodes related to excreting
T	Direct engagement of the senses
U	Communicating without receiving a response
D	Expressing distress
C	Being socially uninvolved, withdrawn
H	Participating in a craft activity
J	Participating in exercise or physical sports
R	Participating in a religious activity
S	Sexual expression or flirtation

**Table 6.3.1/2. Frequency of most common activity codes (RTF%)**

Activity code	Nash Drive	Redpath	Total: care houses	Hospital
B (Passive)	28	19	24	18
F (Eat/drink)	17	21	19	11
A (interacting)	17	14	15	6
N (Dozing)	11	8	9	14
K (Walking)	7	11	9	25
EGL (sing, play)	3	11	6	< 0.1
L (work)	3	9	6	< 0.1
P (physical care)	8	2	6	5
M (media)	6	3	5	0
O (own care)	< 1	1	1	0
C (withdrawn)	0	0	0	13

The hospital observation recorded, in addition to categories shown above, D (distress) at 5% and X (using the toilet) at 3% of RTF%. Table 6.3.1/2 shows that residents in care housing spent more of the observed time in 'passive social involvement', (B - 24 RTF%, range 1 - 56 RTF%) than 'interacting with others, verbally or otherwise' (A

- 15 RTF%, range 3 - 42 ). The code 'B' implies that residents were likely to be aware of, perhaps being an audience to, conversations between others. Despite the fact that DCM scores generously in that any sign, however slight, of involvement during a time frame lifts the score from 'C' to 'B' ('being socially uninvolved and withdrawn'), this was still recorded in hospital. Were a shorter time frame used, C may have been represented in care housing too, but even so, it was to the care houses credit that there C was not observed.

If the activity codes for being withdrawn (C), passively socially involved (B) and asleep (N) are combined and described as passive behaviour, then in rank order, hospital had most passive behaviour at 45 RTF%, Nash Drive next at 39 RTF% and Redpath had least at 27 RTF%.

### 6.3.1/3 RTF% of activity codes by time of day (care housing totals).

Activity Codes	Morning	Afternoon	Evening	Total
B (Passive)	23	25	23	24
F (Eat/drink)	20	16	21	19
A (interacting)	20	15	13	15
N (Dozing)	9	13	5	9
K (Walking)	9	10	8	9
EGL (sing, play)	1	5	9	6
L (work)	7	4	7	6
P (physical care)	6	8	3	6
M (media)	4	4	6	5
O (own care)	1	<1	2	1

Throughout the day, the frequency of code B remained steady, but the proportion where A was observed dropped as the day progressed. It may be that the increase in EGL explains the decrease in A. Whereas P, N and K rose in the afternoon, L and M dropped.

### 6.3.2 Care values

Care values can be presented by distribution of the different care values, it being more appropriate to view the care values as rank order data. The definitions, as supplied by Kitwood *et al.* (1995:18) are as set out below.



- +5 High quality social interaction, evidence of a therapeutic or intimate bond between two or more persons
- +3 Good routine care / pleasant social interaction or strong expression of well-being
- +1 No or minimal social interaction, no ill-being discernible: 'well-being alive but dying'
- 1 Mild ill-being observable
- 3 Moderate levels of ill-being / continuous neglect of ill-being for more than 30 minutes
- 5 Severe ill-being observable, or continuous neglect of ill-being for over 60 minutes.

**Table 6.3.2/1 Frequency of care values as RTF%**

Care value	Nash Drive	Redpath	Care house total	Hospital
+5	6	12	9	0
+3	32	42	37	11
+1	59	45	53	45
-1	2	<1	2	22
-3	<1	0	<1	<1

According to the standard DCM method, care scores can be generated by summing the care values and dividing this by the number of RTF. The mean score stands as a group score, and can be rated from 'much improvement needed' to 'excellent' (Kitwood and Bredin, 1994:56).

**Table 6.3.2/2 Individual care scores by location**

Location	Group Care Score	Individual Care Score Range	Rating
Nash Drive	1.6	1.3 to 3	Good
Redpath	2.3	1.6 to 3.7	Very good
Care house total	2.0	1.3 to 3.7	Good
Hospital	0.7	0.4 to 1.1	Much improvement needed

**Table 6.3.2/3 Individual care scores by category**

<b>Category</b>	<b>Nash Drive (N=12)</b>	<b>Redpath (N=8)</b>	<b>Total Care Houses (N=20)</b>	<b>Hospital (N=5)</b>
<b>Excellent (3.0 and above)</b>	1	1	2	0
<b>Very good (2.3 -2.9)</b>	1	3	4	0
<b>Good (1.5 - 2.2)</b>	8	4	12	0
<b>Fair (0.8 - 1.4)</b>	2	0	2	2
<b>Much improvement needed (0.7 and below)</b>	0	0	0	3

Residents in both care houses fared considerably better than hospital patients according to these observations. There was also a difference between care houses with Redpath gaining higher scores than Nash Drive.

The group care score for different times of the day showed little difference, being 2.0 in the morning, 1.9 in the afternoons, and 2.2 in the evenings. Individual care scores varied in their pattern: one person scored 4.1 in the afternoon. Where both the activity codes and the care values had been recorded, it was possible to calculate care scores for different activity codes. Table 6.3.2/3 overpage presents the most commonly observed activities, this time presenting E, G and I separately.

Table 6.3.2/3 suggests that the more active residents were, the higher the care values. The scoring system prohibits B and N from gaining the best care values, but still this finding is encouraging as it suggests that the activities residents took part in promoted their well-being. The activity codes G, E and L were associated with 'excellent' average care values, while A and F were associated with 'very good' care values. It seems that residents enjoyed the games and expressive activities (for example, singing) and also the work that they did. There were differences between the times of the day. Eating breakfast generated a lower score than lunch or evening meals. As the next section describes, the work observed was mainly connected with clearing away these main meals. Presenting the codes E, G, and I separately suggest that episodes of these staff-led activities could vary in success.



**Table 6.3.2/4 Care scores by activity and time of day**

Activity Codes	Recorded Time Frames	Morning care values	Afternoon care values	Evening care values	Total care values
F	343	2.1	2.6	2.6	2.5
B	439	1	1.1	1.3	1.2
A	282	2.3	2.2	2.1	2.2
N	169	1.0	1.0	1.0	1.0
K	159	1.8	1.0	1.7	1.4
L	105	2.6	3.4	3.4	3.2
P	102	2.7	1.2	1.6	1.6
M	86	2.5	2.1	1.8	2.0
E	55	2.5	3.8	2.8	3.0
G	33	none	3.0	4.7	4.6
I	25	none	3.8	none	3.8

### 6.3.3 Spoken Interactions

**Table 6.3.3 Frequency of types of spoken interactions as RTF%**

	Nash Drive	Redpath	Care house total	Hospital
no spoken interaction	56	48	52	70
1 resident	6	16	10	2
1 staff	22	11	17	21
group including non resident	10	16	13	2
resident group	1	4	2	0
visitor	3	4	4	4

Table 6.3.3 show that residents spent just over half of the time frames (52 RTF%) with no spoken interaction, and just over quarter of the time frames (27 RTF%) talking, however briefly, to one other person. Group interactions took 13 RTF% but a small minority of these were between residents alone (2 RTF%). Spoken interactions between residents, singly or in groups, were more likely in Redpath than Nash Drive, but residents were more likely in Nash Drive to have an exchange with a staff member. In hospital, patients rarely spoke to each other singly, and not at all in a group. There was,

overall, considerably more spoken interaction in the care houses (48 RTF%) than in hospital (30 RTF%). Conversations between staff were not recorded since DCM directs attention to residents. The record of the interactions with myself (2 TTF%) is misleadingly low because at times when residents initiated conversation I stopped observation.

A qualitative observation was that all residents at Redpath could make conversation with me and respond to what I said in a normal way. In each of the other case studies there was more than one resident who I found very hard to understand or who rarely spoke.

#### 6.3.4 Use of the different areas of the care house

Table 6.3.4/1 RTF% spent in the different areas

	Nash Drive	Redpath	Care house total	Hospital
Private room	17	24	20	4
Shared sitting areas	67	65	66	87
Work rooms	12	10	11	4
Out	3	1	2	4

In care housing, communal rooms included dining room, lounge, and conservatory. The bathroom, laundry, kitchen, hallway and office were counted as work rooms. Table 6.3.4/1 shows that residents were present in the two care houses for over 97% of the recorded time. Four residents, two in each unit, went out, but the others stayed in. Three of these outings were for trips out for less than half an hour while the fourth occurred when a resident went to stay overnight with her family while her room was being redecorated. Observation periods were chosen for when residents were likely to be in the unit so this figure may be misleadingly low. Residents used their own rooms for over 20% of the recorded time. Detailed records show that, of the shared rooms, the sitting room was used almost twice as much (42 RTF%) as the dining room (21 RTF%), with the conservatory used for 4 RTF%. In hospital when patients were out of the ward they were at a day club within the institution.

More detailed analysis showed that almost all records of use of the kitchen were in Redpath (7 RTF%) and not in Nash Drive (< 0.1 RTF%). The hallway was used more in Nash Drive (1 RTF%) than in Redpath (< 0.1 RTF%) because two residents habitually sat in Nash Drive's hallway.



**Table 6.3.4/2. Use of different areas of care housing at different times of day (RTF%)**

	<b>Morning</b>	<b>Afternoon</b>	<b>Evening</b>	<b>TOTAL</b>
<b>Private room</b>	30	14	20	20
<b>Shared rooms</b>	56	71	69	66
<b>Work rooms</b>	11	12	11	11
<b>Out</b>	3	3	< 1	2

Several residents had yet to get up by the time observation started, which explains why private rooms were used more in the morning, while in the evening some residents had retired to bed by the time observation stopped. Overall, the amount of time spent in shared rooms did not change much; the figure is increased because in one unit, at least two residents habitually sat in the hallway. Residents did not tend to go out after the evening meal, and at this point the percentage of unobserved time frames rose. In hospital the only work areas in the ward used by patients were the office and bathrooms.

#### **6.4 The daily pattern**

According to kin interviewed, before the onset of dementia, residents' daily patterns had substantially changed on retirement from work or widowhood. They had latterly lived on their own, when typically a day had involved getting up early (by 8.00 a.m.) and taking care of household affairs, such as cleaning the house and shopping, before taking leisure. Socialising was an important feature, either visiting or entertaining neighbours, family and friends, sometimes daily. Some, women as well as men, had strong interests that included church, football, politics, walking, reading, television, films and handicrafts. An exception was someone who had an alcohol problem and was apparently unconcerned about housework and had erratic eating habits. Kin described, with the onset of dementia, decreasing ability to keep to the daily routine and to follow interests. Changes included disorientation in time, a failing ability to recognise one's own needs, to follow conversation or television programmes, or to read.

Observation suggested a daily pattern for residents in care housing. By 8.00, some were up and eating breakfast in the dining room, some in dressing gowns, to return to their rooms to dress after breakfast. Some residents may have been up since 6.30. Staff might rouse people who were still in bed if they were going out that day or if they were not up by mid-morning. Most residents had finished breakfast by 10.00, some lingered over the meal. Residents were offered a mid-morning cup of tea or

coffee, unless they had initiated this themselves. The television or radio was on for periods during the morning. A few residents went to a day centre or lunch club, occasionally others went to local shops with staff. Some took up the invitation to help the domestic or home help clean their flats. Kin rarely visited in the mornings.

Mealtimes are described in more detail later. Residents were reminded just before midday that the meal would soon be ready and started to eat between 12 and 12.30, the meal lasting for 30 to 45 minutes. In the afternoons, there was a possibility of more structured activities led by staff or visits by relatives. A cup of tea and a snack was offered mid-afternoon.

After the evening meal, eaten between 16.30 to 18.30, the television or a music video was often on. Most kin came to visit then and staff initiated bingo, quizzes or singing games. A snack was prepared between 20.00 and 21.30, being tea and toast or perhaps an alcoholic drink. The last observation was made at 21.55 when some residents were still up but others had gone to their rooms. According to staff, while most residents went to bed between 21.00 and 22.00, others sat up into the small hours, talking to the night staff or watching television.

Apart from the minority of residents who went out regularly to day centres, there was little to give a weekly pattern. Some relatives visited on fixed days, a few residents went to church weekly. Some support services had developed a pattern, for example District Nurses or a hairdresser who came weekly to one unit. At the larger unit, a bar evening was a weekly fixture. The smaller units had minibuses arranged occasionally; the larger unit had access to this once, and sometimes twice, weekly, which made weekend outings possible. In the first year of operation, one house had organised a holiday to a Scottish resort for some residents. This had not been repeated: holidays depended on kin and were rarely taken by residents. The staff helped celebrate residents' birthdays and arranged meals and celebrations at Christmas and New Year within the house.

#### **6.4.1 Typical days and varied patterns**

Staff and kin thought the way residents used the house indicated whether they felt at home or not. Did the way residents use the house vary? Did they choose whether to spend time alone or in company? Did they go to their own rooms whenever they wanted? Did they move around freely, making use of the work-rooms? Did they have their own possessions around them?

The observed days for two individuals are described which could be described as 'typical' for observed activities and use of rooms. The RTF% for the four main activities (A, B, F, K) and use of their rooms and shared areas were within the inter-quartile ranges. Mostly, the categories of spoken interaction they had fell within the inter-quartile



ranges, and none showed extreme scores. They had both lived in the house for about 18 months and could walk independently.

### *A resident's day at Nash Drive*

R21, aged 90, was observed over four days in early summer.

*Morning.* She was up, washed and dressed by 10.00 a.m. and had breakfast in the dining room. She said she was tired, although reportedly she had slept well. Her breakfast was specially prepared by staff and brought to her. Over breakfast, which lasted for 20 minutes, she spoke with a staff member and other residents. She then went to sit in the lounge, and dozed or looked around until 11.30; she was dozing while staff were offering residents tea, and was not woken. The domestic went with her to her room, where she stayed. Her daughter arrived and took her a drink in her room. She returned to the dining room for lunch, speaking to staff and one or more residents in each TF. Staff said she regularly used the WC in her own room, this being one reason she returned there, but she also used her room, sitting quietly or listening to her radio.

*Afternoon 1.* She came through to the sitting room from her room at 13.30, and moved soon after to the dining room, perhaps because the lounge was then noisy. Returning a few minutes later, she sat in silence for much of the time, but watched a reminiscence session led by a member of staff. On four occasions she spoke to staff, once as part of a group.

*Afternoon 2.* She dozed in the sitting room between 14.00 and 15.20. The radio was on but she did not seem to listen to it; at one point there were several staff members in the sitting room but she did not speak to any of them. At 15.25 she woke up, spoke to a member of staff, sat in silence for fifteen minutes, and then began a conversation with a staff member for ten minutes. At 15.55 a relative arrived and they went out together.

*Evening* (an interrupted period of observation). Having finished her evening meal at 16.50, she approached me when I was in the office, and took me for a walk round the house. After this, she returned to the sitting room, talked to a resident and a member of staff, then sat for an interval in silence. She then found me again, though I was trying to be unobtrusive, and invited me to see her room. She pointed out her wardrobe and her photos, and said that she was worried her daughter was not there, having forgotten that she was on holiday. At 18.15 she returned to the sitting room, occasionally getting up to stand or walk a few steps, and looked at a photo album with a member of staff. Staff offered residents alcoholic drinks, she had one and then sat looking around but not attending the television that was on. She dozed off at one point, and got up to walk a few steps at another. At 21.10 she addressed me. I did not respond, hoping that a member of staff would instead. No-one else responded and I explained that I did not



work there and could not help her get ready for bed. She had to wait until 21.30, when a member of staff was free to help her to her room.

### *A resident's day at Redpath*

R7, aged 88, was observed on four separate days in late summer.

*Morning.* She was up and dressed by 9.00, eating breakfast in the dining room. At first she did not talk to anyone, but she sat after the meal talking to another resident. At 9.55 she went to the kitchen of her own accord, where she washed her dishes and put them away. She went down the hallway, looking into the office on the way, and spent 40 minutes in her room. She came back down the hallway at 10.50, talking to two staff members en route. She then sat reading the paper in the sitting room, dozing off for 15 minutes at one point, waking up and starting to read again, and then losing concentration. At 11.55 she independently got up and walked to the dining room, and sat quietly talking with others at the table. At 12.15, she began to eat lunch with the other residents and staff, getting up during the meal to pick up her dessert from the kitchen, at this point talking to other residents. She got up from the table at 12.40, which acted as cue for the three others sitting there to do the same.

*Afternoon 1.* She took an active part in a game with other residents and a member of staff in the conservatory for twenty five minutes. Her participation tailed off for the last twenty minutes of this game.

*Afternoon 2.* At 12.55 she told me she had lost a ring. A member of staff told me that she quite often lost things. She went to her flat and returned to the sitting room, singing with others along to a music video. At 13.20 she went to her room with a visitor, who came into the sitting room forty minutes later saying she was looking for the ring. By 15.30, she had returned to the sitting room, and sat dozing, and looking around her occasionally, not talking to anyone, until 17.30. As her eyesight and hearing were poor, she might have been distanced from others in the sitting room. At 17.00 she walked to the dining room, sat down at her habitual place at the table, and started to eat her evening meal, talking to other residents for some of the time. She followed the established pattern of going to the kitchen to pick up her dessert, and getting up after finishing this to wash her dishes with other residents in the kitchen. She helped one of the residents to stand up. At 17.50 she returned to the sitting room, picked up her paper, read it, and moved to her favourite chair. The television was on: it seemed to be her habit to watch the six o'clock news, which was put on at 18.10 by a member of staff. At 18.30 one of the staff asked her if she minded if the news went off, as it was depressing that night. She agreed to this. She needed the television on loud to hear it but this was clearly too much for at least two other residents. She did not take part in conversation and a singing game that other residents and staff were playing. At 18.45



she stood up in the sitting room, looking uncomfortable, and made it known she had indigestion. She walked to her flat, returning to the sitting room at the point when staff brought a tray of tea to the lounge. She took a cup, but looked uncomfortable while drinking it. She asked a member of staff the time at 19.20, and was surprised it was this early. She remained in the sitting room, not talking to anyone and dozing off at 20.15 for 20 minutes. When a music video was put on, she joined in singing, and then ate some tea and toast that staff brought into the sitting room, where she remained until observation stopped at 21.10.

There is a qualitative difference between these two accounts. The second resident acted more on her own initiative and it seemed she decided for herself that she would take part in activities or conversation, or not. That the first resident approached me for help or entertainment suggested she felt more at a loss, or perhaps was bored. Compared to other residents observed, it was unusual to spend this amount of time with kin during the day.

#### **6.4.2 Using private and shared space**

Table 6.3.4/3 showed that residents spent 20 RTF% in their own flats. There was considerable variation: two individuals spent more than 40 RTF% in their own rooms, and two spent under 5 RTF%. The two who spent most time in their rooms were both less well than usual, and were getting medical treatment. One (R15) regularly went to bed at midnight, and got up late in the morning, not making it for lunch on one occasion observed. The other (R19) got up as early as 6.00 a.m., had two breakfasts and then went to bed in the afternoon, preferring to eat there in the evening. The two who spent almost all the time in shared living areas were, according to staff, behaving much as usual. One (R5) was a very sociable person, who often initiated conversation with both residents and staff. She seemed to enjoy sitting by a window and looking out, and was often in the company of a small group of other residents. The other (R6) spent much less time in conversation, and would sit in the dining room for long periods after meals when other residents had left. When in the sitting room, her main enjoyment was to listen to music videos. At interview, kin said she habitually had spent time on her own in her house and tended to be bitter.

##### *Private space*

Interviewees asserted that private rooms were very important, allowing residents to withdraw, have a rest, listen to the radio or watch television, and go somewhere privately with visitors or other residents. Staff helped residents dress and wash in their



own rooms and this was where visiting professionals met residents. One or two frequently sorted through things in their cupboards, not always seen as a constructive habit by staff.

