



Brighter Futures

**A REPORT ON RESEARCH INTO PROVISION
FOR PERSONS WITH DEMENTIA IN
RESIDENTIAL HOMES, NURSING HOMES
AND SHELTERED HOUSING**

**BY
TOM KITWOOD
SEAN BUCKLAND
TRACY PETRE**





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ABOUT BRADFORD DEMENTIA GROUP

The prime aim of the Group is to promote the well-being of all persons who have a dementing condition, whether they are being cared for at home or in formal settings. This aim is fulfilled currently through applied research, training, community support work and service evaluation and development. The Group has also produced a wide range of publications.

ABOUT THE AUTHORS

Tom Kitwood is Leader of Bradford Dementia Group, and Senior Lecturer in Psychology at the University of Bradford. He has wide experience in working with people who have dementia and their family carers. He has also carried out a great deal of research related to dementia care. He is the author of numerous publications related to dementia.

Sean Buckland is a research psychologist with Bradford Dementia Group. He was previously employed in Portsmouth as an assistant psychologist working with persons with dementia in long stay hospital settings. Whilst carrying out this research he has developed his work to include staff training, development and research supervision. His interests include research and interventions in severe dementia, quality assurance and community work.

Tracy Petre is a research psychologist with Bradford Dementia Group, having previously completed her degree in psychology at the University of Central Lancashire. Whilst carrying out this research she has developed a training course on dementia for wardens. Her interests include housing and community care of older people. She has also had a major part to play in training people in the method of Dementia Care Mapping.

TRACY PETRE

Since the time that this Report went to press, a tragic event has occurred. Tracy Petre, who carried out the research on Sheltered Housing, died on November 15, from a sudden and severe attack of meningitis. She was coming up to 24 years old.

Her contribution to the Report will stand as a memorial to her commitment to working for a brighter future for people with dementia. She had the energy and skill to carry out a difficult piece of research, and the courage to challenge the conventional view that there is no proper place for people with dementia in sheltered housing. Many wardens will remember times of encouragement from being with her, either in personal meetings or at one of her training events. In the two and a half years of her work with Bradford Dementia Group she made a notable contribution to the cause of human well-being. We will miss her greatly, and mourn her loss.

Tom Kitwood, Sean Buckland, Bradford Dementia Group
Alison Johnson, Methodist Home for the Aged '
Roger Sykes, Anchor Housing Association

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Note

The examples given on pages 35-38 and 63-65 are entirely fictional, drawing on features found in a variety of settings. They are given for illustrative purposes only.

Tom Kitwood
Sean Buckland
Tracy Petre

PART 1: BACKGROUND TO THE RESEARCH

This is a time when, as never before, the needs of those who have dementia have become a matter of serious and general concern. It is clear now that the old culture of care was often ignorant and heartless; many people were sentenced to a futile and loveless existence in their declining years, and deprived of the personal respect that is their birthright⁽¹⁾. Now, however, we are beginning to see dementia in a more positive light, and standards for care practice are rising.

Several factors have contributed to this new optimism. Perhaps the most important is that many new ways have been found, simply through trial and error, for promoting the well-being of those who have dementia - even when their mental disabilities are severe. Virtually all of these discoveries have been at a human level. They have not required the use of medication; indeed, they have often involved setting people free from drug regimes. In the last few years, also, good practice has begun to be enriched with a social-psychological understanding. This includes detailed research into what is happening to people with dementia in the course of their everyday lives: the nature of their needs, the pattern of their relationships, the way in which they can be enabled to exercise choice and create their actions⁽²⁾. In this whole approach the emphasis is on what people can do even when their mental powers are failing; traditional theory, in contrast, tended to focus on what they could not do, and on the disease process in the brain. The general verdict is that the older view, with its dreadful image of 'the death that leaves the body behind', was not justified. A great deal can be done to offset the disabilities of those who have dementia, and to enable them to remain as persons, in the fullest sense. In some instances long-term changes occur that can even be viewed in a positive light; something of the tragic aspect of dementia is lessened⁽³⁾.