Anyone with experience of shared rooms said they led to difficulties. Residents were restricted in what they could bring; they were sometimes unable to distinguish between their own and their room-mates' possessions. They did not always get on with each other, a problem that was exacerbated by aggressive behaviour or other anti-social habits. It was more difficult to provide physical care in privacy, especially at night: residents might not be tidy in using the WC. Sharing a room was only considered to be appropriate if this was with a spouse.

Making their room their own depended on help from kin and staff. Residents could furnish and decorate their rooms to their own taste, with help from their families. A checklist completed with staff established what those residents included in the observation (28) brought with them. They brought and used their own clothes; most brought ornaments and pictures, and furniture that commonly included a bed, chest of drawers, dressing table, chairs, and small tables and only occasionally included bigger items. This could be supplemented by furniture belonging to the house, though one unit disapproved of this as a policy. Staff reported that, although they advised that familiar pieces were helpful, kin were sometimes keen to buy new things rather than bring old ones; furniture might be too big for the room, or judged to be in poor condition. Those moving from residential care tended to bring less, and if residents were married they might need to leave furniture at home for their spouse to use. Almost all residents had some personal photos with them. Staff thought having residents' own things in their rooms was important to help them settle in, and said that showing these possessions to residents and encouraging them to handle them could help orientate residents who were unsure that they were in the right place.

Some electrical equipment was brought, such as razors, radios, hairdryers, lamps, televisions, kettles and refrigerators that were kept in their own rooms. Kin thought refrigerators could be of symbolic rather than practical importance, though one had been used to store fish when a resident had brought a cat to the house. Kettles were said to be little used: one relative debated whether it was a risk or not.

Interviews indicated how important meals and snacks were to create a sense of homeliness. Above all, having the freedom to make yourself a cup of tea when you wanted seemed to symbolise being at home. While reportedly residents were encouraged to do so, only two residents used their room to make tea, one using this as a resource to entertain other residents and staff.

Given this emphasis on the importance of one's own room, it follows that residents may have felt more at home in some parts of the house than others. However, your own room was not always a haven, as some residents mistook rooms and entered someone else's without knocking. This made some residents anxious, especially



females in mixed gender groups. Possibly, when residents were awake at night, they were then more restricted in how they could use the house.

### *Shared living rooms*

The sitting room was the main area used by residents during the waking day, with the open plan dining area in the smaller units used equally. Staff, in the larger unit, wondered why, when there was a choice of where to sit, residents congregated in the main lounge, but observation indicated they were encouraged to sit there. The furniture, carpeting and decor were chosen by staff to be both practical and in keeping with what residents were likely to use at home. Pictures on the wall were unobtrusive, generally of rural landscapes chosen by staff. Electrical equipment included a television, VCR, and a music centre. The house supplied everyday cutlery and crockery. One house had a photo album of outings and events in the house, kept with other games in a cabinet in the lounge. The larger house had more specialised games and equipment. Residents' influence was limited in the shared areas where they spent most time.

### *Work rooms*

The pattern in both units for using private rooms and going out was similar. There was a remarkable difference in the use of the kitchen. In Nash Drive, three quarters of the residents did not enter the kitchen but at Redpath, all residents used the kitchen regularly throughout the day. Two women (R23 and R16) in Redpath who used the kitchen most (9 RTF% and 15 RTF% respectively) washed up not only for themselves but for other residents, and made cups of tea, again for other residents. It appeared very likely that the design of the kitchen and the expectation of staff were important in explaining this difference. The laundry area was used mainly by staff in both units, though some residents occasionally went there. In Nash Drive, two residents sat in the hallway regularly which increased the apparent use of work rooms. Otherwise, these areas were used little in Nash Drive.

Medicines and cleaning materials were always locked away, but there were different arrangements for food. If large stocks were held, these were locked. Staff at one house had taken the decision to limit stocks in the house, for example of chocolate biscuits, rather than restrict access. One admission was that sometimes, when working under pressure to cook a meal, it was tempting to persuade residents to leave the kitchen as they distracted attention from an urgent task.

Although residents had their own WCs, and in one unit a shower, they shared a bathroom with others. When residents became more dependent and needed more assistance to have a bath, adaptations were made as required.



## *Experience as an observer*

My own experience may have reflected the way that residents were socialised into each house. I was made to feel welcome but the way I was treated varied. At two houses, I used the shared facilities to make myself tea after staff encouraged me to do so. Making tea became a reciprocal arrangement. In Nash Drive, I was at first treated formally and served by staff, but during observation I joined staff who ate separately. Residents' responses to me varied: several appeared neither interested nor surprised when I introduced myself, but others were curious and looked at me carefully. In Redpath, several were alert to my presence and approached me directly to ask who I was and if I was all right, making me welcome when they found out what I was doing.

## **6.5 Getting the work done**

Section 6.4 showed how the daily pattern in each of the three case studies was similar, being punctuated by mealtimes and sitting in the shared living rooms for most of the rest of the time. Activity in the house in the mornings revolved around personal and household care; staff did hand-overs and paperwork in the afternoons. Leisure activities usually took place later on: the evenings saw fewest staff on duty, and the most relaxed atmosphere. This section considers how the work in the house was done, and by whom. It develops the theme, raised in section 6.2, that residents were not always as keen on doing work in the house as staff hoped, and begins to flesh out the finding emerging from the last two sections, namely that the houses emphasised different aspects of a social model of care and possibly had differential success in achieving household care.

### **6.5.1 Personal care**

More practical help from staff was observed (P, 6 RTF%) than self-care by residents (O, < 1 RTF%), perhaps because the latter happened privately and out of sight. Practical help included helping residents to stand, walk, cut nails and dress hair. Sometimes staff were not available to help residents when they were wanted. For example, one evening two residents made it clear to me they were tired and wanted to go to bed, but had to wait for half an hour as staff were busy. According to the staff personal care was given by a minority of kin. One spouse helped on a daily basis and other residents were helped to bath or with their hair or nails. Staff wished relatives did more, encouraging them for example to accompany residents to visit the doctor. Relatives did not necessarily agree this was a good idea. One visit to the doctor was described as a failure, as the relative did not know what staff thought the matter was exactly, and the resident herself denied there was a problem. Another report was given



of a more successful exchange, where a kinswoman was pleased to continue to have a close understanding with her sister, who told her, and not the staff, about a sore on her breast.

When she did speak about that breast thing she said to me: "I didn't want to say to them" - "them" being the staff and she waited until I came in but that's because I had been coping with her, this is what I didn't want to spoil, I felt that there was this rapport between us so this is what I wanted to keep, make sure there wasn't any barrier between us.  
(kontakt 97)

### 6.5.2 Household work

The care score generated for 'L', at 3.2 (performing work), was higher than the mean (see Table 6.3.2/3). The positive interactions surrounding this work together with the opportunity to be supported and to help others, account for this result. Staff differed in their assessment of how active residents were; even within the same unit some had the impression most residents participated, while others said that on the whole residents sat and watched. The observed range was between 0 RTF% and 24 RTF%.

The work that residents took part in included washing up, cleaning and preparing dining tables, collecting food from the kitchen, making snacks, polishing furniture and sorting laundry. Male residents, from time to time, did slightly heavier jobs, such as sweeping outside or cleaning windows. Sometimes, residents were invited to sort things in their flats or to help a staff member in another room, as a diversion from something they were doing which might have been risky or irritating to others. Residents varied in how they approached the tasks, sometimes acting without prompts, willingly working with staff, and at other times acquiescing reluctantly or refusing. Spontaneous work, most common in Redpath, included routinely getting food from the kitchen and cleaning and washing up after meals. This could extend to taking a dirty saucepan to the bathroom and emptying dregs down the WC, or getting cups from the kitchen and pouring tea.

Residents varied between each other in the amount of work they did, and from day to day. During observation, R12 started to do more than had been usual for her. Perhaps she liked the new male cook and was thus inspired, for example, to volunteer to peel potatoes, take plates to the kitchen and empty the tea pot. Previously, she had been reluctant to move from the dining table and had taken minimal part in washing up, despite suggestions from the staff that she might help.

One resident was particularly active. R16, aged 78, spent a large amount of time doing work (24 RTF%) compared to other residents, but also took part in games and other expressive activities, and was above the inter-quartile range for the amount of time spent walking and standing. She was also above the inter-quartile range for the amount of time spent talking to other residents and visitors and for group interactions, but below this range for interactions with staff. She spent more time than most in her flat (32



RTF%), but most remarkable was the amount of time spent in the kitchen (15 RTF%), which explained why she spent less time than others in the shared sitting areas (48 RTF%). Observation notes indicated that she often initiated conversation with myself, as well as other residents, and told me what she was doing, for example that she was on her way to her flat for a rest, or had just put her feet up to help her sore leg. She smoked in her flat as well as resting. She always took part in washing up other residents' dishes, as well as her own, after meals, but joked with the staff about whose job it was to make the tea.

### *Work in the house: whose responsibility?*

As became clear in 6.2, it was a principle of care that residents should be actively involved in household activities to help make them feel it was their home and to enhance their independence. Staff, however, did most of the work, and all the heavy work. They initiated essential household jobs, such as cleaning, laundry, shopping and cooking, and had the additional responsibility of involving residents in a way that offered choice and maintained as much independence as possible. Residents did not necessarily see it the same way and staff in each unit described particular residents who were unenthusiastic in helping with chores. While some residents might be able, for example, to get a snack from the kitchen, they might feel they had earned the right to be served and point out that staff were paid.

S24: Cleaning their own room - we promote that, with the Home Help with all of them, but some believe they should not have to do it: "Because you are paid, and I am not able" and they enjoy watching someone else do it. We try to promote this, but if they refuse, someone else has to. (S24 activities 64)

Some residents could be active and seemed to enjoy companionship, but not all.

S14: Some just sit in chair and watch, as one woman says: "You are my maid, my days for this are over". (S14 activities 25)

I asked if male residents ever helped clean their rooms.

S14: No, you must be joking - [one male] will say : "No, no!" He would rap a duster around your ears, him and [another male] are not men of the nineties, they came from a generation where women did all that, you just accept that. (S14 activities 25)

Residents could be skilled in their refusal to take part, perhaps making a joke or politely declining, saying that they could not manage something, or sometimes simply not responding to suggestions staff made. Kin agreed that residents were not always as active and involved as they could be. One woman, whenever the kin visited, refused to go for a walk and showed similar reticence in taking part in household tasks. Her relatives, noting that she had characteristically been busy in her own house, suggested



she did not think of herself as being at home, and hence that she did not think that it was her job. Other kin reported residents' dissatisfaction with being made to work and that they could even discourage kin from helping.

KF: Does she do as much for herself as she could?

K5: No, I think she could do a lot more. Like Sunday after lunch, she will ask what I am doing, washing the dishes. She will say: "You shouldn't be doing that, its not your job". They try to encourage them to do things like that, if you push her hard enough, she will, but in general if she can get away with it she wouldn't do anything. (K5 activities 14)

K9: That's something she used to complain about, that they made her wash the dishes, some of them were sitting there doing nothing and she had to wash all the dishes ... but obviously - one time we went in and one of the women was ironing. They were getting them to help. (K9 activities 102)

Staff developed strategies to persuade or invite residents to take part:

S17: I say "Will you supervise me doing your housework?" And of course they come down. They'll do the dusting, tell you about the china, when they bought it. Involving them in doing their rooms. I feel it gives them something to do, keeps their mind active. (S17 activities 18)

With subtlety, the domestics could even persuade male residents to help. Sometimes, faced with rebellion, staff could simply say to a resident that they needed to do this kind of thing, otherwise they would just sit and this would be worse for them. Staff might make it clear that they were doing something on behalf of the resident. For example, when a resident sat at the table and did not move to take her dishes to the kitchen, a staff member eventually said: 'I'll just take your dishes through' and then said 'I've put them in the sink for you'. These negotiations could be handled with humour. One resident told me she was waiting for tea. I asked her when that would be. She said: 'When they make it!' looking at the staff-member in the kitchen, then quickly said: 'They are very good in here.' 'What's that?' said the staff-member, brandishing a mop, and people around laughed. Another conversation between two residents and two staff members was recorded.

R13: So you are here all evening, what are you going to do?

S9: I'm going to make the tea, unless you do?

R13: Oh no, well

S9: Let's toss for it - see who's to make the tea? You - or you (to resident 2)? Head or tails?

R13: Heads.

Another staff member tossed a coin.

S9: Heads it is. R13 - you are to make the tea.

R13: Oh no, I'll not tonight, I feel too lazy.

S9: So we'll all starve, you'd rather starve? What about you, R17?

R17: No, I'll away to my room.

The conversation continued, with the staff member asking what the residents would have cooked at home, and asking residents about what they would like. Staff could discourage residents from helping each other, if they felt someone was not pulling their weight, or were worried that the helper was not strong enough, for example, to help



another walk or stand up. Staff varied in their skill in giving encouragement, and sometimes missed opportunities, perhaps preferring to talk to other staff members while they themselves did the task. One example occurred when an inexperienced member of staff brought a tray of tea to the lounge, and maybe keen to be seen to be contributing, adopted a waitress' role of serving the tea and collecting the cups and saucers. Residents acquiesced, but there was little conversation and the clientele seemed bored.

At the time of observation, seven residents received practical care from kin (five of these in Nash Drive) such as decorating and furnishing rooms when the resident moved in, going to the bank, shopping, or laundry. Kin at interview suggested a higher level of involvement than this, perhaps because those interviewed participated more. Where practical help was given daily, staff saw this as a success:

S9: In most cases, there has been good family contact. One of best examples is a man whose wife was still living. She was here nearly every day. The unit reached its fullest - she was doing things like washing and cleaning. Not every family likes to do, or can do, these things - they have other commitments. But as husband and wife, she did not work, she could give full time. She still had time for herself because obviously she had things to work out for herself. A lovely relationship. They loved each other - his face lit up when he saw her. He appreciated what we did, but you could tell it made a difference when she did things. He would only for example have accepted her help him to toilet when she was around. It brought home the truth that they are people first, he loved to give her a wee kiss and cuddle. (S9 kontakt 66)

Kin, reportedly, could also sometimes think that staff were paid to do the work. More generally, a manager drew the following conclusion:

A2: We have not really been successful with relatives. Some are more comfortable than others at doing things like ironing. Others have a vision of residential care where everything is done by staff, and they would intrude. It's been very difficult. (A2 kontakt 5)

It could be hard to strike a balance in sorting out tasks. On one observed occasion, a visitor was offering to help a resident when a member of staff stopped her, by saying 'Promote independence!' The visitor commented how good another resident was, doing such a lot with the others. This resident was close by and smiled. The member of staff said 'Yes, too much sometimes!'

### *Money and shopping*

At one unit, each resident held a rent book and if kin could not help, the manager became the appointee, but this rarely happened. In the other two units, Department of Social Security payments were normally directly transferred to the managing agencies' accounts office, though relatives could maintain responsibility. Residents were persuaded to keep small amounts of money : staff gave examples of when purses were lost and false accusations made, or money had been given away. Several staff



members believed that residents were relieved that they no longer had responsibility for money, and said that residents had been pleased that staff would handle their affairs when given the option. From kin and staff reports, it appeared that residents' expenses were covered; rather, the revenue funding headaches existed at unit level. Anxiety about money could however persist:

S24: A lot worry about paying for it here, and how will manage. It is difficult explaining that their pension actually does pay [for them being here]. They say that is doesn't, and don't understand how come someone else is paying. Others worry about all their savings getting spent on it, and what is going to be left, what will bury them. For a lot that is the main worry. (S24 well-being 43)

Kin varied in what they thought should happen with residents' personal finances. Within the same unit, one was determined to keep control and not pass this on to staff, who were seen as extravagant, but another thought it perfectly appropriate that staff should administer these relatively small sums, since staff knew best what was needed. Some kin were relieved that they were no longer responsible for sorting out residents' money.

Residents were involved in shopping for their personal items, using catalogues if unable to get to the shops. Some female residents were said to love shopping, and benefit from being within a short distance of the town centre. The household needed to buy food and cleaning materials on a large scale. Two units bought in bulk, either having it delivered or using staff's own transport, buying occasional extras locally. While this strategy diminished costs, Redpath had a more devolved budget, chose to shop locally for everyday needs, and took decisions from day to day about what meals to cook, and what to buy. Residents were included in the daily shopping trips.

### *Housework and laundry*

Clothes were laundered in the house. The most successful arrangement was where staff had learnt to recognise residents' clothes, which were not labelled, and residents had their own washing powder. Here staff reported that some residents, at least, put their dirty clothes in the laundry without prompting. In each unit, staff hoped that residents would help them iron or fold laundry, but seemed to receive only occasional help with the lighter work. A resident who had formerly worked in a laundry was particularly willing to help, staff using this as an activity that could calm and occupy her.

### *Meals*

Mealtimes are potentially an active and social time in residential care, but may not always be exploited to best advantage (see 2.6.5). I observed several mealtimes, as

reflected in the high proportion of 19 RTF% recorded for this activity. The 'F' (eating and drinking) care score was 2.2, slightly higher than the mean. The following accounts show that mealtimes had a different character in each house.

### *Heartfield*

The menu was in principle decided in advance by staff according to residents' known preferences, but this might be adjusted to what happened that day. Care staff prepared the meals, occasionally with some limited help from residents. Staff prepared the tables, sometimes with residents' help, and served the meals. Staff and residents shared tables, unless there were too many people present, when one or two staff-members would sit in the adjacent sitting room. It was assumed from the start that I would sit at table with residents. There was often lively conversation, lead by staff and including the residents. Staff brought the deserts through from the kitchen, and cleared the plates. If residents wanted help to get up and leave, this was given. Some stayed sitting at the table. The staff would wash up, and afterwards would take a break in the sitting room with residents. Reportedly, in the past, residents had taken a more active role in helping with meals. The only remotely similar previous experience I had would be a visit to a large shared student flat.

### *Nash Drive*

The uniformed cook asked each resident what option on the menu they would like, ticking off their response on a list. The cooks prepared the meal, which was served by junior staff who stood by the hatch between the dining room and the kitchen. Residents sat at tables, with generally little conversation between them. At the end of the meal residents rarely lingered unless they ate particularly slowly. Staff then had their meals in the staff room. At first I was served formally elsewhere, until I asked if I could eat with residents. Though staff said they sometimes ate with residents, this was not usual. It reminded me of a tea-room, an association supported by a staff-members quip to a resident, saying that she would be charged extra for bringing tea over after being thanked for doing so.

### *Redpath*

The cook, who did not wear uniform, would sit with residents at the dining table after breakfast and talk about what to buy for lunch. The cook bought the food and prepared it, frequently with participation at some level by residents. One male resident habitually prepared his own porridge with staff supervision. With a reminder, residents laid the tables, and sat at their own places. The meals were put on plates which



residents collected or staff brought to them. Staff had decided that it was permissible to plate meals rather than serve them in dishes on the table, since residents had found this difficult to manage. Staff sat at a separate, but adjacent table, and talked to each other quietly during the meal. At first, I was invited to eat in the conservatory next door, to talk about the research and preserve residents' privacy. Once accepted as an observer, I joined staff at their table. Sometimes staff addressed residents to remind them of something, for example that there was a dessert waiting next door in the kitchen. Residents talked a little, quietly to themselves. After the meal, residents cleared away their dishes and washed up. The cook, at interview, said she had learnt to accommodate to the fact that things would be put back in different cupboards after each meal. Staff remained seated, prompting residents who were slow to leave the table to take their dishes, and offering help only if it appeared to be needed. My closest similar experience was a youth hostel.

In each unit baking was an activity separate from preparation of main meals, and required considerable support from staff. Staff saw the cooker as a potential hazard, standing by if residents used it.

S2: When we have them in the kitchen [we] will encourage them to do all that they can do, like weighing ingredients and mixing them. You really have to be there every step, like teaching a child what to do. Obviously leaving them to do as much as they can, but mainly we are saying: "Do this, weigh this, cut this out". And you are saying: "Cut out scones close to each other!". Once they are in the oven, eating is the easy bit! When it comes to icing, most residents can't comprehend they are icing them for tea tonight! Sometimes we have not had enough left! (S2 activities 47)

### **6.5.3 Making conversation: staff input**

Conversations were recorded, time permitting, when they illustrated either the promotion of well-being or the provocation of 'ill being' according to DCM, and also, after a period of observation, to exemplify types of exchanges that were often repeated between residents.

Making conversation appeared to be one of the main activities at Heartfield. It was mostly initiated and sustained by staff, who provided a type of conversation which was open, much of the time, for others to join in. Residents took part, made jokes with staff, and the more extrovert ones would join in songs that arose out of conversation. Half of the residents rarely initiated conversation, only making direct requests to staff, and these residents tended to be the audience. The banter could be fast and some residents may have been outpaced, though others could quip and cap comments made by staff. Residents were teased, for example about liking their food and putting on weight, or about their sexual appetite. Sex provided the topic for several conversations and jokes, and some residents were thought to be attracted to each other, or to people who visited the



house. An example of such a conversation was when residents, waiting for the bus to the day centre, were entertained by the possibility that they might play Postman's Knock when there; a resident made it plain that he looked back with nostalgia to times at the dance hall, and particularly girls that he met there. Another resident was teased for keeping an eye out for a member of staff's husband, which she denied by saying he wouldn't be good enough.

Such 'kidding on' made observation entertaining, and before long I was the butt of jokes as well. This had the effect of making me feel accepted rather than criticised. At times, I was puzzled about the effects of these conversations on residents. Comments could, on paper, step beyond what was polite or respectful, and, according to DCM classification, should have generated ill-being, but were received with a grin or returned by a dig in the ribs. Success demanded fine judgement on the part of the staff, and could sometimes appear to endanger privacy, but meant that the atmosphere was lively in a way which was apparently enjoyed by residents. This unit had a vitality because 'backstage', informal, behaviour was encouraged.

In the other two care houses, this kind of banter between staff and residents was not so common. In Nash Drive, it took place occasionally, perhaps in a corner of the room, between a few residents and staff, but never involved everyone in the room. My qualitative impression was that here residents were at least as able to make conversation. In Redpath staff, rather than providing an infrastructure for conversation, concentrated instead on supporting residents in their daily activities, which meant retiring to the background to observe what help was needed. Conversations arose and jokes were made, but these were overall quieter and more often were initiated by residents.

This suggested that where staff put priority on building up relationships and communicating, the atmosphere was different to where priority was attached to promoting independence and responding to residents' initiatives. With the first approach, staff could provide more companionship for residents. With the second, staff were perhaps most effective in supporting residents to be independent. Between the houses, what was acceptable in terms of 'kidding on' and how close to the bone jokes could cut, seemed to vary.

Staff sought to promote residents' well-being, with more or less success, in the ways described in 6.2. Staff did not always live up to the high expectations of them. It seemed that residents who were anxious or depressed tried patience, and could attract unsympathetic responses. If this happened, there was, in my view, a lack of insight into the state of mind of the resident and the potential impact of what was being said. Opportunities could be lost for offering choice and staff could act on behalf of residents, for example by assuming that residents did not mind if staff showed visitors residents' rooms. Sometimes staff firmly exerted their authority, for example asserting that it was too early to go to bed, or even insisting that a resident ate their sweet while standing over them. Comments staff made to each other could be overheard. For example, sitting in the



dining room where residents were mainly sitting in silence, a conversation took place between staff about people they knew outside of the house. Sometimes staff exchanged practical information, that strictly should have been seen as confidential, and were perhaps too relaxed in their assumption that they could not be heard or understood.

Residents could closely observe events, and staff were not always in touch with residents, as this summary of field notes shows.

A resident was waiting for her son to come and take her away, which was unfortunately not likely. She accepted that she had a room in the house, and when I asked her directly she said that she liked it, but all the same wanted to get out. As we were talking the alarm rang, and she said: "I think someone has got away." The television was on, and in the film, *Chitty Chitty Bang Bang*, that was showing, some children were trapped and wanted to go home. She said to me "So do I." She knew that I was not a member of staff. When one came up she told them that they were doing wrong, meaning that they were detaining her. I privately agreed with her when she suggested that the night staff were not doing things in the right way, though she meant they were detaining her while I thought it was a mistake to immediately confront her by saying that she would have to stay here. The staff member continued to try to reassure her and suggested that she was in the best place and deserved a rest. Eventually the resident stopped responding, whether because she acquiesced or wanted to withdraw from the conversation, I could not tell.

#### **6.5.4 Leisure and outings**

Dozing and sleeping accounted for 9 RTF% (range 0 to 29 RTF%), by definition the resident being asleep for the entire 5 minute period. All this was defined as 'appropriate' according to the scoring system, meaning that it did not last for more than thirty minutes and could be allocated a positive care value. Residents may also have spent time asleep in their rooms. Walking and standing accounted for 9 RTF% (range 0 RTF% to 30 RTF%). 'Wandering' was not distinguished from purposeful walking but notes suggested that most walking was purposeful. This category also included time spent standing, perhaps talking to others, which was what the person with the highest RTF% did.

Records of using the media consisted of watching television or reading newspapers, which accounted for 5 RTF% (range 0 to 18 RTF%) and scored the same as the mean care score (2.0). The high score was when a resident (R26) was absorbed in a television programme one afternoon, though at other times she had ignored the television or complained about it being on too loud. Sometimes, the television and radio were used well, but at other times they were on in the background. Staff could suggest to a group of residents, who they knew enjoyed the programme, that as *Coronation St* was starting they could put the television on. One morning, several residents were sitting in silence in the lounge, while a religious programme extolled the benefits of communication and suggesting the Scottish tradition of holding ceilidhs was a good one. There was no apparent reaction from residents. It changed to a Gaelic programme,



which, as far as I knew, no resident could understand, and was not adjusted. The video and radio were used to prompt singing, which could be done with staff. More passively, a video of a popular singer was left running, while some staff were at tea break, and some residents sang along to it. Residents were sometimes dissatisfied with a programme or its loudness. On one occasion, a resident sat restlessly, got up, and eventually conveyed to a member of staff that the television was annoying her, as it was too loud. The staff member turned it down. On another occasion, a resident simply got up and turned the television off themselves, suggesting a stronger sense of ownership. There were times when both the television and newspapers were used by staff for themselves, but, on other occasions more positively, staff looked at the television to gather news of a national event and then explained to residents what had happened.

Overall, games or other activities led by staff took up a relatively small part of the day. An example of such a game was bingo in the evening, which involved all in the sitting room, including a visitor and myself. Two rounds were played, and residents opted in and out. Dominoes was popular in another house, which residents played together at a table. The staff nurse at Redpath led games that were chosen to both be entertaining and assist her assessment. One kin noted that a resident could refuse to be involved in what she reportedly termed 'party games'. This respondent was asked about the ways the resident exerted choice.

K1: I know this because they asked her to play games, bingo and so on. [She] just tells them: "No". She still can hold her own on that one, she's never been into games. I don't think she likes playing bowls and she tells them, I don't think she'll say she doesn't like it, she's crafty enough to say "Not just now" or something like that. (K1 activities 38)

The observation data are likely to under-represent the amount of time residents spent outwith the houses, as times were selected to map residents when they were most likely to be in and not, for example, at lunch club. Outings, staff told me, were most likely to happen at weekends, and observation occurred only on weekdays.

Staff believed that it was good for residents to go out. One surprising observation was that residents' social skills were better when they were out. The local buildings could remind residents where they were and provoke conversation. More simply, residents were said to enjoy going out shopping or for a pub lunch. There was a possibility that residents would meet friends and acquaintances in the town, if they had lived there for a while. However, staff also noted that some people were reluctant to leave the house, and others were too physically frail.

The type of outings observed ranged from a spontaneous walk to have a cigarette outside to theatre events planned a week or two in advance. Staff spoke as though visiting pubs, going shopping, to church, or for walks happened frequently. The larger unit found that to go out with all twelve residents proved too confusing and tiring for all concerned. Residents might enjoy going out singly with staff more. Shortage of



staff and difficulties in arranging transport were said to limit outings, as did poor weather in winter.

I joined two outings, where meals were eaten out. On one occasion staff had made a special arrangement with a small restaurant they knew that stayed open just for our party. Staff recreated the same arrangements they had in the unit, eating with residents and keeping a lively banter. Residents were lively and apparently enjoying themselves very much. On the second occasion, staff also recreated the same arrangement as they adopted in the unit, sitting at table in a tea room separately while watching residents carefully. Residents sat in twos and threes at the small tables. Though this was more normal in that no special arrangement was made, my impression was that it was slightly less enjoyable for all.

### **6.6 Keeping in touch: kith and kin**

During the observation stage, staff were asked who was in contact with each resident and how often the resident was visited. One resident had no contact with relatives. This person had moved to the area to be with a relative who was now too poorly to visit. All other residents received visits, though some only very occasionally. Most (19 of 28) were reported to be in touch with kin only. Eleven were visited more than once a week. Apart from kin, other people in contact included a former home help (1), and friends or neighbours (7). Kin interviews suggested that even residents who formerly had large networks were now only regularly in touch with close kin. Staff reported that in some instances that the frequency of visits had fallen over time.

The larger unit had a pay phone in the hallway, but here residents used it the least. The smaller units had an ordinary phone in the hallway or office. Altogether, according to staff, eleven of 28 residents received phone-calls but rarely made outgoing calls. Some families phoned the staff to ask how the resident was or to make arrangements. One family who lived far away had been in the habit of phoning, but the resident was said to have become less happy to talk to them and to make excuses. No resident had taken up the possibility of having their own phone in their room. Kin who spoke about this did not see it as necessary, and one who had been repeatedly phoned was relieved that this no longer happened.

Sixteen residents at least occasionally went on outings with relatives or friends, but twelve never did. Only nine people went out at least weekly. While staff were reasonably optimistic that residents could successfully go out with kin, kin interviews suggested outings were not often successful, becoming more difficult as dementia progressed. Overnight visits to the family house could disorientate residents: if tried they seemed rarely to be repeated. Churchgoing played a part in two residents' lives whose kin were interviewed. The ideal of using the house as a base to go out together



from, perhaps to have coffee, go shopping or visit other family members, was achieved rarely, though most likely in Nash Drive. Kin were more likely to visit on special occasions than take residents out. For example, kin felt that Christmas was more successful and enjoyable if families visited residents in the care house. Kin remembered family gatherings with sadness, implying these were unlikely to be repeated. Some residents found getting into the family car increasingly difficult; kin had had to adapt to what residents could manage.

**K2: What sort of contact do I have with him? Well, I visit him, we took him out last year in the summer but we found that he's not very at ease in the car now so what we intend to do this summer, we won't take him on long drives at all, maybe just take him to the park or in for a coffee. (My husband) takes him for a walk sometimes if he wants to go, but he only ever goes down to the rails. He hasn't really got any notion to do anything, like he never even asks to go in the car now, so we just go and visit him. I always go and clean his room and make him a cup of tea, if he wants. (K2 kontakt 141)**

Social visits then were the main form of contact, but a few kin gave practical or personal help while they were at the care house. Relatives used the house differently when visiting. Some always went to residents' rooms, because they said residents were otherwise distracted or jealous of their attention, or because it was easier to have a conversation.

**K1: I never stay with her in the lounge when I go in, I always take her along to her room because I get a one-to-one conversation with her, as far as I can get, because she's distracted if there are other people round about. (K1 kontakt 88)**

Others sat in the living area, or moved between the spaces, as the resident wished. One family preferred to meet in the sitting room as otherwise the resident became unsettled and would repeat questions to which there was no easy or satisfactory answer.

**K11: We go and sit in the lounge with my mother because I find when we take her to her room she's more inclined to start "Have you been at your granny's? Have you got the keys for my house?" But if you sit in the lounge with other residents and speak to them, the two or three roundabout, she joins in the conversation and appears to be happier. (K11 kontakt 116)**

Having a choice of sitting areas was helpful to relatives as it could provide privacy. When a resident shared a room, one relative said that it did not feel like visiting him 'at home': there was nowhere to sit and be 'a family', and to make one's own cup of tea. One respondent never went to the resident's room because it was shared and she found visiting far from ideal.

**K4: Sometimes its embarrassing, if you are trying to keep up a conversation, he cannot really have a conversation back. You start to run out of things to say. If I was in here in my own home, it would be totally different. I think it's because there are other people there, it doesn't make you feel awkward, I just feel a bit embarrassed. (K4 kontakt 6)**



Being able to make tea was symbolically important to kin as well as staff. They had been urged by staff to feel free to do so. I asked one respondent if she made tea in the resident's room.

K2: No, we use the kitchen, but you are told when you go, the first time you go, they make you a cup of tea and they'll say, "Now if we are busy, please don't feel that you need to wait on us to get a cup of tea." They showed us where everything was and we can just go and make a cup of tea. (K2 kontakt 151)

Although visiting was the main form of family contact, kin often found it difficult. Making conversation, as the main feature of social visiting, was, it appeared, often laborious. At best, residents would be able to talk over events in the past with their relatives.

K2: We talk about things long past as if it's today, because that's how his world is now, so we just have a conversation about Scouts coming to camp or him going to D-, or various different times, we usually manage a bit of a conversation about something. We tell him about the wee lads because he likes to see the kids and when they do come, [my husband] takes our granddaughter, she loves to see him, she's coming up for three and he just adores it when she goes, loves it. We try and have a conversation about the children and the family and things like that, but he doesn't take it in very much. (K2 kontakt 145)

Kin struggled with the consequences of memory loss and the difficulties residents had in recognising visitors and their relationship to them. A sister might be confused for a mother, or grandchildren seen as their parents, and residents were sometimes unable to recognise people in photos, which kin found upsetting. Kin noted that residents could often seem unconcerned what had happened to them and did not ask how they were. Residents could not tell kin what happened between visits, such as who else had visited and what they had done that morning. At worst, there could be a strained silence, which this interviewee described as an emptiness.

KF: What contact do you have now?

K3: Laundry and visits once a week, that's all really.

KF: Does that feel about right?

K3: No, it doesn't feel right, I would like to have better contact but it's just I'm hitting my head against a brick wall. There was one night in particular, we went up and I had exhausted all I had to say, like "How are you? What have you been doing?" and I timed it. I sat for fifteen minutes and my mother just sat and stared into space. I said "Will somebody talk to me?" and she just had nothing to say.

K3 spouse: You can't turn round and say "Oh R-, the grand daughter, she's gorgeous, she was up seeing us the other day". "Who's that?" Or somebody she's known for as long as we have, that's it, so that conversation is finished, she's forgotten. (K3 kontakt 189)

One resident found it extremely hard to speak, though he seemed to be frustrated and to know that he wanted to say. Another could speak but what she said made no sense to her family.

K7: It's a difficult situation. We can't take her out, can't sit and reminisce, can't take her to see anyone, can't have a conversation with her, so now what we are doing is to talk to her,



to tell her what is happening, and she smiles, giggles, she chats to us, we don't know what she is saying, but we carry on the conversation. She likes to see the children.  
(K7 kontakt 56)

Efforts made by the staff to welcome visitors were appreciated. Staff were potentially helpful in describing day to day events, which one family suggested could help them make conversation on visits. Another family particularly enjoyed talking and laughing in the sitting room with a group of residents. Some kin had developed strategies to improve visits, such as combining a social time with practical tasks, making a feature of having tea and snacks together, using a visitors' book as a prompt to discuss recent events, welcoming broader conversation with other residents and staff, or taking sweets to offer around. They might play dominoes with a number of residents, or go to a resident's room and listen to music. Kin wanted information about what had happened in the period between visits from the staff to be able to find topics of conversation. Kin were reluctant to abandon attempts at social conversation and some were more at a loss than others about how to make a visit work well. While staff were confident that family contact was important, kin were not sure what effect their visit had, as residents were generally unable to recall that they had been.

Staff thought successful visits included ones where all generations were present, or when visitors talked to other residents. Less successful visits included those where a resident was aggressive and his wife frequently stayed only a few minutes, if a family found dementia hard to accept, or had fallen out over supporting the person with dementia. Where they had been able to support relatives in the contact they had, the staff were pleased. A successful intervention was described where staff had helped a husband and wife find time together and for the husband to continue to feel he contributed to his wife's happiness by taking her out.

## **6.7 Summary and discussion**

The evaluative question this chapter has addressed is the success with which care housing created a homely setting for people with dementia. From the findings reported so far, the ideal of home that was expressed may be contrasted with what the residents were both observed and reported to experience. Some demands and dilemmas of implementing household care emerged from staff interviews, and its success was assessed through observation of activities and well-being, as derived by DCM and the use of the rooms in the care house. The finding that residents in Redpath spoke more often to each other than staff will be explored and discussed in Chapter Seven, which is concerned with interactions and relationships between residents.

The literature review concluded that where people with dementia live can be taken as an important component of their quality of life, and noted that current opinion



about good quality dementia care emphasises the social environment. Observation data showed that residents spent almost all of their time in the house and most of the waking day in the company of other residents and staff in shared areas. This confirms that the quality of home-life, and especially the social environment shaped by staff and residents, can legitimately be given priority in evaluation. However, readers are reminded that there are determinants of quality of life that were outwith the scope of the care houses to influence, some recognised by staff at interview, including the personal history and characteristics of individual residents, their relationship with their kin, and the constrained resources of the care houses themselves and the wider neighbourhood. Factors beyond the scope of this study to investigate included the influence of the physical environment and the quality of physical care on residents. Despite these considerations, the questions addressed here are of particular interest given the central aim of care houses to provide household care.

Chapter Four showed that staff and kin interviewed thought that care housing was homely, or at least the 'next best thing' to an ideal of home. The ideal of home that appeared was a comfortable place, where you can live to the end of your life with those closest to you. Home was understood to be a private place where you can please yourself about how and where you spend your time, and whether to be alone or in company. In evaluating care housing as 'home', respondents adjusted for the presence of dementia and other constraints and by asserting that care housing was the 'next best thing' to living at home, implied that it was the best that residents could expect. There was a clear consensus that care housing was better than institutional alternatives.

The case studies fell short of being the homely ideal in several ways. Interviews with kin suggested that it was not the residents' decision to move and, if they were moving from community housing, they did not welcome the idea when it was presented to them. Chapter Five has already shown that residents could well have to move out so care housing was not always a home for life.

Sections 6.1 and 5.2 showed that it was particularly difficult for people with dementia to adjust to a move of house and to acknowledge their new setting as 'home'. Geographically, while residents lived within the defined catchment areas, this did not always mean that the street was known to them. Feeling at home was possibly influenced by whether residents believed it was a temporary move, which in part depended on how kin had presented the move, and whether residents thought there was a better alternative. The atmosphere of care houses was pervaded by its occupants' periodic sense of being misplaced and having been betrayed. Feeling at home was made additionally difficult by living with others whose presence could be hard to explain. The staff had the role of reinforcing the message that this was where residents lived, and sometimes enforcing that they stayed there. Both kin and staff accepted that it was unlikely that they would ever succeed in making residents feel entirely at home but, all the same, the way staff handled their role was thought important in helping them settle



in. The presence of dementia, resulting in disorientation, misidentification and restlessness, can therefore be assumed to have undermined residents' sense of well-being and satisfaction. Interviewees were ready to suggest that residents would have been more unsettled in other settings, an assertion that could not be tested. Even disregarding dementia, home acquires layers of meaning during life, and the aim to recreate a 'homely' setting for a group of eight or more old people from different backgrounds who did not previously know each other is ambitious.