The issue of care provision is an urgent one. As the population in societies such as ours has grown older, the total number of those with some form of dementing condition has risen steadily. In the United Kingdom now

the total number is probably between half and one million, and in around a third of these the condition may be severe⁽⁴⁾. By 2010 the overall numbers will almost certainly have risen further. There are many difficulties in obtaining accurate information, partly because of the different ways of diagnosing dementia⁽⁵⁾. Nevertheless, there is now considerable agreement on the figures. Social policy, associated with the NHS and Community Care Act of 1990, has moved towards enabling people to remain in their homes wherever possible, rather than taking them into long-stay care. There is much to commend in this, provided that care in the community is properly funded and delivered (which is certainly not the case at present). One consequence of these changes is that there will be more people with dementia in all 'formal' care settings: either those who can no longer manage on their own, or whose needs can no longer be met by family, friends and neighbours. Also, and rather against the original intentions, there will be increasing numbers of people with dementia in sheltered housing. It is vital, then, that we bring sound knowledge to bear on these issues. We need to know how to make good provision and how to plan for the next 10-20 years.

In all of this the non-profit making providers have a leading part to play. Already, of course, they have built up a rich stock of experience in providing different kinds of care, and this will prove to be of lasting value. They have, in addition, two special advantages. One is that they are able to operate in, and through, a clear commitment to human values. While finances have, of course, to be sound, policy need not be driven by the urge to produce large profits for shareholders. The second feature is there is less hindrance from a dead weight of tradition or bureaucratic regulation. Responses can be flexible and adaptive; there are fewer barriers to innovation.

This, then, is the background to the research reported here, whose funding was provided equally by Anchor Housing Association, Methodist Homes and Bradford Dementia Group.

The research consists of two parallel studies. The first relates to residential and nursing care. It focuses on the actual lives of some 132 persons with dementia, in 26 different care homes. Its aim is to describe, in as much detail as possible, the special combination of factors that is most likely to lead to good care, taking into account the great variety of personality and background. It is the most thorough study in this field that has ever been undertaken in Britain. The second piece of research concerns sheltered housing. It explores how 92 people with dementia are faring in 51 settings of this kind, and the effect of their presence upon other tenants and the wardens. So far as we know this topic has never been subject to research. Perhaps the

reason is that sheltered housing was not designed originally for persons with dementia; we have been overtaken by changes which were not foreseen, and must now explore the positive possibilities that they hold.

The gender and age-range of the persons involved in the two studies is shown in table 1 below.

Table 1: Distribution of ages for both residential and sheltered housing studies.

Age Band	Residential, Specialist and Nursing Care Study		Sheltered Housing Study		Total
	Women	Men	Women	Men	
63-69	1	4	1	0	6
70-76	9	5	1	1	16
77-83	36	11	35	5	85
84-90	37	5	35	8	85
91-97	19	4	7	1	31
98+	1	0	0	0	1
Total	103	29	79	13	224

Note. The division into 7-year age bands has proved convenient in other research (see ref. 29). By far the majority (64%) of the participants were in the age range 77-90 years.

One key concept in both studies is that of 'relative well-being'. In the old culture of care dementia was seen as a path of tragic loss. We can easily get this impression if we focus on such mental abilities as memory, orientation and planning. If, however, we try to see the whole person, and especially to recognise emotion, relationship and spirituality, the picture looks very different. There are certain clear signs when a person with dementia is in a state of relative well-being: for example showing pleasure, having concern for others, using humour, and being relaxed in body. Similarly, there are signs of relative ill-being. People vary in which signs they tend to show, according to their personality. The recognition of these signs is a central and innovative part of this research.

In both studies due attention was given to matters of ethics. Permission for inclusion in the research was obtained from the persons with dementia themselves, and from their close relatives. Great care has been taken to respect confidentiality. We have also tried, so far as possible, to ensure that carrying out the research has been of direct benefit to all who were involved.

Both studies come to optimistic conclusions, but with cautions too. It is

clear that many people can be enabled to cope far better with a dementing condition than would have been thought possible 10 years or so ago -provided that their needs are properly taken into account and that the care environment (in all its aspects) is of an appropriate kind. Above all else, both pieces of research tell us that it is the general quality of human relationships that is crucial, not the severity of the mental disabilities in individuals. Also, while it is important to have suitable architecture and physical environment, these can never be a substitute for skill and awareness in staff. As a result of these two studies, we now have a much clearer understanding of what to aim for, and of what to avoid. Some of the key points are summarized at the end of parts II and III respectively. The final section of this report draws some practical conclusions from the findings.