Being at home and participating in household activities was held by respondents to be capable of generating well-being in residents, given the respect of individuality, choice, independence and privacy. This should be understood within a wider contemporary assertion (noted in the literature review, see 2.3.2) that home is the best locus of care and independence is a desirable state of being. Such assumptions place a moral obligation on individuals to avoid dependency and on staff not to induce dependence. Staff had the task of implementing the aims of care housing and this demanded skill, fine judgement, flexibility and confidence. The better the care, the less conspicuous was the intervention. All staff interviewed asserted the worth of household care and its capacity to enhance residents' self-esteem, but this required support and team-work to continue to work towards this ethic. Encouraging and supporting residents to take part in household life required optimism from staff that what they did made a difference to residents, even when dementia was advanced. Staff tended to be more pessimistic if they thought the realms in which residents could exercise choice and independence were trivial. It seemed staff might find faith in the value of persisting with their humanistic ethos if they could see the residents in the context of their biographies and in relationship with their families.

Staff had found spontaneous rather than structured activities more likely to be successful, but accepted responsibility for providing a daily routine to frame residents' lives. They encouraged residents to be active, believing this to be therapeutic, and it seemed this could amount to suggesting a moral obligation. What if residents resisted the encouragement given by staff? Residents' involvement was interpreted as ultimately a matter of choice, a therapy and a right rather than a responsibility. However, staff felt most fulfilled in providing care when residents were most involved.

Exercising choice could be risky for people with dementia and staff had to determine who took responsibility for possible consequences. This was most at issue when people with dementia wanted to leave the house on their own and did not acknowledge their disorientation. While staff could state explicitly how they promoted 'independence', they did not readily articulate how they could encourage interdependence and reciprocal relationships. Given that they also emphasised the advantages of communal living and valued the attributes in residents that helped this, it



seemed that the balance of independence and individual choice with interdependence and communality was unresolved.

Residents' privacy was compromised by having to live communally. While individuality was seen by staff to be nurtured in a smaller rather than larger group, they accepted responsibility for protecting privacy according to individual residents' preferences. This study could not assess how successful they were seen from the perspective of residents.

Care housing aimed to involve residents' kin in the day to day running of the household, to enable them to maintain their relationship through visits and by giving practical care, and to support kin through carers' groups. Staff could not easily compensate if kin did not wish to be involved with residents, as it could be difficult to make links between the residents' present lives and their past histories. Kin were not actively involved in the affairs of the house, and the role of the relatives' groups was unclear. Kin did not necessarily agree with staff about the role they should play. Some thought that staff were the 'experts' and were content to leave day to day matters with them. Kin observed staff carefully, but were reticent to make criticisms, which staff were not necessarily sensitive to. Kin were more likely to provide practical rather than personal care. Going to the general practitioner or handling personal finances could symbolise whether staff or kin assumed overall responsibility. Kin were, at times, at a loss about what to do, especially on social visits that were the most common form of contact. Some visitors were skilled in using opportunities and the facilities of the house, while others were constrained by the physical environment, poor communication, and a sense of hopelessness. Underlying the awkwardness of social visits was distress at the changed nature of their relationship with the resident and uncertainty about how much, and what, these visits meant to residents, saying for example that residents swiftly forgot they had been.

Observation data provided a quantified record of aspects of the daily life of residents over weekday hours in two houses. Qualitative field-notes assisted interpretation of these data. The daily routine in care houses matched the pattern that kin reported for residents when they still lived at home. Household matters and personal care took up the morning, with more leisure and social activities in the later part of the day. With the onset of dementia, residents had already found it hard to keep to their established pattern while still at home, even when they were well supported. This draws attention to the complexity of judging what is normal, possible and desirable for people with dementia living at home.

Given that the houses were supposed to encourage individual patterns, variation between residents in activity and pattern of interaction can be seen as a positive outcome. While staff had accepted a role of reminding residents of a daily pattern, there was considerably more individual variation than suggested by, for example the hospital routine described by Lidz *et al.* (1993, see 2.6.3). The degree of variation was not,



however, compared directly to other settings, nor to individuals preferences. Meals, eaten communally, were at fixed times each day, but residents had lee-way in when they got up and went to bed. They were at times restricted by whether staff were available to help them. Qualitative observation, for example at mealtimes, suggested that in the larger unit, residents depended more on staff to initiate activity than in the smaller units. No conclusion, however, can be drawn from this study as to the degree to which routines were developed in response to the residents' wishes or levels of disability or how much the residents accommodated themselves to staff expectations and the ethos of each unit.

The DCM care values derived in two care houses show they were successful in providing good quality social care according to DCM classification as well as with a comparison with hospital. The DCM method also suggests that the range and nature of residents' activities is important, although these activities were not tuned to household care. It was impressive that there were no records of residents being withdrawn and that passive involvement and sleeping and dozing together only amounted to 33 RTF%. It is difficult to compare these data to other observational studies (see 2.6) because of the idiosyncratic system adopted by DCM, but the hospital observation in this study gave a combined total of withdrawn, passive and sleeping activity codes at 45 RTF%. Observation notes suggested residents were bored for some of the time at least, and sometimes eager to get away. They could not always get out when they wanted, or go to bed when they wished, because staff were not available. This raises the question of what can be fairly expected of living in care housing. People may have spent much time being bored or arguing with each other previously and it would be unrealistic to expect a move to care housing to change this.

The activity codes associated with higher than the mean care values were eating, interacting with others, work and games, quizzes and expressive activity (EGI). That residents spent about as much time joining in leisure activities led by staff as doing household chores is indicated by the fact that total of observed time spent in EGI and work was the same. More work was observed to be done in Redpath than Nash Drive where, exceptionally, one resident spent almost a quarter of the observed time doing household work. Redpath, as concluded in section 4.1, was best equipped to be successful in achieving its aims. It provided most personal space and facilities to its residents, was more domestic in design and equipment, and had a staff group who had the ethos of care strongly instilled in them and were well supported externally. The care values were higher in Redpath than Nash Drive. This chapter has shown how aspects of physical design and the house-keeping arrangements could help staff entrust residents with tasks. A striking finding from the structured observation was how much more residents used the kitchen in Redpath than in Nash Drive. Such activities might be easier to promote if residents came directly from home, could walk easily and could communicate verbally. It would be naive to think that enhancing independence, or



functional ability, could diminish the cost of care. The reality was that the work residents did in the house could have been done more quickly by staff, and that what they did was light if related to the overall workload.

The finding of different group care scores between Nash Drive and Redpath could suggest the conclusion that a smaller unit may enhance well-being, but, as noted in Chapter Four, the staff at the larger unit were more moderate in asserting household care and were influenced by more conventional residential care approaches. Regime, as well as scale and design, may therefore have been a factor.

Interviewees stressed the importance of having their own rooms with their own things, but observation showed that residents spent most time in shared areas during the day. Paradoxically, residents spent least time during the day in their rooms, which were arguably more 'homely' to them because this was where their own possessions were. They did make some use of their rooms during the day, often at their own initiative. Residents who were physically unwell spent most time in their own rooms. These data therefore do not negate the importance of having a private room, but suggest that this is not where most residents choose to spend most of the day. It was not surprising that someone who was highly sociable spent a particularly high proportion of time in shared living areas, but another resident, who did not often talk to others, also did. These two residents had worked out different patterns of where they sat and whether they sat in company.

Especially in the smaller units, it was striking that, when working out whose responsibility it was to do household work, there could be conflict between residents and staff. If residents did not pull their weight, this was not necessarily because they were impaired and unable to help. Humour could be very helpful, allowing both sides to make their points. There were different ways of resisting, but several residents were able to decline in a knowing, sometimes joking, manner. They could be aware enough of the circumstances to point out that while they were retired, staff were paid employees. Some residents were willing workers and, in Redpath, could make an important daily contribution. For others their contribution was more sporadic and could depend on how attractive the work was. Differences were apparent between residents - and between houses - in residents' sense of ownership and entitlement. Arguably, the more residents accept responsibility for household work and do work without being prompted, the more successful staff have been in conveying the message it is their home.

Staff had the task of dividing and allocating responsibilities; observation suggested that a different balance each unit had been struck in each house. This was exemplified by meal-times, which in one house were marked by lively conversation. In another, household care worked particularly successfully, with mealtimes being exploited as a chance for residents to work together and relate to each other. In the

larger unit, it has to be admitted that mealtimes were unremarkable, except for the quality of the food. Household care is, in effect, a value judgement on what is best for people with dementia. This makes the subtle differences in emphasis in the two smaller houses of interest. One priority, in Heartfield, was to nurture individuality, informal relationships, conversation and spontaneity. The staff had possibly adapted their emphasis in response to the number of men living here (at least half of the residents were male) and the increasing physical dependency of the group as a whole. Here the staff were least willing to define their role in professional terms. In Redpath, respect for privacy and independence guided staff, who paid detailed attention to what was socially normal. It may be that household care, revolving around tasks conventionally defined as women's work, may be most readily adopted by females. Oakley's findings (1985) about the unpopularity of housework should be remembered. The compensation of autonomy, and the development of one's own routine, was not possible for the case studies' residents in the way it might be for a housewife at home. However, residents could expect company and this is explored further in Chapter Seven.



## CHAPTER SEVEN

### GETTING ALONG & LIVING WITH OTHERS

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## Introduction

Chapter Seven is concerned with care housing as a form of group-living. The way that residents interacted with each other and the demands of group-living may be taken as important aspects of the quality of care, since residents spent so much time together. Section 2.7 noted the argument that living in small groups could promote beneficial relationships between people with dementia, their relatives and staff (e.g. Cohen and Weisman, 1991). However, there is an absence of information about how people with dementia adjust to living with each other. In residential care, people who are not confused may find it difficult to live with those who are (e.g. Allen *et al.*, 1992). Work on people with mental health problems living in supported accommodation has suggested that the success of group-living may depend on careful selection of group members (e.g. Pritlove, 1985) and also that living in a small group does not necessarily lead to close relationships but may generate tensions (Petch, 1992). I have made a distinction between groups convened for pragmatic and therapeutic reasons. Both reasons seem to apply to the case studies. Chapter Four showed that kin and staff interviewed thought that the company and stimulation of living with others was beneficial, even though to live with non-kin was a discrepancy with the ideal of home. Only a few residents knew each other, or of each other, before they moved. They had no opportunity to choose who they lived with. As noted in 5.3.1, there was a suggestion, but no consensus, that people who were used to living anonymously in long stay care could find it particularly difficult to adjust. Most residents had lived on their own immediately before the move to care.

One aim of this study was to explore the nature of group-living in the case studies and influences on residents' interactions. The findings are set out here. Firstly, data from structured observation in Nash Drive, Redpath and a hospital ward are presented in more detail than in Chapter Six. Secondly, qualitative data from observation and interviews are used to consider the relationships between residents and the role played by staff.

### 7.1 Patterns of spoken interaction

Overall, residents spent much time in silence, but in each other's company in shared living areas, usually with a member of staff present. The observation data suggested that residents spent on average two thirds of the waking day in shared sitting areas (see Table 6.3.4/1). Collectively, just under a quarter of the RTF was spent sitting passively, looking around (see Table 6.3.1/2) and over half of the RTF showed no



spoken interactions, though there was considerable variation on this, the range being 19 RTF% to 81 RTF%. The observational data on frequency of spoken interactions suggests two contrasting patterns of spoken interaction. Data from Table 6.3.3 are re-arranged to show the rank order for particular categories of interaction in Table 7.1 below.

**Table 7.1 Rank order of interaction categories by location**

<b>Category of spoken interaction</b>	<b>Rank 1</b>	<b>Rank 2</b>	<b>Rank 3</b>
<b>with no-one</b>	Hospital (70 RTF%)	Nash Drive (56 RTF%)	Redpath (48 RTF%)
<b>with one resident</b>	Redpath (16 RTF%)	Nash Drive (6 RTF%)	Hospital (2 RTF%)
<b>with resident group</b>	Redpath (4 RTF%)	Nash Drive (1 RTF%)	Hospital (0 RTF%)
<b>with mixed group</b>	Redpath (16 RTF%)	Nash Drive (10 RTF%)	Hospital (2 RTF%)
<b>with one staff member</b>	Nash Drive (22 RTF%)	Hospital (21 RTF%)	Redpath (11 RTF%)

One pattern was exemplified by the hospital where there were least RTF including spoken interactions and, where these occurred, the great majority were between one staff member and one resident. Spoken interactions between two residents rarely occurred in hospital and there was no recorded spoken interaction between residents as a group. The individual range for RTF with no spoken interaction was 57 to 89 RTF%.

Another pattern was exemplified by Redpath. Here, over half of the RTF contained a spoken interaction, but the individual range was much wider than in hospital, at 19 to 81 RTF%. Conversations between two people were more likely to occur between residents than between a staff member and a resident. Here there were least RTF recording spoken interactions between one staff and one resident. Most group

conversations were recorded here. Overall, in both case studies, staff were involved in markedly more group conversations than in hospital. Section 6.3.1 showed that the greatest proportion of passive codes were recorded in hospital (45 RTF%) and least at Nash Drive (27 RTF%).

This finding strongly suggests that residents were most socially involved with each other at Redpath, but also had the choice of either withdrawing or being sociable. It also suggests that staff at both case studies were able to implement a social model of care, while hospital staff had to concentrate on physical care that was limited and rationed between residents, who were more passive.

Residents talked to each other both in pairs (10 RTF%) and in groups (2 RTF%), but in Redpath there were more spoken interactions recorded between residents than between residents and staff, while in Nash Drive residents spoke more to staff.

Qualitative observation suggests that residents varied in their communication skills. As already noted, all residents in Redpath could communicate directly to me in ways I could understand, but this was not so in the other case studies. One resident talked for much of the time, but it was hard for anyone to know what was meant. Staff were piecing together her life story; the memories she recalled could make her both happy and sad. Sometimes staff rephrased her words to construct a story. Sometimes she would respond with agreement, but at other times she would apparently not notice, or move away. Other residents were more able to express themselves, describing specific anxieties or observations. For example, one resident criticised another for waking a third, and then told a member of staff that this had happened. Conversation, as an activity supported by staff, has been considered in section 6.5.3.

## **7.2 Living with others**

The move to care housing was seen by both kin and staff to bring potential advantages of company, stimulation and mutual support. Staff thought it was important to coax residents into becoming part of the group and take part in communal activities. People described as by nature 'mixers' were, not surprisingly, thought to benefit especially from having company. Kin of one of the residents, described as a 'success story' (K9, see 5.2.3), had been anxious that she would not be considered suitable for the unit as she did not mix with other residents, but sat in her room and complained about the other residents. In time, this resident used the lounge more, said that she liked care house, and gave the impression she did not want to miss out on what was happening. Things had also improved for another woman, who had 'just sat and stared into space' before the move, according to her next of kin.



K3: I think up there she's got company of her own age and they are maybe repeating the same things over and over and over to each other again, but still they are talking to people. (K3 group 64)

Staff, particularly in the smaller units, stressed the intensity of relationships. They themselves felt part of a close-knit group, with closer relationships than they were used to at work (see 4.3.3). Communal living was acknowledged to make demands on residents and to generate tensions. Parallels were drawn to the demands of living in a family, with the assumption that falling out, from time to time, with people you live with is part of everyday life. Living with others could, however, also bring out good qualities. Kin agreed that residents' behaviour was, at least in part, a natural response to living in a group, and described the general atmosphere of the houses positively, for example as 'a sociable place, like being among friends'; a place where 'they take you as you come'; or as a 'big happy family'.

The opinions of staff varied about the ways that residents related to each other, ranging from statements that residents simply cohabited without developing relationships, to assertions that staff and residents had become closely bound in a family-like group. Respondents were inconsistent in their replies, and opinions varied within staff groups. Staff vacillated between making allowance for the impact of dementia on relationships, and asserting that the interactions between residents were normal and that any differences between individuals were healthy. Many respondents had closely observed residents' interactions, and struggled to work out what perceptions and experiences underlay their responses.

Despite inconsistencies, a picture developed that, though it took longer because of dementia and varied between individuals, residents at least became accustomed to each other and staff, possibly getting to know each other's ways and accepting them. It seemed residents could find a place within the group and, to some extent, chose their company. New relationships took time to develop and friendships could be interrupted by new residents moving in, or others leaving, and changes brought by dementia.

Some staff tended to compare life in the care house negatively to situations where people did not have dementia. They noted that residents could not always recognise each other, despite seeing each other daily, and even if they had known each other before the move, they did not necessarily remember this. Residents' concern for each other was seen as sporadic and socially conditioned. One interviewee, who had worked in another group-home, explained why it was different:

S2: Probably because all of the residents here have dementia, so probably you are just a face to them, but going in there, group-living was much closer, so you felt that you were intruding into their group. In here, one or two have conversations between themselves, but generally they are individuals, and not part of a group. (S2 group 44)



Other staff took into account the presence of dementia, but saw signs of recognition and concern. They considered both residents' behaviour and what they said and had observed that residents recognised faces even if not names. One staff member described being able to convey the news of a particular resident's death by referring to the resident's characteristic habits, at which point co-residents had acknowledged the news. Residents could notice if someone were missing, or ask staff who strangers were. Reportedly, a resident said about me: 'That girl keeps coming in and out: the more I see her, the more I know her.'

Relatives affirmed that residents were aware of each other. A man with poor communication ability could still convey which residents he liked and which not (K4). One female resident was apprehensive about men in the unit, and advised her relative to 'just ignore' one who had a habit of picking at the carpet (K5). Kin also got to know residents and other relatives through their visits, one saying it was only natural that she would get to know the people 'living' under the same roof' as her mother. Kin could get attached to other residents.

K5: With [my relative] having been here for two and a half years, I have seen the changes in people... [One woman] was a 'nippy sweetie'...she had stroke, and died in here, I can't remember exactly, but I came in to see her, and [another resident] says come along, see her. I hate to say it, it brought a tear, she couldn't speak, she just grabbed my hand, and held it tight, I said you'll be all right, I felt really sad when she died. (K5 change 17)

The question about how residents related to each other generated very different responses. The prompts were whether this was like friends, neighbours or family, and one reply was: 'All of these things' (S14). The difficulty describing residents' relationships may have arisen because this kind of communal living is unusual - residents were not typical 'flat-mates' or 'lodgers'. Respondents supplied their own interpretations which have to be treated cautiously, but it rapidly became clear that not only were there differences between individuals, but the same person could see people differently within a short space of time. Given the overall agreement that residents did at least establish patterns of interactions with each other, and sometimes consistent relationships with each other, what was the nature of these patterns and relationships?

Where relationships were likened to a family, this was because residents were seen to rely on each other, and to sometimes be short with each other. People lived in close proximity and everyday interactions were informal.

KF: First, how do residents get on with each other?

S10: To harp back to the family situation, this is like a family, they shout at one another, tell each other what they think. They do get on very well, considering it is a broad mix from different backgrounds. They may say about each other - for example one used to pass wind, and then R17 would say: "Disgusting!" We would say: "He can't help it!" Back to family, at times they get on with each other and at other times they won't - nobody is nice all the time. (S10 group 86)



On the other hand, residents remembered and asked about their own family, and were well aware that other residents were not their kin. As one house opened, residents moved in three stages; the first group was said to have been upset by the arrival of the second. Having been assured that this was their new home, they then had to accommodate to strangers.

Did residents regard each other as neighbours? While staff could think of some instances where residents referred to neighbouring rooms in the corridor, this did not describe their relationships. The exception was in Redpath, where several residents had previously lived near each other, some in the same street, within a close-knit community, and retained neighbourly relationships. In another case study, a woman appeared to have been recognised and ostracised by other residents who called her 'a lady of the night', though staff could not understand why.

A picture of the group as a whole at Nash Drive was drawn by a staff member.

S: Most tend to get on quite well, a few interact quite well with each other. There is a core group of maybe five who will chat, with staff initiating it. A lot of residents have difficulties with conversation, tending to sit there, waiting to be approached, conversation starts around them. A couple of ladies are argumentative, one being disdainful and sarcastic. The other getting frustrated, due to her speech being muddled, and taking it out on others. And because of their personalities they can clash, and can clash with other residents - but they tend to be the ones who start the argument. The two gents, one tends to sit outside of the office, not interacting with residents, the other, tends to wander. They tend not to initiate conversation unless they want something. (S group 54)

It appeared that most of the time, residents got on well with each other, but some, for whom 'group-living was hard', found themselves in disputes. One respondent was not sure if they actually 'got on' or 'tolerated each other', but others were more optimistic, saying they got on very well and even quantifying it as 'eighty percent' or 'ninety percent' of the time, and saying it was normal to have occasional arguments.

### **Friendships and disputes**

Friendship meant, to staff, a consistent concern for each other, which they thought rarely occurred. From their accounts, it appeared that, occasionally, residents were able to maintain pre-existing friendships with other residents. In friendships, residents had to contend with the changes dementia brought, not only in their own perceptions but also in their friend's. Some formed new friendships, others nurtured personality clashes which could develop into persistent enmity. Over time, staff had seen small groups form and grow apart. It was difficult to keep in touch if a friend moved out. This section examines the nature of friendships that developed, and also the disputes that could arise.



## *Friendships*

While it appeared that male residents were aware of each other's presence and behaviour and tended to sit apart from women, they did not build friendships with each other. Attachments could, however, form between the sexes. One man who was considerably less confused than his co-residents, was said to choose his company carefully from women who could make conversation.

S14: He has a specific seat that he sits at, and you will see him pick out who he wants to sit with him, the people who are less affected by illness than others. He will ask R5 and R14 because they can hold a conversation, he won't ask R4 to sit, because she has severe dementia and cannot communicate, nor will he ask R11 to sit with him because she has a communication problem - expressive dysphasia. He won't ask R20 to sit with him, though he is another male. Why I'm not sure, but you'll see him - he knows what time dinner is at and he will be through there before anyone else, and as they come through the doors, he will signal to residents who he wants to sit next to him. (S14 group 33)

Apart from choosing to keep each other's company, staff noted signs of friendship such as greeting each other in the morning or missing and waiting for each other. One pair of female friends already knew each other before the move, and had retained a special bond. They spent time in each others' rooms, and helped each other with the daily tasks. One was becoming more confused than the other, who was puzzled by this and turned to staff for support and explanation.

S28: Some times, R23's [dementia] is worse than R18's, R18 gets upset, and says: 'You know your mother died!', and then R18 gets upset, because she knows that R23 is getting things wrong, sometimes she just shakes head, but it's a shame when it happens. They two are always talking to each other, in each other's flat. (S28 group 65)

Observation notes described how these two residents laid a table together, a task they did twice a day.

R23 came from the kitchen with the cutlery and asked R18 how many places to lay. R18 said six, though actually four were needed, and they could not exactly work it out. They could not remember if they should lay the staff table or not. R18 encouraged R23 to go ahead and lay her own place, and she put them down in a slightly odd way. R18 asked R23 if she didn't think a dessert spoon was rather big for her tea cup. R23 said that no, she thought it was OK. R18 politely acquiesced. Later on in the meal, R23 was struggling with her dessert spoon when she wanted to stir her tea. R18 suggested that she used the other end of the spoon and this would do the job, which it did.

This quote describes a friendship that was considered unusual.

S24: One lady (R5) - when another lady died and we told her, she asked to go and see her. She gave her a kiss, and said good-bye. What we had noticed previously [was that during the illness] probably she was missing the friendship. After she had said good-bye, she seemed to come back to herself, and formed another friendship.... She could calm [her friend] more than staff could: she would say: 'But you live here now', and she accepted it, which was a blessing for us. She does it for [another resident] now. The new relationship is with her. (S24 group 69)



Reportedly, friendships could be one-sided, in that the more dependent friend turned to someone more able for support and help. Friendly groups of female residents could form, and spent time together during the day.

S21: Other residents, over time, get to know each others' ways and pretty much accept them. Now and then R17 will say something - she is outspoken, but it's done in a joking manner. Overall they pretty much look out for each other. R17 and R24, and (another resident) when she was alive, there were always the three of them together, and they spoke up for each other. They looked after each other more or less. (S21 group 76)

One of these three women consistently called another by her former best friend's name. This woman was said to tolerate this mistake from her and not to correct her, but would correct any one else who picked up that this was her name. This group had its moments: reportedly, a fourth woman had taken against one of the three and tried to turn the others against her. They had kept the peace with this dominant personality and changed their behaviour by being less friendly when she was around, returning to normal when she was out of the room.

R14 had moved in recently and gave the impression of looking for company for much of the time, approaching both residents and staff, and often seemed both uncertain and dissatisfied, perhaps bored, during these conversations. She asked repeatedly what there was to do, was there anything to do? The following conversation was recorded as a typical exchange, after I had heard many similar. One resident, had some minutes before, crisply told R14 that she should do something, and not let herself get bored. R5, (see quote S24 group 69 above) was more sympathetic.

R14: Well, we're sitting here, what are we sitting for?

R5: I dinnae ken.

R14: Well we'll just have to wait. There's nobody here to tell you anything. They talked a bit about the flowers outside.

R14: Nice place this, I dinnae ken why I'm here though.

R5: It's a wee blether, we get along fine together.

R14: Nice place here.

R5: Yes, its comfy, I like it here.

R14: TV and everything.

R5: Nothing to complain about.

They talked about how you needed to pay attention, things could get out of your head.

R5: There's nothing to grumble about, they are awfully nice, you get your meals.

R14: As long as you've got the money though.

They were still talking when a staff member joined them, she agreed with them that it was a nice place. She said they had their own "house" to go to if they wanted. They continued to talk about it being a nice place. You eat what you got brought.

R14: Just wait and see, you can't do anything else, we don't quarrel, get a laugh now and then.

I was left with the strong impression that these residents were bored and were seeking to comfort each other about being in a place they found slightly strange.



## *Disputes*

The interviews may have concentrated too much on disputes between residents, compared to other aspects of their relationships. This may have been because staff focused on disputes, as they had to judge whether to intervene. Triggers to disputes could vary: it seemed that arguments over possessions often happened in Nash Drive. Mealtimes and kitchen chores were contentious at Redpath, where residents seemed most prone to gossiping about each other. More strident personality clashes and aggressive behaviour were described at Heartfield. Particular times of day were difficult, for instance mealtimes could be fraught. A range of disputes was described at each unit.

When asked about disputes, staff gave the strong impression that residents were closely aware of each other. Residents were said to be, at times, quite critical of each other's antisocial habits, such as appearing unkempt, passing wind or having poor table manners. Intolerance and gossiping was mentioned, particularly by staff at Redpath:

KF: How do residents think of each other ?

S: Different things. One lady weeps a lot, and others talk about her: "Greet a minute". They talk about each other terribly sometimes, I daresay they talk about staff as well.

KF: Have you heard this?

S: Yes, heard it many a time, they do not always realise you can hear them. [One resident had told another she disliked something the speaker was wearing]. It can be really funny - you have to be quite thick skinned, they do tell you ... they are candid in what they say to each other, and to staff. One woman goes by and they say she smells, they will be quite loud about it, it could hurt others' feelings. They say what they think. (S group 30)

Staff saw some differences arising independently from dementia, being due to either long-standing characteristics of individuals, or as a consequence of living in a group. Personality clashes had led, in at least two instances, to staff suggesting that residents should sit at different tables. The following quotes give examples of sparring between two residents.

S: ... they kick, stick their stick out to trip each other, mostly we let them get on with it, but if at mealtimes, we have to say 'Let's try to avoid this'. We suggest different tables, they are really bitchy to each other. But, as I brought up at the carers' meeting, you have to remember that if there were eight women in kitchen, wouldn't there always be fall-outs? Sometimes we try to make things absolutely perfect, they are all used to having their own domain, they stand in front of the cupboard, block the sinks, silly things, but I think it's little to do with dementia, but because we have seven ladies. (S group 17)

Despite having disagreements everyday, two residents, reportedly, were habitually very polite at breakfast, and inquired after each other's health. Two women also sparred at Heartfield:

S: Its not exactly disputes, but one will say for example: "I'm so bored that I could run a mile." Then [the other] says: "Well go!" But that's good. Those are the only two. (S group 45)



Displays of assertiveness were often seen as 'healthy' and the company to be an important stimulation. Some residents were seen as dominant and, as in any group, needing to be restrained. Residents sought to establish their territory in shared spaces, for example in the kitchen, or for a particular chair.

### **7.3 Influences on interactions and relationship**

Kin interviews suggested a number of influences on the interactions and development of relationships in care housing. These included the lifelong characteristics and habits of the person with dementia, the changes wrought by dementia on the resident and their co-residents, adjusting to living with others, the design of the unit and especially the privacy afforded, and changes over time where people got to know each other, or the composition of the group changed, and the activities and conversations initiated by staff. Only one interviewee suggested gender was a factor and no reference was made to class or ethnicity. These possible influences were explored further in staff interviews.

#### **7.3.1 Dementia**

It appeared from the section above that living communally in confined and shared spaces could generate conflict between residents that was interpreted as normal, though regrettable. However, a distinct set of problems arose as a consequence of dementia, where people misidentified each other or possessions, or upset others by their behaviour. Where dementia interfered with perceptions of the situation, disagreements were less likely to resolve themselves than the 'everyday, normal life' kind described above, perhaps because they took place when anxiety was heightened.

Some staff asserted that residents knew they had dementia, and were prepared to remind residents of this. An idealised view was that residents understood that they were 'all in the same boat' and were tolerant of each other. Another possibility was that fear of their own dementia getting worse underlay residents' responses to people with more advanced dementia, who were not always treated sympathetically.

Dementia made it hard for residents, or at least some residents some of the time, to keep in mind where they were. They were apt to misidentify their setting and who was in it. While they were encouraged to see it as their home, and sometimes accepted it as such, they also saw it as a club, or a hotel shared by acquaintances, or even as a waiting room with strangers. Other people were mistaken for friends, family or neighbours from the past, sometimes consistently. Men and women had mistaken each other for their spouse, and perhaps another resident of the same sex as a rival. Mistaken identity could provoke aggressive behaviour if co-residents were taken for strangers or intruders in their house, or as adulterous rivals. One woman, reportedly, thought she was employed



to wash the dishes and would become agitated if they did not get this done in what she considered to be the correct way.

Residents accused one another of taking possessions, which may well have been mislaid, or were shared property that one individual thought to be personal property. Handbags could easily get lost but, some staff said, were important to make female residents feel secure. Possibly, when residents became more relaxed, they left their handbags in their rooms. One resident never relaxed in this however, and spent much of the time searching for her bag. The situation was aggravated when residents acquired new handbags they did not recognise.

Though misunderstandings could arise, dementia also could mean that people forgot their differences soon after. However, when one person's short term memory was poorer than someone else's, the situation could get difficult.

S5: Five minutes later, for example, one said: "Let's go outside." And the other said: "I already told you I'm never talking to you again", but the other could not even remember the disagreement. (S5 group 29)

Collective reactions occurred when one resident, wanting to go 'home', upset others who would also then wish to leave. These situations were described by kin, as well as staff, and are the subject of the following two quotes.

- K1 ... there seemed to be an agitation, they seem all to go on the move - the patients were all in a mood and wanting to wander somewhere. (K1 group 32)

- K11: In her better moments she's quite happy there, but they're all the same, you go there and you meet a different one at the door every time.

K11 spouse: Aye, they've all got their coats on wanting to go home.

K11: "I'm going to see my mother."

K11 spouse: They're all going home to see their mother, mother will wonder where they are, that's what they live for now, their parents, their own parents they think are still there. Gran's the same. (K11 group 36)

### *Differing levels of disability*

What influence did the progression of dementia have on group-living? Staff were inconsistent about whether residents were aware of the level of each other's disability. On the one hand, residents were presented as being peers, in that they all had dementia (S10 group 85), or as being insufficiently 'compos mentis' to know that they were at different stages (S22 group 49). On the other hand, they were presented as sensitive to, and potentially very critical of, each other's abnormal and apparently meaningless behaviour. Respondents presenting the first point of view contradicted themselves and most data suggested that people with less advanced dementia, or at least with less anti-social habits, were irritated by the characteristics of those with more obvious problems. Saying this, staff sometimes reiterated that residents got on well overall, even surprisingly so. One respondent summarised the conclusion reached by the majority: 'If someone has a far greater or lesser level of dementia than the majority, that causes



problems.' (S19 group 10). As noted in 5.3.1, staff believed it was best if residents 'were on a par'.

At the time of interviews, each unit had at least one resident who seemed worse affected than the others. One pattern of progression was taken as withdrawal from group relations, an example being a resident who spent increasing amounts of time sitting on her own. Another resident, whose dementia had advanced, became more prone to irritable outbursts. If residents lost the ability to speak, or spoke unintelligibly, this signified to staff that they were severely disabled.

S20: R22 gets chased a lot. When she starts (to speak to herself), residents say: "What are you talking about?" They can't follow what she is saying, so they more or less dismiss her. (S20 group 28)

Diminishing ability meant loss of social skills. Eating with one's fingers, fingering objects apparently without purpose, and other repetitive actions were irritants. Lifting objects could make it difficult to fit in with others:

S24: The only thing - and this is because of the other residents who object - and that is people who lift things, like cups and handbags and plants, and are continually on the go. The other residents find it hard to accept and try to constrain them to their seats.

KF: Can you give me an example?

S24: One lady used to wander all the time, she was happy in doing so. So she fitted in here but the other residents used to drag her and tell her not to move. One in particular, so it affected the other residents, not her. (S24 group 67)

Physical frailty, especially immobility, could stimulate concern - at least to merit the phrase 'poor soul' (S5 group 32) - or perhaps attract help. Incontinence was less acceptable. Residents' attitudes could vary:

S29: There are two ways to look at this: the condescending: "Isn't that a shame." With physical disability, someone who can't walk. This happened with two who were wheelchair bound and R4 who does not communicate. With speech difficulties, with some residents, they can get exasperated, because they don't understand what someone is saying. "Condescending" is perhaps not the right word. But also there's the caring aspect: "Can I do anything to help?" which some of the more able residents say. (S29 group 58)

Individuals differed in their levels of tolerance, and also between occasions. Staff described more negative reactions than positive. Residents were said, at times, to become agitated, bewildered, annoyed, worried, critical, nasty, cruel or intolerant. They could dismiss each other, exclude each other, treat the person as a troublesome child, avoid or constrain them and be very critical. More able residents could physically withdraw to their own rooms. Staff thought the more disabled people needed protection, and tried to persuade others to be compassionate to someone who was too ill to behave differently. Residents could be jealous of more attention being paid to someone who needed more support. One resident may be helpful and caring to another but this could wear off.



S30: Occasionally because of the mix, it can be a slight trial to the others. For example R22 cries a lot, no matter what you do, and the new gentleman worried about this at first, and we tried to explain it to him. At first he sympathised and wanted to help, then it got on his nerves I think, and he would ask: "What's up with her? Can't she stop?" (S30 group 97)

Several examples of intolerance were given.

S25: The ones who are witnessing someone with advancing dementia are very, very nasty at times [and we might separate them which I think is wrong] - but at the end of the day, they are thinking: "Am I going to be like that?" They know they are here for a reason, but they are not sure what that is, but then they see someone who cannot eat and drink on their own, and they get upset, and wonder if this will happen to them while they are here.

KF: Can you give an example?

S25: They will say : 'Oh look at her, pouring that into a sugar bowl!', "Oh for god's sake!" They will sit and talk: "Eating like a baby"; "Can you not use your fork right"; "You are silly, you should not be at table"; "Shouldn't be here, should be in hospital'. They can be really rude, I think it's just a fear, and not nice, to watch someone who's mind can't co-ordinate itself, and is possibly drooling - the others do have to witness it." (S25 group 39)

A man who could not speak, but silently stood looking at new male residents for long periods, sometimes provoked aggressive responses. Some people got used to this and could ignore it, with the help of staff. Sometimes he would stand on others feet and not respond to their complaints: other residents found it difficult to understand why he could not see them. His next of kin noted that this man was shy and had always found it difficult to be with strangers, but thought that his dementia meant that he could not build relationships, so his co-residents remained strangers of whom he was apprehensive. He was also described as a 'plunderer', meaning that he moved things and went through them even if they were not his own, which caused arguments. He had three different room-mates and this was felt to make it difficult for him to adjust. Another change that had happened to him since the move was thought perhaps to be a response to living in a group.

K: [He's] getting greedy and protective. If food is put on table, he's the first to snatch it, I think its because of living with strangers. To him, because he's not in a sound mind to get to know them as people, so he has developed this thing: "This is mine, don't you touch". It might be part of the dementia as well, I don't know if its the move or dementia. (K group 3)

It seemed that the everyday arguments, considered normal for group-living, were exacerbated by dementia. A senior staff member, who had thought carefully about the way residents got on, was sure that the more severe the dementia, the more disputes there were. Staff tended to keep a closer eye on more affected residents, guiding them away from confrontations (S8 group 21). Respondents assumed, however, that less disabled people were more likely to be irritated and aware of the differences.

The picture developed in this section was drawn by people without dementia. Respondents suggested that the less disabled people could discriminate and even 'think of themselves apart' [S3 group 29]. Compared to the many comments about the



perception of less disabled people, there were few references to the possible anguish and frustration of those who found themselves less able than their co-residents.

### **7.3.2 Personal and social background.**

Kin interviews suggested that residents brought with them patterns of relating established over their lives, for example being a 'mixer' or a 'loner', or the experience of working under orders, which might mean they saw senior staff members as 'the boss'. Habits, that had developed over the years, were important; for example one man had lived on his own for twenty years and preferred to have his meals sitting on his own.

Staff asserted that there was very little difference between the backgrounds of residents and did not (and it was implied, should not) discriminate against each other on the basis of money. Residents' loss of short term memory was also taken to mean that they took each other at 'face value' (S14 group 36). Several staff saw dementia as 'a leveller', in that it could diminish people's capacity to discriminate. Two other 'levelling' agents were at work. Firstly residents were offered the same accommodation at the same price, whatever previously may have distinguished them (A2 group 6). Secondly, staff insisted that they, themselves, did not discriminate and that they treated each resident in the same way.

As 5.1.2 indicated, there was a reason why staff thought residents as sharing 'working class roots', though perhaps some had got used to having more money. Concluding that there was 'nothing terribly obvious', this respondent noted:

**A2:** We have some tenants who fund themselves and came from their own house, from a fairly wealthy background, to people who have nothing as far as finances go. There's a mix of past occupations - people who have never worked and stayed at home, because their husband provided all, to tenants who had to clean other people's clothes to see themselves through the week. (A2 group 6)

Care staff, though younger, came from the same localities and could share values and prejudices. Although they thought they had a duty to moderate residents' negative responses to each other, staff were unsympathetic to anyone who 'put on airs and graces'; was 'hoity-toity' or 'spoke down' to others. It was completely unacceptable to think of oneself as better than others. Perhaps because I was English, middle class and studying for a PhD, they wanted to make this particularly clear to me. Staff responses suggested that some residents *did* see themselves as better than others, which could become evident at mealtimes, when they criticised each other's table manners. They might not appreciate visitors' behaviour:

**S15:** Residents can be quite rude sometimes to visitors. R13 for example, when we get R24's family in, who can be rough and talk slang, she can ask: "Who is that trash?". We may have to remove her and remind her and take her aside, maybe suggest polishing her room. (S15 group 38)



Residents were said to knock down each other's airs and graces. For example, one resident had been irritated by the attention another paid to her appearance. Relatives had also objected to staff about what they saw as a resident's unwarranted superior attitude. One woman had been shunned by others, to what seems to have been an unusual degree. She was described as follows:

S24: She was the only one who was a home-owner, and drove her own car, this was unusual for a woman of this age; she always dressed properly with a coat and hat; she had very good jewellery before she ruined it. She spoke proper. These would seem the only indications. But she did not come from this area. People here are cagey about outsiders, if you do not have [the local] accent. (S24 group 75)

Differing standards about table manners, what one wore and whether people swore or not were revealed by group-living. Class, which was taken as synonymous with money, experience of marriage and children, and whether women had worked or not were potential influences on how people interacted, but no illustrations were obtained. Ethnicity was a potential discriminating factor that the care houses had little experience of, though being English was recognised by this respondent as a potential difference.