PART 2: DEMENTIA AND RESIDENTIAL CARE

INTRODUCTION

At present the term 'residential' covers a wide variety of settings. People with dementia may find themselves in a hospital ward, a nursing home, a specialist home, or a traditional residential home. There are a whole range of living arrangements within each of these settings. Few homes have identical designs, and even where similarity exists, the decoration and furniture arrangements may vary. However, while the issues relating to good design are still strongly contested amongst designers and researchers, they are not the main focus of this report.

The background to this research is the rising proportion of people with dementia living in all 'formal' care settings, and the implications of this for residential caring. On the whole, staff see themselves as 'care assistants' taking care of domestic and physical needs, while only a handful see themselves as 'dementia carers'. As the need for high quality dementia care grows, there needs to be a change of emphasis in carer role. Staff increasingly require a specialist set of attitudes and skills, attributes which are often undervalued and unrewarded.

In particular, this research draws from the works of Booth⁽⁹⁾, Kitwood and Bredin⁽²⁾, Moos and Lemke⁽⁷⁾ and Wilcocks et al.⁽⁶⁾. The research draws from the work of these authors, constructing a model of the situation of individuals with dementia, and observing them during the course of their everyday life. This research takes a practical look at the physical, social and individual factors that may relate to resident well-being. The aim, therefore, was to identify the important aspects of environment and individuality in which a person with dementia can continue to fare well.

METHODS

Residents' homes

In all, twenty-six homes were visited. The homes were split into three categories: mixed residential, nursing home and specialist dementia care. Mixed residential homes were defined as homes for the elderly registered by social services, where not more than half the residents had evidence of memory problems. Typically, there were 10-20% of residents with memory problems. Nursing homes were homes registered by the health authority; in these fewer than 80% of residents had evidence of memory problems. Specialist dementia care homes were either homes registered by health or social services; in these more than 80% of residents had evidence of memory problems. Table 2, below, also shows the distribution of homes according to type of ownership.

Table 2: Type and ownership of residents' homes

Ownership	Mixed residential	Nursing	Specialist dementia
Anchor housing	5	3	2
Methodist homes	9	0	1
Private*	4	0	2

* Half these homes were owned by private-chain organizations and the other half were directly managed by the owner.

Residents with dementia included in the study

Overall, 132 people with dementia, (103 female, 29 male), and their next of kin were included in the study. Participants were selected on the basis of several criteria. All had memory problems as their primary care need. The Mini-Mental State Examination⁽¹⁰⁾ was used to identify people considered to have severe cognitive impairment. All residents achieved a score of 10 or less on this scale. (A person without cognitive deficits would usually score around the maximum of 30.) Residents who had lived in the home for less than 3 months were excluded, as it was felt that a 'settling in period' was necessary. People under 65 were excluded, as were any who took any behaviour modifying medication which was prescribed for other medical conditions, such as schizophrenia or epilepsy.

Contact with next of kin

Next of kin were contacted for all residents. This was done by telephone in most cases, and next of kin were told about the study. They were asked if they

Table 3: Number, sex and cognitive ability of residents for each type of home

Mixed residential	Nursing		Specialist dementia		
Number of participants	61	(46%)	15	(11%)	56 (43%;
Mean age (range)	86	(68-99)	85	(78-93)	81 (67-96;
Proportion female	84%	87%	70%		
Cognitive ability (range)	6.3	(0-10)	-	1.9 (0-9)	0.3 (0-8)

had any objections to their relative or friend being involved, and also asked to fill in two forms about their kin, one relating to background, and the other to personality, (prior to onset of dementia). There were four next of kin (3%) who did not wish to be sent the forms. 66% of the forms were returned, of which 2% were not filled in at all.

Structure of the research

The research was designed to study the lives of people with dementia living in residential care. This took three main forms: observing people with dementia in the course of their lives, measuring social aspects of the home, and measuring physical aspects of the home. The measures were chosen to gather information about aspects of the care environment thought to have a direct effect on the experience of a person with dementia.

The aspects of life studied were categorised into six main sections. The first five of these covered the homes and care environment, and the specific measures used are listed in tables 4 and 5. Table 6 lists the measures which comprise the profile of each resident.