KF: What happens if resident come from different social backgrounds?

S29: I don't know if we have come across that here. I'm trying to think, a lady was very deaf, she could swear which the ladies didn't like. Nothing too marked. A lady who is English, none of the other residents notice, or pay any attention, but she feels they might not like her because of her English accent, we reassure her. We haven't really come across this. Bad language, that's not really the same. (S29 group 59)

According to another staff member, this resident overcame the potential problem of being English because she had a working background like the others, having cleaned other people's houses. One staff member speculated that residents would discriminate against a black person, as people of the residents' age were unused to living in a multi-racial society. One resident had gone to hospital and was treated by a black person, and responded by saying: 'Get away from me!' When a black person had moved in to a care house, it was not clear that this was handled with insight. While staff denied any racism, residents had, however, remarked on this person's presence.

S8: R29 kept saying 'Is that a black man sitting over there?' They found it a great source of topic.

KF: How did (the black resident) react?

S8: He would be quite verbal to her. R29 would come out with things, and his dementia was - he was still aware of things ...

In summary, despite the perception of a number of staff that dementia was a leveller and that residents had similar social backgrounds, it seems that residents actively noted differences between themselves, in terms of personal standards and



attitudes to each other. These values and prejudices were what could be expected in the wider community and were possibly shared and reinforced by staff. The residents noted departures from social norms, to be either more or less refined. While lack of social graces was criticised, it was even less acceptable to think of oneself as better than others. The family background - whether people had children, had worked and their expectations of living with others - may have been important but was not investigated in this study, and nor were sectarian divides. At the same time, the differences between residents were diminished because they shared the same physical environment, and also because staff arbitrated between them. It appeared that staff tended to deny or disguise some differences between residents which might have been in conflict with providing individualised care.

### **7.3.5 Gender and sexuality**

The gender balance in each unit was noted in 5.1.3. Where there had been several male residents, staff were sure that an equal balance was ideal, and that problems did not arise as a result. Senior staff might try to keep this balance, even though fewer males were referred. In each house, men were seen to tend to sit separately, join in less with conversation, and to have their own preferred activities, such as watching television or sport, while women talked. Staff sympathised with males who were alone in a mainly female group; it seemed to them that men would appreciate each other's company. One man who moved into an all female unit was reportedly resented by some of the residents who thought staff should not have allowed this. He apparently could enjoy the situation:

S11: He thinks this is great. They are all concerned about him. He joins in with the sing songs, they play dominoes and whist together. He says: "I am here to keep these ladies straight" - he gets on great with them. He may say: "Is that woman greeting again?" if he has had a bad day, but they are concerned about him. (S11 group 58)

A male presence could mean women talked less freely about pregnancy and sex, but in the instance above (S11 group 58) the humour of the male resident compensated. Having a male in the group was thought to be good for women, perhaps making their 'eyes light up' (S14 group 32). Sometimes the single male could be 'pampered', having sugar and milk put in his tea, but at other times he was pushed out of the kitchen. Staff assumed that gender relations would be traditional for people of the residents' ages, and that both men and women would expect women to undertake domestic work.

S9: It [gender mix] also allows women to run after men, as this age group always did. Better get him a cuppa. Most of their married life, they got their tea ready for their man. (S9 group 5)



In the third unit, a single male resident had been popular with the female residents, especially one who thought that he was her husband. He was described as easy going, with an angelic look that made him popular with both staff and female residents.

KF: How did the gender mix work out?

S24: Really there is not a lot. Men keep themselves to themselves. [A former resident] did not mix with female residents at all, he wanted nothing to do with them, apart from one who saw him as her husband and he went for that on a one to one - she used to tuck him up, and he quite liked that.

KF: Did it go beyond that?

S24: It never went beyond that as far as we know, they used to be on their own in the room, we would leave them if they were both comfortable with it, but I don't think so. (S24 group 73)

This man was described as a 'sultan in his harem' (K2 group 52) - sometimes enjoying the attention, at other times chasing away the women who 'fussed over' him. Males could be irritated by females, and described them pejoratively as 'gabbing' or 'gossiping'. One man had failed to understand why there were these 'old biddies gossiping' in his house, the staff member presumably using his words. Respondents did not raise harassment of females by males as a problem, but female could be alarmed when a male resident mistook their room for their own. An instance of jealousy occurred unexpectedly during lunch, when a male resident accused another man of having an affair with his wife and hit him. The accused man said he didn't even know his wife.

While staff mentioned difficulties in getting men to join in group activities, it was not clear if the type of activity was important. Sing-songs and dances were said to be much better if male residents were present.

In summary, if anything, the absence of males was seen as a problem rather than their presence, except by some residents at one unit, which was hitherto all female. Mixed gender groups were thought to improve group relations. Gender differences were described by staff, men tending to sit separately from women, and to talk less. Women were seen as more gregarious. No sexual disinhibition was referred to, and perhaps would not have been tolerated. No reference was made to homosexuality; like other aspects of the expression of sexuality, time did not permit exploration of this.

### **7.3.6 Managing relationships: staff interventions**

From the above sections it is clear that staff had an important influence on the pattern of interactions and the relationships that formed between residents. Staff introduced new residents to others, and brought them into communal activities. Apart from their egalitarian attitude to class, interviews indicated that staff also played a part in smoothing over clashes between residents. Staff distinguished between differences of opinion that amounted to healthy assertiveness and those which could result in



emotional or physical harm. They thought the first kind were part of everyday normal life, when people lived together, and preferred to leave this kind of difference to resolve itself:

**KF:** Are there ever any disputes? If so, what happens?

**S9:** Yes. Staff leave residents to resolve it themselves, unless physical aggression comes into it. But if they are stating their points of view, and are in no danger of being hurt, then we leave it - it is their house. For example R13 has annoyed R17. R17 will shout. R13 will shout back - quite right, as she is entitled to do what she wants. Sometimes R17 thinks things should revolve round her way, so others do have to say: "No: It's as much my house as yours". (S9 group 4)

While staff had different skills and inclinations, they agreed that if a difference between residents escalated, they should intervene. Staff might initially try to turn the mood by humour, or diversion such as putting music on.

**KF:** When do you intervene?

**S14:** When it comes to the stage that someone has been upset by what has been said, or a conflict has become physical, if they lift their hand or throw objects, we do. If it's a heated argument - jollying them - they start to laugh, you can bring them round to see funny side, it's all down to how you handle it. (S14 group 29)

Staff might try to talk it out, and establish what the problem was, without taking sides. If the problem was between two residents, one of whom was more severely affected than the other, staff might try to win the support and sympathy of the more able resident.

**KF:** What happens if some residents are more severely affected than others?

**S10:** This can be a difficulty, other residents may ask- for example, R29: "What is this we are getting in here, the folk that we let in here is terrible." That's as far as it affects residents, they may comment, we try to explain it away, we say they have dementia but slightly worse than you, say they can't do something because of their illness. We try to get them to be more tolerant and understanding. It works to get them more involved. Like R10 fell outside his room, R29 came out of her room, and asked: "What is it?" and came along, we got him up, and then she took him along - she got involved. If you can explain why they are behaving like that, they are fine. (S10 group 90)

If clashes were persistent, staff tried to keep residents apart, most likely by suggesting they sat at different chairs, or at different tables at mealtime, though not all accepted this was in keeping with the ethos of care housing. Separating people because of personality clashes seemed more permissible to staff than to separate people on the basis of declining skills. It was not always possible to resolve situations. Staff in one unit had been shaken by violent incidents.

**KF:** Are there ever any disputes? If so, what happens?

**S1:** We have had a few, one resident was violent. I find that normal wee arguments die down quickly, they forget it. But this violent man, we had to take the resident he shared with out of the room to defuse the situation. Sometimes we could not get him out. The more you tried, the more angry he got. It's not otherwise a great problem. (S1 group 55)

As section 5.3 made clear, failure to modify behaviour into what was socially acceptable could lead to the exclusion of individual residents. The difficulty in balancing



the interests of the individual versus the group was a theme at each unit. Staff saw it as within their role to protect residents from each other's behaviour.

KF: What are your aims, from the residents' point of view?

A2: Our aims? Each resident has their own individual problems. No matter how much we say there will be individual care, if your behaviour is affecting the lives of seven other people, then we will have to do something about your behaviour. That has brought problems in practice. It's all right to say come in and do your own thing. But if your own thing is never to change your clothes nor have baths and you're smelly, and I have to sit beside you at lunch, we may say, well continue as you are, but you can't eat here, but you will have to eat in your flat. (A2 group 3)

While there were perceived advantages of bringing people together, the presence of different degrees of dementia could threaten group balance. For example, a respondent talked about the difference it made to other residents to have someone with advanced dementia with them:

S25: We are not going to hide it that this person is unable to do these things, but they are not comfy even sitting in lounge when [the affected resident] cannot eat and drink and are showing other signs, can't join in group activities, there's no communication. But I don't believe in moving someone. They have had a big move here, and then to somewhere else, it's too much for them. But we have to weigh it up, is it suitable for others to watch? (S25 group 40)

Ultimately, disruption to the group could be the deciding factor as to whether staff thought someone should move or not, and aggressive behaviour was most likely to lead to expulsion.

#### **7.4 Summary and discussion**

Chapter Seven has explored the interactions and relationships between residents. Having company could be stimulating, but also generated tension. The nature of the relationship between residents was hard to categorise, partly because it fluctuated and their living arrangements were unusual. Residents could adjust to each other, but it was a matter of opinion as to how deep their relationship and concern for each other was. Friendships and helpfulness occurred, but relationships between residents were complicated by changes in individuals and in the composition of the group.

Staff described disputes in detail, perhaps because they had to consider carefully whether to intervene or not. Residents, it appeared, observed each other closely, and sometimes critically. Healthy assertiveness and everyday tensions were distinguished from situations where staff needed to prevent residents getting hurt. Dementia could complicate disputes, for example if residents misidentified each other and their settings, or mislaid possessions.

It became clear that the way that people got on could be influenced by the existing differences of social background, gender, and personality, as well as the progression of



dementia. Residents could be intolerant of those who were most affected by dementia, but interviews suggested staff found it easier to see the viewpoint of those least affected. The examples given illustrate why living in care housing could create tensions. In the opinion of staff there were fewer tensions if residents were similar in how advanced their dementia was. Dementia was not in itself a leveller, despite some claims that this was the case, and staff had at times to actively smooth out relationships. Failing this, they believed it was necessary to control who lived in the house for the sake of social relationships, out of fairness to other residents and to maintain household care.

A number of points arise from this summary that deserve discussion. Care housing demanded communal living and, especially at the smaller units, was an arrangement with few precedents. Residents, most of whom had previously lived alone, were faced with the task of sharing a household with non-kin who they had not chosen to live with. This happened at a point in their lives when their ability to adjust was diminished and they were likely to become still more disabled within a matter of years, or even months.

The data presented in Chapter Seven has confirmed that tolerance, humour and a preference for company are attributes that could help residents settle into care housing. While the skills of collective living were required, the ethos of care housing more explicitly exhorted the individualist virtues of independence and choice. This tension between individualism and collectivism could be resolved if the group was seen to resemble a family, where, as one respondent suggested, you could expect interdependence. Rather than being like a family, the resident groups were pragmatically convened with therapeutic justification and contained a variety of different kinds of relationship.

Residents did not choose to live with each other, but were selected by managerial staff, though one case study had less discretion than the other two about who moved in. The accumulating experience of the staff was that a homogeneous group was preferable, but as discussed in Chapter Five, homogeneity could be couched in both clinical and social terms. Staff were not clinically expert and rejected a medical model but, all the same, found it easier to legitimise the rejection of a resident on clinical rather than social grounds. While they tried not to judge residents' behaviour at interview, the data showed that they had closely observed interactions and relationships between residents. The implication is that individuality could only be tolerated and supported within fairly narrow constraints.

Staff shared the assumption made in the dementia literature that small groups were preferable, but the optimum size of these groups remains an open question. Staff also accepted the responsibility proposed by Kitwood, Buckland and Petre (1995) of promoting contact between residents and visitors and supporting good relations between residents. This chapter's findings support the view that staff play an essential role in promoting good relationships between people with dementia in groups, and that these relationships may be taken as an aspect of good quality care.



This study has shown two contrasting patterns of interactions. At Redpath, residents, as a group, spoke to each other more often than to staff, while in hospital interactions between patients were rare and outnumbered by interactions between staff and residents. These data suggested that staff at the case studies were indeed implementing a social model. Why Redpath should be so successful has already been suggested in the discussion in Chapter Six, but in this chapter a question is raised about why residents in Redpath addressed each other more than in Nash Drive. Possibilities include that residents were better able to communicate and had possibly known each other previously. Residents at Redpath had a longer mean length of stay than at the other units (see 5.1.2), which may have permitted the development of relationships. They had a closer age range. These possibilities may have worked in combination with the culture of care developed by staff at this case study, where household care was most insistently and persistently worked towards. Unfortunately structured observation data were not obtained from Heartfield, where a qualitatively different emphasis was recorded.

The discussion so far has indicated that people with dementia are particularly influenced by their environment, and that staff intervention is important to help them relate well to each other. It would be misleading, however, to think that residents were passive, since intense relationships, of both friendship and hostility, were recorded and residents could use situations to their own advantage. According to Reed and Payton (1995), mutual support and the development of friendships has been underestimated in residential care, and these findings suggest that this could equally apply to people with dementia. The most important actors to consider are those with the most advanced dementia because their perspective is the most neglected and difficult to ascertain. This exploration has suggested that while the interactions between people with dementia are shaped by influences common to us all, the relationships between those with more and less advanced dementia have a specific character. People without dementia can read the perspective of those with least advanced dementia most readily, but it is dangerous to assume that the advance of dementia makes one more passive within a group, or less influenced by other people's responses.



## CHAPTER EIGHT

### CONCLUSIONS

This thesis has had to address methodological issues in some detail in order to investigate the effectiveness of care housing. This chapter sets out conclusions about the research strategy and then turns to the research questions as set out in Chapter Three and dealt with consecutively by Chapters Four to Seven. These conclusions are drawn from the summaries and discussions concluding each chapter.

The task of this thesis is to contribute to the evaluation of a model of care that aims to provide good quality long stay care for people with dementia, a commodity which is sorely needed. Although there was considerable interest in establishing cost-effectiveness of care housing, I argued that this would be premature given the state of knowledge about care housing, and would be outwith the scope of this study. I decided not to adopt a production of welfare model and measure predetermined outcomes, but was persuaded that a pluralistic approach could usefully generate discussion of the aims and success of care housing and suggest relevant outcomes. This was helpful in identifying both the different interests and the shared concerns of participant groups interviewed, and establishing foci for further work. I have argued that the questions addressed in this study extended previous evaluative studies and could complement an economic approach. The expectation that there would be diverse aims for care housing, and that these would develop and change, was borne out. For example, at the beginning of the study, commitment to providing a home for life was strongly expressed by case study employees, but this was considerably modified by the end, with consequences that may have disappointed kin and not necessarily have been to the benefit of the residents who had to move. This study found that the houses operated within a wider context which influenced their operation, and that the household care ethos was interpreted slightly differently in each case study. In short, a qualitative approach has contributed to the evaluation of care houses and it would have been premature, at this stage of knowledge about care housing, to adopt a research design which fixed care housing as a closed system and sought regularities.

A qualification of the pluralist view obtained by interview is the respondents' potential bias in favour of care housing. During the application of REPDS and DCM, doubts about their use in this setting strengthened. Both methods have contributed to the study, but comparison with qualitative data has been important. Using multiple case studies has contributed to confidence in the study's findings.

This study has raised concerns that seem inherent to household care and which have particular relevance to practice. Questions are raised whose relevance extend beyond the three case studies. However, the title of the thesis claims only that this is a



step towards an evaluation. Thus the costs of care housing have not been related to the consideration of appropriate aims and quality of care. The preferred approach of using the individual residents' needs and preferences to frame evaluative comparison could not be achieved. A normative approach was adopted with the use of DCM. The subjective appraisal by residents was not achieved, but concerns were selected that were arguably important to them. The evaluative comparisons with alternatives made by kin, staff and managing agency representatives were established, but the scope of these was constrained by the predominant reference point, poor quality hospital care. Evaluative research is applied research and should, according to Robson (1993), be of direct utility. This was constrained by the study's status of a studentship. Despite these necessary limitations of the research strategy, this thesis has contributed substantively to the body of knowledge about care houses and raised further questions.

The case studies were in line with proposed reforms to the residential care sector and were not products of Community Care legislation. They demanded communal living and were not a form of private living. The adoption of household care was consistent with contemporary views of good practice for people with dementia and was influenced by the normalisation movement. While there was a national policy commitment to such a model, local frameworks for collaboration and strategic planning were poorly developed. This process was characterised by opportunism and compromise, and it took individual persistence and commitment to develop the case studies. Understandably, agencies were preoccupied with negotiating the division of health, housing and social care responsibilities in an uncertain time. The model has not expanded to the extent that its proponents hoped, one reason being that the demand for facilities has taken precedence over experimentation with new models of care which may be more expensive. The presence of a few care houses has done very little to expand the real range of choice open to people with dementia, and their kin, in Scotland.

Respondents were convinced that the care offered was superior to any alternative and brought benefits to residents. There was remarkable consistency about what the important characteristics of care housing were, namely 24 hour support with a relatively high ratio of staff to residents, company and stimulation, a domestic scale of design and location. The staff elaborated and endorsed the aims stated in the operational policies; all respondents were committed to a social model of care, and almost all staff shared a therapeutic optimism encouraged by the psychosocial approaches to dementia care reviewed in Chapter Two. Respondents mentioned the social environment most frequently, but those who had experience of residents sharing bedrooms made clear that this created tensions.

In accepting and implementing household care, respondents were ambivalent about the contribution of clinical expertise, derived from a medical model that was tainted by their condemnation of psychogeriatric long stay care. There was a danger that an uncritical acceptance of a social model led to the assumption that this approach



determined all positive changes, while negative changes were attributed to the progression of dementia.

The larger unit was less clearly committed to a household model of care and less well designed to achieve this. Both interview and observation data suggested differences in the units as to what staff prioritised. One staff group prided itself on creating an atmosphere where individuality and close, informal relationships were nurtured, while another staff group had a strong insistence on promoting independent participation in household activities. Staff were proud of the work they did, and it seemed likely that knowing the care houses were considered innovative helped staff feel valued, while the work itself could be thankless, emotionally demanding and physically tiring.

Kin who were interviewed believed that care housing was the best available option for their relatives, and the move offered kin themselves both practical and emotional relief. For the residents' part, indirect reports suggested that the move did not take place on their initiative, and that they rarely agreed that they needed support for which they had to move. If moving from private living, they most likely had to forgo private amenities, though people moving from institutional care might have moved to improved facilities. Perhaps for the first time in their lives, they moved to live communally with non-kin.