Observing well-being and ill-being

The term well-being is used extensively in health and organizational literature. It has, however, rarely been defined in any way beyond the scales used to measure it. There are two main exceptions to this. The first is the work of Bradburn⁽¹⁵⁾ who developed the ideas of well-being and ill-being in competition with each other, resulting in an "affect balance". This idea is also taken up as "resilience" by personality theorists⁽¹⁶⁾. The second is the more recent work by Kitwood^(2,17), who develops a theory of personhood and well-being in dementia care. He argues that the main aim of dementia care should be to maintain a relative state of well-being, giving far less weight to cognitive impairment.

The idea of well-being and ill-being can be illustrated using the image of "the fragile web of experience"⁽¹⁸⁾. People form strands of well-being through

Table 4

Section	Scale	Source/ Developed by	Ref	Variables	Completed by
Physical environment	Rating scale	Moos R & Lemke S(1992)	7	Physical attractiveness	Researcher rating
				Environmental diversity	Researcher rating
	Wilcocks survey	Wilcocks D et al. (1987)	6	Socio-recreational aids	Interview with senior
				Physical amenities	Interview with senior
			Architectural choice	Interview with senior	
			Space availability	Interview with senior	
Social and care environment	Rating scale	Moos R & Lemke S(1992)	7	Staff functioning	Researcher rating
				Resident functioning	Researcher rating
	SCES (Social and care environment scale)	Moos R & Lemke S (1992)	8	Cohesion	Researcher rating
				Conflict	Researcher rating
				Independence	Researcher rating
				Self-disclosure	Researcher rating
				Organization	Researcher rating
				Resident influence	Researcher rating
				Physical comfort	Researcher rating
	Wilcocks Survey	Wilcocks D et al. (1987)	6	Engagement	Interview with senior
Religious environment	Buckland S & Kitwood T (unpublished)		Religious environment	Interview with senior	
Dementia care Mapping		Kitwood T & Bredin K (1992)	11	Engagement	Researcher observation
				Variety of behaviour	Researcher observation
				Quality of social life	Researcher observation

Table 5

Section	Scale	Source/ Developed by	Ref	Variables	Completed by
Home policy and regime	POLIF (Policy and information scale)	Moos R & Lemke S (1992)	7	Acceptance of problem behaviour	Interview with senior
				Availability of socio-recreational activity	Interview with senior
	Wilcocks survey	Wilcocks D et al. (1987)	6	Resident oriented policy	Interview with senior
				Staff oriented policy	Interview with senior
				Privacy	Interview with senior
				Involvement	Interview with senior
	Institutional regimes questionnaire	Booth T (1985)	9	Choice	Interview with senior
				Segregation	Interview with senior
Participation				Interview with senior	
Privacy				Interview with senior	
Staff resources & morale	RESIF (Resident and staff information scale)	Moos R & Lemke S (1992)	7	Staff resources	Interview with senior
				Wilcocks survey	Wilcocks D et al. (1987)
		Job Satisfaction	Care Worker interview		
		Worry about work	Care worker Interview		
Provision For disability	Wilcocks survey	Wilcocks D Et al. (1987)		Prosthetic aids	Interview with senior
				Orientation aids	Interview with senior
				Safety Features	Interview with senior

Table 6

Section	Scale	Source/ Developed by	Ref	Variables	Completed by
Individual profile	BRS (Behaviour rating scale) - from the CAPE (Clifton Assessment Procedures for the Elderly)	Pattie A & Gilleard C (1979)	12	Physical dependency	Key worker interview
				Apathy	Key worker interview
				Communication problem	Key worker interview
				Social disruptiveness	Key worker interview
				Total dependency	Key worker interview
				Vision problems	Key worker interview
				Hearing problems	Key worker interview
				Outside contact	Key worker interview
				In home relationships	Key worker interview
				Relationships in residential care	Buckland S (1994) (unpublished)
WAIBS (Well and ill-being scales)	Buckland S & Kitwood T (unpublished)			Ill-being indicators	Researcher observation
				Global well-being	Researcher observation
				Global ill-being	Researcher observation
				Type of dementia	Medical notes and
Health & medical profile	Buckland S (unpublished)			Other diagnoses	Key worker interview
				Medication	
Abbreviated mental test	Jitapunkel S et al. (1991)	13		Cognitive score 1	Resident assessment
Mini-mental state examination	Folstein M et al. (1975)	10		Cognitive score 2	Resident assessment
NEO-FFI (NEO five Factor Inventory)	Costa P & McCrae R (1985)	14		Neuroticism	Key worker interview and parallel form in next of kin survey
				Extroversion	
				Openness	
				Agreeableness	
				Conscientiousness	
Biographical interview	Buckland S (unpublished)			Various qualitative	Next of kin survey

the course of their lives. These strands weave together into a web which catches difficult life events and experiences, and provides inner strength. Exceedingly traumatic experience, (too great for the web to catch), rips through and lies, unresolved, as a pile of "broken experience" beneath. It is possible to weave such damaged material into new strands through such processes as therapy and personal development. Both well-being and ill-being live side by side, and we need to be aware that a high level of one does not preclude a high level in the other.

For the purposes of this research, well-being and ill-being are precisely defined in terms of observations of specific behaviours. These behaviours are listed in table 7 below, and comprise the statistically significant items on the Well-and-Ill-Being Scales (WAIBS). The results from the WAIBS were used to predict overall levels of both well-being and ill-being. During the initial observations the researchers also made judgements about each person's overall levels of well-being and ill-being. These judgements were compared with the statistical predictions, and a high level of agreement was found, (around 80%). Under ideal circumstances, validity would have been better assessed by using other people's judgments of well-being and ill-being. However, under the practical constraints of completing the whole project, this approach to validity was the most appropriate.

Table 7: List of behaviours which predict well-being and ill-being

Well-being indicators	Ill-being indicators
Assertion of desire	Bodily tension
Initiating social contact	Physical discomfort and pain
Warmth and affection	Fear
Social sensitivity	Intense anger
Self-respect	Sorrow and loneliness
Helpfulness	Apathy, withdrawal and passivity
Humour	
Creativity and expressiveness	
Relaxation	

Observations of residents

Dementia care mapping (DCM) observations took place over a ten hour period from around 9am to 7pm. This is a method for making systematic observations of people with dementia in a communal setting⁽¹¹⁾. Every five minutes two pieces of information were recorded per person: the type of

behaviour, and the state of relative well-being or ill-being. This second observation is based on behavioural evidence of well-being or ill-being, and the nature of any social interaction taking place. At the end of the visit to the home the WAIBS was completed for each observed resident, detailing the different forms of well-being and ill-being each resident had shown.

A great deal of information is available through the dementia care mapping system. This study makes particular use of the "care value profile", which looks at the proportion of time a person spends in certain states. These states are briefly defined in table 8 below. Averaging a person's set of scores yields the "average quality of social life" measure discussed later.

Table 8: Definitions of scores used in the dementia care mapping tool

State	Description
+5	Used only when there is high quality social interaction, and 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, but no ill-being discernible, "well-being – alive but dying".
-1	Mild ill-being observable
-3	Moderate levels of ill-being observable, or continuous neglect of ill being for more than 30 minutes.
-5	Severe ill-being observable, or continuous neglect of ill-being for more than 60 minutes

FINDINGS RELATING TO WELL-BEING

The main findings relating to the measures affecting well-being are described in this section. They are described in an approximate order of statistical significance, with the most significant first. The specific details of the statistics are outlined in Appendix 1.

Social setting

One measure of particular importance is engagement⁽¹⁹⁾. This represents an active and conscious link with the world around. Slumped, half-asleep in a chair is not a state of engagement; on the other hand both reading and talking with another person are. A measure of engagement was derived from the DCM data. Counted as disengaged were categories such as sleeping, sitting doing nothing, unattended distress, wandering around aimlessly and fiddling with things without paying attention. Any form of purposeful action or interaction counted as engaged.

It is important to draw a distinction between engagement and 'doing activity'. All that is required for engagement is that the person's mind is consciously active, or mindful. This can be difficult to observe at times, and it is important, for example, to distinguish between a person looking bored or disinterested on the one hand, and paying attention, looking lost in thought or day-dreaming on the other. 'Doing activity' is often taken as getting a group of people together and everybody taking part in some activity, such as a game or handicraft. This approach is only one way of creating engagement, and is often insufficiently sensitive to be very successful at meeting individual need.