In drawing comparisons with alternatives, respondents frequently suggested that it was 'the next best thing' to living at home, implying that the ideal was unattainable. There was tacit recognition that living at home had proven impossible, with the implication that care housing was the best that residents could expect. All institutional alternatives were unpopular, but hospitals exemplified the polar opposite to homely ideals, and were used as a negative contrast to the quality of care offered at the case studies.

The units aimed to support elderly people with dementia, who have specific and extreme difficulties in remaining engaged and oriented in their social worlds, and whose capacity to do so predictably diminishes within a matter of years, or even months. How could household care be preserved in the face of this? The brief answer appeared to be that people who become too dependent, or developed anti-social or aggressive behaviour, had to move out.

The consensus of qualitative assessment was undoubtedly that a move to care housing, for some residents at least, led to improved physical health and mental well-being. This was evident in general appearance, improved communication, ability to care for oneself and participate in household activities. Following Lieberman (1991), this strongly suggests that care houses could offer an enhanced environment. Respondents explained the presence of positive changes by the confidence and self-esteem that residents could regain through the social support given, together with a basis of good physical care. According to the model put forward by staff and kin, the benefits were



most evident after a period of settling in but, following this, the progression of dementia and increased physical frailty meant negative changes again became apparent. This is consistent with other evaluative research of care housing developments (Annerstedt, 1995; Dean *et al.*; 1993; Ritchie *et al.*, 1992, Plaisier *et al.*, 1993, 1995), but this is very difficult to investigate. Methodologically and ethically, the consequences of relocation are difficult to establish.

Further work is needed to identify the full range (negative and positive) of effects that care housing may have. Investigation should take into account environmental discrepancy (Lieberman, 1991), and consider the extent to which the setting is prosthetic to individuals' specific disabilities, taking into account the pattern of cognitive impairment, personality, attachment to previous home and attitude to the move.

In practice, residents moved to accommodation which was fixed in the nature of support offered. Less than half of the 127 people who had moved into Scottish care housing by the end of October 1994 remained residents of care housing until they died. People who were admitted to hospital with medical emergencies died shortly after, while still residents of the case studies. People who had short terminal illnesses could be supported in the house, as long as, in the case of the smaller units, temporary additional resources were provided, including increased staff cover, community nursing services and family support. People with longer term needs for nursing care had inevitably moved out. Sustained aggressive behaviour could not be managed in the care houses. Further work is needed on how, and whether, aggressive behaviour can be accommodated within social models of care.

The decision that an individual should move in the interests of other residents and staff has a number of implications. The residents who moved may have gone to somewhere with poorer quality care, but where their disturbed behaviour was dispersed in a larger group, rather than to an ideal setting which matched their need for more specialised support. Interviews with residents' kin strongly indicated that a move out of the care house would be unwanted. For other residents the loss of a group member was, according to staff, outweighed by the benefits of maintaining a resident group whose abilities were similar. The staff had a sense of failure and sadness if someone moved, and satisfaction if they could support a resident until they died. Despite this, their experience led them to think that it was sometimes necessary for residents to move.

Care housing operated to support people with dementia able to live communally and, for some, for a limited period in the course of their illness. If aggressive behaviour is as prevalent as Patel and Hope (1993) suggest, a substantial number of people could not successfully move to care housing. A parallel process of refining by experience which people with dementia suited care housing was happening in *gruppboenden* in Malmö-Lund, Sweden. While in Scotland staff were reluctant to define explicitly who suited care housing, both social and clinical criteria remaining vague, Annerstedt (1993) calculated what proportion of people suited *gruppboenden* according to clinical



characteristics. Whatever criteria were deemed most important, care housing, like *gruppboenden*, in practice proved able to support only a proportion of people with dementia.

The operation of care housing depended upon the availability of long stay hospital care, both medical and psychiatric. As Bleeker (1994) suggested, people who have multiple pathologies alongside dementia test the limits of social models of care. While hospitals were believed to provide inferior care, care housing still exported residents who were the most difficult to look after to these settings.

It seemed that some local hospitals might have been in particular need of reform, but one case study operated with the support of a modernised psychogeriatric service to the satisfaction of all those directly involved, and with reported benefits to residents. This suggests that ongoing teamwork between health and social services may be advantageous, if difficult to achieve. The close involvement of psychogeriatric services may have been a factor increasing length of stay, as may the fact that all residents moved in from the community and staff could select residents carefully.

While kin and staff regarded care housing as a homely setting, the evidence was that residents found this more difficult. It seemed that it was particularly difficult for people with dementia to adjust to a move of house and acknowledge their new setting as 'home', and that this was rarely achieved and sustained, whatever the setting. From time to time, residents were restless and had a sense of being misplaced and betrayed. Staff had the role of reinforcing that the care home was where residents lived, and sometimes had to enforce that they stayed there. Feeling at home depended in part upon biography and personal relationships, but this was not helped by living with people whose presence and behaviour were at times hard to explain. Residents were, in practice, restricted to some extent in how they could use the house, and depended upon staff to structure the daily patterns. Private facilities qualitatively assisted in creating a sense of homeliness, even though they were not used as much as shared areas of the house.

While the intention was that residents and their kin were supposed to be closely involved in the daily life of the household, they, or their representatives, played no role in the management or development of the units. In practice, kin rarely provided substantial practical or personal care, though a few did use this as an opportunity to sustain their relationship with the resident in care housing. Social visits were the main link retained by kin, but it seemed from interviews that they could find these difficult and painful, although perhaps much better than if the resident had lived in a hospital or care home.

Living in care houses demanded communal living, and a conflict between collectivist and individualistic ideals was evident. The case studies explicitly sought to promote independence and choice, but staff also encouraged interdependence. While the ideals of home expressed suggested that group-living was a pragmatic arrangement,



the advantages of company and stimulation to residents provided a therapeutic justification.

Taking part in daily household activities required considerable support and encouragement from staff, who in turn required support and supervision to sustain therapeutic optimism. One of the smaller units, Redpath, was most successful in providing household care. This case study provided most personal space and facilities to its residents, was most domestic in its design and equipment, and the staff group had the ethos of care strongly instilled in them and were well supported externally. Housekeeping arrangements had been carefully thought out to ensure residents could participate. Here, all residents moved in from community housing. Residents had a greater mean age but, according to REPDS, as a group had least problems with self help. The REPDS median scores for physical problems and confusion were not, however, the lowest, illustrating the complexity of separating environmental effects from the impact of impairment. Success was indicated by the highest group care score, as indicated by the DCM method, and the lowest level of passive records for how residents spent their time, compared both to the larger care house and patients in a hospital ward. Residents in Redpath did notably more work in the kitchen. Differences in residents' sense of ownership of the house, and responsibility for household work, was qualitatively observed both within and between houses.

It was not clear that scale alone made the difference, but creative organisation of time and space and staff ethos could also have contributed. Household care and institutional settings need not be mutually exclusive. Residents' resistance when encouraged to do household work was evident in observation, and highlights that this model of care makes value judgements about appropriate activity for people with dementia. The model is supported by a contemporary ideal of living independently at home, but the cultural and historical influences on such ideals need to be remembered. An open question is whether men and women can settle equally well into household care. Evaluation of residents' life outwith the care house, their use of community facilities and relations with non-kin in the neighbourhood was not achieved in this study and requires further work.

Staff required, and most had developed, considerable skill to enable them to encourage residents with humour, to avoid confrontation through diversion and tact, and to support different individual patterns of daily living. This achievement should be seen as highly professional, but the informality of the setting, and the unobtrusive nature of good quality care, disguised this. Given that residents would rarely express appreciation of the support given, providing a high quality of care is all the more impressive.

Group living was demanding for residents, and this aspect of care housing meant that it might not suit everyone. The everyday tensions were expected and accepted by staff, but the presence and progression of dementia gave these groups a specific flavour. Dementia was not a 'leveller', but living in the same circumstances might have



been. Dementia was by no means the only influence on relationships, and the social background of residents should be taken as a factor important to the characteristic and potential success of pragmatic groups. Whether residents would always agree that living with others was an advantage is debatable. In the judgement of staff, kin, and any evaluative researcher using engagement as a measure, the care houses were successful in ensuring that residents were socially involved. An interesting finding was the strong suggestion that household care can generate a pattern where residents interact more with each other than with staff, but that there was considerable variation in this. The interactions and relationships that occur between people with dementia deserve considerably more attention, with special attention to the factors that may promote good relationships. A more detailed analysis of who relates to whom in pragmatic groups, and how, would be a starting point.

The ideal of living at home in the community is a contemporary value, and one that is particularly difficult for people with dementia to achieve. The ideal of homeliness, and the aversion to institutional care, pervaded participants' descriptions of care housing. The most succinct evaluative summary was made by the respondent who suggested that care housing was 'housing within a Home'. This thesis has contributed to a more detailed discussion of what aspects of homeliness can be recreated, and how these may bring benefits. The challenge for care houses was to sustain care as dementia progressed, and to extend good quality care to those with more substantial behavioural and physical support needs.

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Appendix One

REVISED ELDERLY PERSONS DISABILITY SCALE

NAME/CODE NUMBER:

SEX:

M  F

DATE OF BIRTH:

DATE OF ADMISSION:

LOCATION:

DATE OF ORIGINAL  
ASSESSMENT:



# PHYSICAL PROBLEMS

## REVISED ELDERLY PERSONS DISABILITY SCALE

NAME:.....

OTHER IDENTIFICATION:.....

DATE

1. *When walking, with or without an aid or using a wheelchair, the person requires:*
  - No assistance 0
  - Observation and/or encouragement 1
  - Assistance from one person 2
  - Assistance of 2 or more people 3
2. *The person suffers from:*
  - No obvious limb disability 0
  - Minor restriction of movement or weakness 1
  - Moderate restriction of movement or weakness reducing self help skills 2
  - Major restriction of movement or weakness reducing self help skills 3
3. *The person's vision, when using spectacles if necessary, is:*
  - Apparently good 0
  - Slightly impaired 1
  - Moderately impaired 2
  - Extremely poor 3
4. *The person's hearing is:*
  - Apparently normal 0
  - Slightly impaired 1
  - Moderately impaired 2
  - Extremely poor 3
5. *The person will fall from his bed unless protected by rails:*
  - Never 0
  - Occasionally 1
  - Often 2
  - Every night 3
6. *The person will fall from a chair unless protected by a harness:*
  - Never 0
  - Occasionally 1
  - Often 2
  - Every day 3
7. *The person can negotiate stairs:  
(if no stairs indicate your opinion of person's ability):*
  - Independently with no risk 0
  - Requires observation and or encouragement 1
  - With help of one person 2
  - With help of two people 3

Total  
Percentage


# SELF HELP SKILLS

	DATE				
1. <i>When eating or drinking, the person requires:</i> No assistance Observation and/or encouragement Some "hands on" assistance Full assistance	0				
	1				
	2				
	3				
2. <i>When bathing/showering, the person requires:</i> No assistance Observation and/or encouragement Some "hands on" assistance Full assistance	0				
	1				
	2				
	3				
3. <i>When dressing, the person requires:</i> No assistance Observation and/or encouragement Some "hands on" assistance Full assistance	0				
	1				
	2				
	3				
4. <i>When not helped, the person's appearance is:</i> Neat and tidy Occasionally untidy Often untidy Always untidy	0				
	1				
	2				
	3				
5. <i>In keeping his bed space tidy and making the bed, the person requires:</i> No assistance Observation and/or encouragement Some "hands on" assistance Full assistance	0				
	1				
	2				
	3				
6. <i>The person cares for his health:</i> Completely. Understands cause and prevention Requires observation and prompting Requires clear instructions Does not report sickness or follow instructions	0				
	1				
	2				
	3				
7. <i>The person is incontinent of urine:</i> Never, or has a catheter## Occasionally Once a day Regularly more than once a day	0				
	1				
	2				
	3				
8. <i>The person is incontinent of faeces:</i> Never, or has a colostomy## Occasionally Once a day Regularly more than once a day	0				
	1				
	2				
	3				
	<b>Total</b>				
	<b>Percentage</b>				

## The extra care required by the catheter and/or colostomy is covered in Question 5 of the Nursing Dependency scale.





# BEHAVIOUR

		DATE				
1. <i>The person is restless or agitated:</i>	Never	0				
	Occasionally	1				
	Often but not every day (or night)	2				
	Every day (or night)	3				
2. <i>The person is destructive of things:</i>	Never	0				
	Occasionally	1				
	Often but not every day	2				
	Every day	3				
3. <i>The person disturbs others by being noisy, interfering or threatening:</i>	Never	0				
	Occasionally	1				
	Often but not every day	2				
	Every day	3				
4. <i>The person physically tries to harm others, including staff:</i>	Never	0				
	Occasionally	1				
	Often but not every day	2				
	Every day	3				
5. <i>The person tries to abscond or wander:</i>	Never	0				
	Occasionally	1				
	Often but not every day	2				
	Every day	3				
6. <i>The person is co-operative when asked to do things:</i>	Every day	0				
	Often but not every day	1				
	Occasionally	2				
	Never	3				
7. <i>The person intentionally steals from others:</i>	Never	0				
	Occasionally	1				
	Often but not every day	2				
	Every day	3				
		<b>Total</b>				
		<b>Percentage</b>				



# S O C I A B I L I T Y

		DATE				
1. <i>The person plays games, has hobbies/interests:</i>	Daily	0				
	Once a week or more	1				
	Occasionally	2				
	Never	3				
2. <i>The person reads or watches T.V.:</i>	Daily	0				
	Once a week or more	1				
	Occasionally	2				
	Never	3				
3. <i>The person joins in group activities:</i>	Daily	0				
	Once a week or more	1				
	Occasionally	2				
	Never	3				
4. <i>The person physically helps others without being asked:</i>	Daily	0				
	Once a week or more	1				
	Occasionally	2				
	Never	3				
5. <i>The person has:</i>	Many friends	0				
	Two friends	1				
	One friend	2				
	No friends	3				
6. <i>The person mixes with the opposite sex:</i>	Freely	0				
	Occasionally without being prompted	1				
	During organised activities only	2				
	Rarely or never	3				
7. <i>The person has an activity that takes him out of his living area:</i>	Daily	0				
	Once a week or more	1				
	Occasionally	2				
	Rarely or never	3				
		<b>Total</b>				
		<b>Percentage</b>				





# NURSING DEPENDENCY

		DATE				
<b>1. Routine medications are:</b> Taken independently Taken with prompting/supervision Administered by staff Taken reluctantly even when administered by staff	0					
	1					
	2					
	3					
<b>2. The person sleeps well at night:</b> Always Often (with sedation when required) Occasionally (with sedation when required) Rarely (even with sedation)	0					
	1					
	2					
	3					
<b>3. Problem behaviours require:</b> No additional attention Less than 1/2 hour individual attention per day, except for crises At least 1/2 hour individual attention per day or 2 or more hours at least once a week More than one and a half hours of individual attention per day	0					
	1					
	2					
	3					
<b>4. Assistance with self help skills:</b> Requires no assistance Requires observation and/or encouragement Requires physical assistance Totally dependent on staff	0					
	1					
	2					
	3					
<b>5. Specialised nursing procedures:</b> No specialised nursing procedures Less than 1/2 hour of attention per day 1/2 to 1 hour of attention per day More than 1 hour of attention per day	0					
	1					
	2					
	3					
<b>6. Safety with appliances e.g, T.V., knives, etc.:</b> Needs no supervision Needs observation but rarely gets into difficulties Often gets into difficulties Cannot be left alone, turns furniture, T.V., etc., over or uses objects dangerously	0					
	1					
	2					
	3					
<b>7. Toileting:</b> Requires no assistance or has a colostomy and a catheter# Requires observation and/or encouragement Requires "hands on" assistance with some but not all activities Requires full assistance with positioning, toilet hygiene and adjusting clothing	0					
	1					
	2					
	3					

# NURSING DEPENDENCY

8. *Transfers to and from bed, wheelchair, etc.*  
 (Bedfast residents should be rated 2 or 3):

- Requires no assistance
- Requires observation and/or encouragement
- Requires "hands on" assistance from one person
- Requires assistance of two people or lifting device

0  
1  
2  
3

9. *Prevention of pressure areas:*

- Infrequent or no attention
- Attention 1 to 3 times per day
- Attention 4 to 6 times per day
- Attention more than 6 times per day

0  
1  
2  
3

**Total**

**Percentage**

**Total % Score**


## *The extra care associated with a colostomy and/or a catheter is covered in Question 5.*

## ADDITIONAL COMMENTS:

Note here any other significant problems or specific requirements.

PROBLEMS	REQUIREMENTS
DATE	
DATE	
DATE	
DATE	
DATE	



***DEMENTIA SERVICES DEVELOPMENT CENTRE***

**&**

***PRIORITY SERVICES RESEARCH TEAM***

**Monitoring Survey**

**Residents of Specialist Housing Units in Scotland**

Kate Foster  
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University of Stirling  
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0786 473171

Jenny Henry / Isobel MacPherson  
Priority Services Research Team  
Department of General Practice  
Foresterhill Health Centre  
Aberdeen AB9 2AY  
0224 683648

Please complete one form for each person who is or who has been resident in this unit

**Section 1: Resident Information**

1.1 Date of Birth day month year

1.2 Sex *(please circle)* male female

1.3 When did this resident move in? (start of trial) day month year

1.4 How long does the trial period last? *(if appropriate)*

1.5 Who referred this resident?  
(e.g. family, GP, social worker, consultant)

1.6 What was the main reason for this resident being admitted?



1.7 Where did this resident move from? *(please tick one of the following)*

Geriatric hospital - assessment

Geriatric hospital - long stay

Geriatric hospital - other *(please specify below)*

Psychogeriatric hospital - assessment

Psychogeriatric hospital - long stay

Psychogeriatric hospital - other *(please specify below)*

Acute hospital

Nursing home

Residential home - Local authority

Residential home - Private

Residential home - Voluntary

Community - own home / mainstream

Community - sheltered housing

Community - very sheltered housing

Community - relative's home

Community - other *(please specify below)*

Other *(please specify below)*

**Section 2: Admissions to hospital**

**This section should only be completed for residents who stayed beyond their trial period in your unit**

2.1 Has this resident been admitted to hospital during their stay in the unit?  
(please tick appropriate box)

Yes

No

If Yes, please give details of each admission below

Date of Admission to Hospital	Date of Discharge from Hospital	Name of Hospital	Reason for Admission (see note below)

Note: Reason for admission may be one of the following:  
Psychiatric, Medical, Surgical, General, Rehabilitation, Other (please specify)



You may wish to make other notes to explain the admission

**Section 3: Residents whose tenancy has ended**

**This section should only be completed for residents who are no longer in the unit or whose tenancy is about to end.**

3.1 When did / will the resident leave the unit? day   month   year

3.2 Did the resident die while still in the unit?

Yes

No

**If YES, what was the reason for death?**

**If NO, please answer questions 3.3 and 3.4**

3.3 Why did the resident move from the housing unit?

3.4 Where did the resident move to? *(please tick one of the following)*

Geriatric hospital - assessment

Geriatric hospital - long stay

Geriatric hospital - other *(please specify below)*

Psychogeriatric hospital - assessment

Psychogeriatric hospital - long stay

Psychogeriatric hospital - other *(please specify below)*

Acute hospital

Nursing home

Residential home - Local authority

Residential home - Private

Residential home - Voluntary

Community - own home / mainstream

Community - sheltered housing

Community - very sheltered housing

Community - relative's home

Community - other *(please specify below)*

Other *(please specify below)*

**THANK YOU VERY MUCH FOR YOUR HELP**



## Appendix Three: Semi-structured interview schedule for next of kin

### STUDY OF CARE HOUSING FOR PEOPLE WITH DEMENTIA SEMI-STRUCTURED SCHEDULE FOR RELATIVES

Kate Foster, Dementia Services Development Centre, Stirling University. March 1993.

- Unit
- Interviewee
- Resident
- Date
- Time
- Location

*\* These questions give me a broader view of the project*

*\* Want to find out how c/h works out in practice for you and your relative*

*\* Some questions are about your own experience*

*\* Others are more to do with R's life and experience*

*\* Confidential - not talking to staff about this*

*\* Tape recorder*

*\* First section is about R as a person, before the memory problems began.*

*\* Second section is about the move to care housing.*

*\* Third section about R's life in care housing now - most important part*

*\* I'll need to look at the questionnaire to remind myself where we've got to: I'll also need to keep notes as we go through.*

#### Some details about yourself:

- What is your current occupation?
- What is your date of birth?
- Relationship to R?

## SECTION ONE: ABOUT R BEFORE THE MEMORY PROBLEMS BEGAN

*\* Can think of this as starting the story of R's life before he/she moved to c/h*

- What did R do during for most of his / her adult life ?

*If R had paid work for most of life;*

- What was the last job R had?
- Why did R stop working?
- When was that?

*If R married:*

- What did R's partner do?

- Did R study at all after he/she left school?

*If yes:*

- What did he/she study?

• Now, if you were asked to describe R (before the memory problems began) in a few words, what would be the important things to say?

- Personality
- Ethnicity
- Physical health
- Religion (denomination)
- Particular hobbies or interests
- Pets

### About the communities where R has lived

- What areas has R lived most of his/her life?
- Can you say what sort of area or community R likes to live in?

### **Thinking about the accommodation that R is used to:**

- Where did R stay just before he/she moved to care housing?
- How long had R been there?

*If this was temporary accommodation trace back where lived before.*

- Lived alone?
- What rooms did ---x--- have?
- Describe it as a flat, house or how?
- Who owned the property?

- Did anything make it hard for your relative to live here?

- Access could have been better (eg top floor, steps)
- It did not have all the amenities that were needed
- It could have had a better design
- The locality could have been better



## Your relative's way of life

*\* It is helpful to know something about what kind of lifestyle your relative is used to, before he/she moved to care housing.*

*\* Thinking about latterly, around the time or just before the memory problems began.*

- Could you describe what R would have done on an ordinary day at home?
  - Time of rising and sleeping
  - Mealtimes
  - Getting out and about
  - Socialising
- Could you, in just a few words, say whether you think R was content with his/her life?
- Is there anything else that you think it is important for the people who look after R to know about his/her life before memory problems began?
  - Anything that R did not like to do?

## About the people that are important to R at the present time

- If we think now about the people who R knows, can we start by sketching out the immediate family links:
  - siblings
  - spouse
  - children,
  - grandchildren
- Which -if any- of the immediate family keep in touch with R now?
- Are there any more distant relatives who keep in touch with R now?
- Are there any friends or neighbours who keep in touch with R?
- For those who keep in touch, where does each live.

## SECTION TWO: ABOUT THE MOVE TO CARE HOUSING

\* Now talking about after it became clear that R had memory problems

\* Want to find out how it came about that R moved to c/h

### 2.1 Things leading up to the move

• Just before R moved to c/h (or any temporary accommodation or from of long stay care), what was situation at home?

- informal care
- formal care

• What lead up to the move to c/h?

- what made a move necessary
- were any alternatives considered
- were any alternatives tried out

• In your opinion, what would have been the ideal option at this point?

### Expectations

\* Now thinking specifically about care housing

\* Thinking back to before the move:

• What did you think care housing could offer?

- self
- R

• Did you have any worries or reservations about the move?

### The move itself

• When did R move to care housing?

• Were you involved in the move? If so, what did you do?

• Can you say how R felt about the move?

- What this opinion is based on
- Whether R was consulted
- Whether R moved willingly

• What are the financial consequences of R living in c/h?

- Are these advantageous or disadvantageous for R?
- For yourself?



• **Did R take any of these things with him/her?**

Ω Clothes

Ω Furniture

Ω Linens

Ω Crockery

Ω Ornaments and pictures

Ω Electrical equipment

Ω Personal belongings, eg photos

Ω Other: if so what?

---

• **Did anything important have to be left behind?**

Ω No

Ω Yes: What was this?

---

## SECTION THREE: ABOUT R'S LIFE IN CARE HOUSING NOW

*\* Thinking about now, with R settled in C/H:*

- From your experience of c/h, can you say how it compares to other care settings that R might have moved to?

### About your contact with R now

- What do you do with or for R now?
  - Care-giving
  - phone
  - letter
  - visits
  - outings
- Has this changed since he/she moved to c/h?
- Does the contact you have with R feel about right?
- Can you describe what happened the last time you went to visit R?

### About quality of life generally

- Has c/h offered what you hoped for, firstly from your own point of view?
- And secondly what was hoped for from R's point of view?
- Overall do think being in c/h has made any difference to R's quality of life?
- In your opinion, has R changed since he/she moved to c/h? Physically? Mentally? Is there anything that stands out to mention?
- Can you say how R perceives living in c/h?
- Does R tell you if he/she is content or not, living in c/h?
- Is there any other way you know if R is content or not, living in c/h?
- Does c/h feel homely to you?

### The future

- Where do you think the right place for R is at the moment: care housing or somewhere else?
- What do you see happening in the future: for example do you see R staying in c/h?
- Have you discussed this with the staff at all?



## **RELATIVES INTERVIEW SHEET: QUALITY OF LIFE**

**1. Can you tell me about the physical care that your relative gets in care housing:**

- Does anything need to be different about physical care?
- What might need to be different?

**2. Next I want to ask about your relative being able to choose to do what he/she likes:**

- Does anything need to be different about R being able to do what he/she likes?
- What might need to be different?

**3. What about those times when your relative has feelings to express and needs to be understood:**

- Does anything need to be different about expressing feelings?
- What might need to be different?

**4. And what about the place itself, as somewhere to live:**

- Does anything need to be different about the place itself?
- What might need to be different?

**5. Just thinking about the place in a slightly different way, do you now feel you know enough about how things are run in c/h and have enough say?**

- Does anything need to be different about how the place is run?
- What might need to be different?

**6. Can you say how easy it is for your relative to make links, between the past and the present; between care housing and the community?**

- Does anything need to be different about making links?
- What might need to be different?

**7. What does it feel like in the house to you?**

- Does anything need to be different about how the place feels?
- What might need to be different?

**8. Are there any other topics that you think are important?**

- Please tell me what these topics are and how much needs to be different?

## Appendix Four: Standard letters sent to kin

### Appendix 4.1. Letter forwarded by project managers

#### Study of specialist housing projects

Dear \_\_\_\_\_ ,

This letter has been forwarded to you by \_\_\_\_\_ who has given her support to this research project.

Because of your connection with the project in \_\_\_\_\_, you have information and experience that would help me get a broader view of the project. I am therefore writing to ask if you would be prepared to be interviewed by me at some point over the winter months.

I hope very much that you will feel able to help with the research. I also would like to talk to staff about the help they give your relative. During the spring I hope to spend some time in \_\_\_\_\_ to find out more about what it is like to live and work there. I will at all points respect the privacy and confidentiality of people taking part in the study. The information I collect will be used to write up a thesis. I will not name the project itself nor any individuals taking part in the study, and the information collected will only be used for research purposes.

If you have any questions about the study, either concerning yourself or your relative, I would be very happy to discuss it further with you. You can get in touch with me at the address given at the top of the letter.

If you are willing to help, I would be very grateful if you could complete the form attached and return it to me in the stamped addressed envelope enclosed. I would then contact you to make an appointment for interview.

Yours etc.



## Appendix 4.2 Letter sent to kin volunteering for interview

### Study of specialist housing projects

Dear \_\_\_\_\_ ,

Thank you very much for replying to my letter asking for your help with the research into the care housing project at \_\_\_\_\_. I am now writing to give you some more information.

The research is about what makes for good quality of care in places like \_\_\_\_\_ and how this new project is working out in practice. I would like to meet for an interview so that I can learn more about your contact with the project. I am also interested in what lead up to the move to \_\_\_\_\_ and how well you think it suits your relative.

I will treat anything you tell me as confidential. If you agree, I would like to tape-record the interview, just for my own use, in order to save time during the interview. I will use the information you give to pool together different views and experiences of this kind of project. I will not identify who gave what information when I write my thesis.

Perhaps you could think about when you could spare an hour or two to meet. I will phone you over the next few days, and we can decide to meet, and where would be most suitable..

Once again, thank you very much for offering your help with this. I would be happy to answer any other questions you may have about the research.

Yours etc.

## Appendix 4.3

Letter sent at discretion of project manager in preparation for observation.

### Study of specialist housing projects

Dear carer,

I am a research student, based at the Dementia Services Development Centre, looking at care housing projects for people with dementia. \_\_\_\_\_ is one of three case studies, and, as you may already be aware, I have been collecting information from people who have been connected to it over the past 18 months.

The research will enable people outside the project to learn about this way of looking after people with dementia. Units like this have attracted a lot of interest because they may be a model for the future.

This letter has been forwarded to you by \_\_\_\_\_. Throughout, I have discussed with staff what is the best way to approach the collection of information. One important point that we are agreed on, is that the data is collected in confidence: this means that the research will be written up without identifying individuals involved or the name of the unit. Another important point is that the rights of the residents of \_\_\_\_\_ are fully respected in terms of privacy and dignity.

I write now because the most intensive stage of data collection is under way at the moment. I thought it might be helpful to let you know this, so you are not surprised if the staff mention it, or if you meet me should we be both be visiting the unit at the same time.

Unfortunately it is too soon to report on findings, but if you would like to know more about what I am doing, please do not hesitate to get in touch.

Yours etc.



**GUIDANCE NOTES: STAFF INTERVIEWS**

**SPECIALIST HOUSING PROJECT FOR PEOPLE WITH DEMENTIA**

This is an interview which gives you the opportunity to raise what you believe are the most important things for me to know about the care housing projects. Thank you very much for your help with this. You have important experience with which to understand care housing better.

- The topic list is a framework to help me learn from your personal experience of working in the unit. You might not have experience or views on every topic: if this is the case, we can just move to the next question.

- It is very helpful if you use examples to illustrate what you are saying.

I would like to make notes during the interview, and if you have no objection, back this up with a tape recording. After the interview, if you wish, you can have a copy of my notes to check through. I regard what you say as confidential, which means that I shall not quote you to your colleagues or anyone else.

I will use the material you give, for example to write up short case studies, and to think how it fits in with the other information that I have collected. If I quote what you have said, I will make sure it is not identified with you personally.

**Topic list**

- Your involvement with the project
- About your work here, how things work out in practice
  - \* the people that live here
  - \* what happens over time
  - \* this being someone's home
  - \* people living together
  - \* the activities that people do
  - \* keeping independent
  - \* friends and families
- How things work out for the different people connected to it:
  - \* residents
  - \* relatives
  - \* staff
  - \* agencies who fund and/or manage it
  - \* anyone else?
- A little more about your job

## STAFF INTERVIEWS: TOPIC LIST

### Your involvement with the project

- When did you start working here?
- What made you apply to work here?
- What experience or skills do you think are useful to your work here?

*What do you draw upon to work here?*

### Taking an overview of the unit:

- In your experience, how does this unit compare with other places where the residents might have been living? What / how?

*?: Could you tell me more about the differences?*

Thinking about things work out in practice overall, thinking about both the plusses and minuses.

- How do things work out for people with dementia living here?  
Plusses / minuses?
- How do things work out for relatives of people living here?  
Plusses / minuses?
- How do things work out for staff?  
Plusses / minuses?
- How do things work in relation to the agencies who fund and/or manage the unit?  
Plusses / minuses?
- Is there anyone I have left out, who may be affected by or helped by the unit?
- Is there anything that would make a significant difference to the quality of care that you can provide here?
- Is there anything else you think its important for me to understand about how care housing works for the people who live here?



## **About your work here and how things work out in practice for the residents**

### **About the people that live here**

Thinking about residents of the unit:

- Can you say what makes someone fit in well?

*Who do you think was a good referral?*

- And is there anything that makes it difficult for someone to fit in here?

*Have you had any bad referrals? or was there anyone for whom it has not worked out, living here?*

### **About what happens over time, after people move in.**

- What changes have you seen in residents you have cared for in the unit?
- Is there anything that makes it difficult for you to continue to support someone living here?
- Has there been a time when you could support someone here until they died?

### **About this being someone's home**

- In what ways do you try to make it homely for people who live here?
- Is there anything that makes it difficult to make it home-like for the people who live here?

### **About people living together**

- First, how do residents get on with each other?

These are specific issues about how they interact with each other.

- Do residents think of each other as friends / family / neighbours?
- Are there ever any disputes? If so, what happens?
- How does the gender mix work out?
- How do they get on with each other when some residents are more severely affected than others?
- What happens if residents come from different social backgrounds?

## **About the activities that people do while they are here**

- For residents, what are the main activities they take part in, living here?
- Would you say that residents use the unit as though it was their own home?
  - personal care - bathing and dressing
  - household activities- cooking, eating meals, shopping, laundry
  - personal household activities - own finances, cleaning own room
  - socially - having visitors, going out
- Is there anything that would make a significant difference to the activities residents do?

## **About keeping as independent as possible**

Accepting that residents have dementia:

- What are the ways in which you can help residents keep independent?
- Is there anything that makes it difficult to help residents remain independent?

## **Friends and families**

- Can you give me an example of what you think is a good relationship between residents and their family or friends?
- Have there been any occasions when the relationship was not so good?
- Thinking about staff, can you say what makes for a good relationship with relatives?
- And have there been any occasions when the relationship was not so good?



## **About your job**

- Is there anything that would help you do your job better?
- Is there anything about your job that you particularly enjoy?
- Is there anything about the work that you find hard to handle?
- Is there any aspect of your job that you find inappropriate for you to be doing?
- Is there anything else that you think would make a significant difference to your job here?
- Anything else that you think it is important for me to know about working here?

**THANK YOU VERY MUCH**

# Specialist Housing for People with Dementia

## Questionnaire for all staff

Thank you very much for agreeing to help with this questionnaire. It will help to give a profile of the staff group working in care units for people with dementia. This will not, of course, identify individual care staff, nor the name of the unit you work in.

It does not take long to fill out. Most questions have boxes for you to tick, but sometimes you need to write a few words.

There is an envelope provided for you to put this questionnaire in. I shall collect it from your unit on a date to be arranged.

If you have any questions or difficulties, please do get in touch.

*Kate Foster*  
*Research Student*  
*Dementia Services Development Centre*  
*Stirling University*  
*Stirling FK9 4LA*  
*Tel 0786 467740*



**First some facts about you:**

• Sex (*Please circle*): Female  Male

• Age (*Please tick which applies*)

- Under 21....
- 21-30 .....
- 31- 40.....
- 41- 50.....
- 51-60.....
- 60+.....

**Now some questions about your job**

• What is your job title?

*Please write in* \_\_\_\_\_

• How many hours per week are you usually employed in this job?  
(Not counting overtime.)

*Please write in* \_\_\_\_\_

• Do the hours that you work suit you?

Yes  No

What makes you say this, about the hours that you work?

*Please write in your answer.*

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• When did you start working here?

*Please write in month and year* \_\_\_\_\_

- Thinking about the training you have had for this job, are you:

*Please tick the answer that applies to you*

- Very satisfied
- Satisfied
- Dissatisfied
- Very dissatisfied

- What makes you say this, about the training you have had ?

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- Thinking about the supervision you get in this job, are you:

*Please tick the answer that applies to you*

- Very satisfied
- Satisfied
- Dissatisfied
- Very dissatisfied

- What makes you say this, about the supervision you get?

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## Appendix Six: Coding categories used in analysis of interview data

### Appendix 6.1. Coding categories: semi-structured interviews to kin

**ACTS:** Includes activities that resident did before and after move - sub-divided 'pre' or 'now'. 'Pre' includes ordinary day at home, and ways time was spent. 'Now' includes activities daily living, housework, leisure and going out.

**COMPARISONS :** What did relatives think were the alternatives (if any) to care housing for the resident? Did they view care housing comparatively positively or negatively? In what respects? What did they have prior experience of? [Direct / indirect]

**CHANGE :** Any observed changes in resident after moving to care housing. May be physical, mental, or other well-being.

**BIOGRAPHY:** Occupation, education, marriage and family, house and place where has lived, personality, religion, health problems.

**FUTURE:** What were the hopes for the future? Had the possibility of moving from care housing been considered? Had this been discussed with staff, resident or relative?

**GROUP:** Reference to interactions and relationship with one or more other residents. Including sharing bedrooms.

**HOME:** Specific reference to care housing as 'home', or to general concepts of homeliness. Also includes where resident perceives themselves to be at home - perhaps outwith care housing.

**HOPES:** what did the relative hope for with the move, both for themselves and for the resident. Any evidence of what the resident themselves hoped for? Also includes worries, both in the past and present, and satisfaction with how care housing has worked out.

**KONTAKT:** Who: the family and friends now in touch, and their relationship.  
Visits: reports of visits to care housing

**LEAD UP:** The onset of dementia, and health status prior to the move. Circumstances that lead up to admission. Support received prior. The process of referral.

*MOVE:* kontakt immediately prior and during the move - their role. The trial period and assessment. The possessions taken with the resident.

*PLACE:* Views and comments about the location, and about the layout, decor, equipment and use of space.

*STAFF / REGIME:* References to what the staff were trying to achieve, and how they set about it, and the pattern of life in care housing.

*WELL-BEING:* Expression of autonomy, choice, independence and individuality. Security and restraint. Respect of personhood and malignant interactions as described by Kitwood.



## Appendix 6.2. Coding categories: semi-structured interviews to staff

**ACTIVITIES** : activities of daily living, housework, leisure and going out.

**AGENCIES**: References to their own external managers or developing / managing agencies.

**CHANGE**: Any observed changes in resident after move - physical, mental, other well-being.

**COMPARISON**: What did the staff compare care housing to? Differences to where have previously worked? Differences to other forms of care? What was their experience of these other places? In what ways was care housing thought to offer advantages? disadvantages?

**COMMUNITY** References to neighbours - attitudes to people with dementia.

**GROUP** Interactions with other residents and staff: regard for each other; disputes; gender and sexuality; differing degree of impairment; social class and background.

**HOME**: specific reference to care housing as 'home', or to general concepts of homeliness. Also includes where resident perceives themselves to be at home - perhaps outwith care housing. The ways in which staff try to make it homely.

**HOME FOR LIFE**: Reference to what enables or inhibits providing a home for life. Case studies of people who had to move, or stayed until they died.

**HOPES**: Views of how care housing has worked out for residents, relatives and staff. Any other reference to what care housing aims or succeeds in doing. Includes aims, reservations, and failure, and any expression of satisfaction. Includes what would like to do.

### **KONTAKT**

- who residents were in contact with, and reported changes
- the relationships with relatives: prior relationships and the impact of dementia
- maintaining relationships in care housing: what did relatives do: participation in care
- Visits: reports of visits
- contact with staff - including relatives group

*MEALS*: reference to eating meals and their preparation.

*MOVE*: reference to the move in, the trial period and assessment. The possessions taken with the resident.

*PLACE*: the location, layout, decor, equipment and use of space. Includes use of space by visitors; influence of activities by physical design.

*STAFF JOB*: staffing and management structure; staffing qualifications and previous work - including informal caring that they have done; training and supervision; own comments on job; composition of job.

*STAFF STRATEGIES*: A catch-all for the ways that staff attempt to implement the aims of care housing. Overlap with hopes but is specifically to do with what they, the staff, do. Includes of course barriers to success, and what promotes success.

*SUIT*: who suited living in care housing- views of staff and managers.

*WELL-BEING*: expression of autonomy, choice, independence and individuality. Security and restraint. Respect of personhood and malignant interactions as described by Kitwood.