There has been a great deal of work to show that providing a structure and opportunity for interaction does create engagement in people with dementia of all levels of ability⁽²⁰⁾. It is therefore both possible and crucial that provision is made for a structured day, including planning for activity relating to individual need. When developing this programme, staff need to be sensitive to the normal need for people to have time out, by themselves. This need varies from person to person. However, those who prefer to be by themselves are still likely to benefit from being in a varied and stimulating environment. Some examples could include being able to watch others playing a game, having something to read, watch television, sit in the garden and so on, (depending on individual likes and dislikes). In all cases, however, it is important to avoid letting people withdraw into boredom or apathetic states. An example of this was found in some formal activity arrangements. If they went on too long, residents became bored, and switched off. This happened

most often when the facilitators held the activity, (and its successful completion), as more important than the relationship and social aspects.

Homes were most effective at providing a structured day when there was a member of staff with direct responsibility for the overall organization of the structure and opportunities for activity. This was especially so when that person had a strong commitment to spending time with people with dementia, and any activities were aimed at stimulating relationships. Prior organization led to a great deal more being achieved in terms of structure and interest. This planning enabled relevant people to make sure the necessary materials and space were available, and know what was expected. This does not mean that the day should be rigid; simply that people are prepared, and that momentum can be maintained.

More exciting and enjoyable days were observable where many of the people in the home were involved: staff, residents and visitors alike. However, it is important to remain clear that every person has different interests, and different social needs. To cater for this, staff need an awareness of each individual's preferences, and to give structure to the day. Activities should be chosen so that they neither go on too long, nor are too similar. Many of the people who were most engaged and confident in group settings were those who had received a good deal of one to one friendship from a group facilitator beforehand. This friendship building often had taken place over several months.

Cognitive ability

There were many examples of people faring well, despite having very damaged cognitive abilities. Well-being can be expressed in many different ways, according to level of cognitive ability; well-being is never taken away simply because of cognitive decline. However, there is a strong link between cognitive impairment and lower well-being. Since expression of well-being is possible regardless of cognitive ability, this suggests that those who are very severely impaired are less able to benefit from the style of care currently available. In order to allow residents choice and control over their own lives, current care styles often leave people to generate their own stimulation and interest. There is an assumption that residents would prefer to use the home as if it were an hotel. However those with very damaged cognitive abilities have lost much of their power for independent action, and therefore are as restricted as those who had to live in very institutional surroundings. The principal finding relating to cognitive ability is, therefore, that staff need to develop ways of enabling choice and control in people's lives, in a way which is

sensitive to individual ability. One primary feature of this 'positive choice' is having something to choose from.

Dependency

For those who have forms of physical dependency which isolate (e.g. visual impairment), there is an especial need for help in maintaining contact with the social world. A person who is isolated from social contact is deprived of nourishment for their well-being.

Personality

Well-being is specifically related to two dimensions of personality, openness and conscientiousness. Perhaps surprisingly, extraversion was not a factor influencing either well-being and ill-being.

The person who is open to new experiences is better able to fare well with their changing and confusing circumstances. Those who are less open require the time and patience of others around them when dealing with change. For people who are closed to change, a structured and purposeful day is likely to be particularly important in maintaining well-being. Figure 1 below shows levels of openness and the proportion of people at each level. It is clear that only a few are "highly open", thus showing many need encouragement and individualised structure to the day.

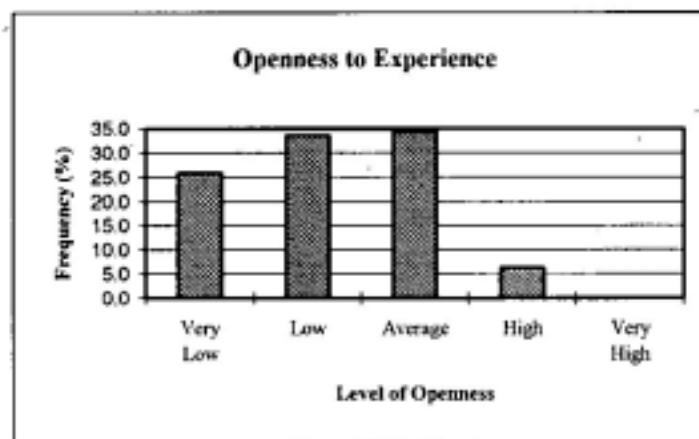


Figure 1

Conscientiousness reflects a person's "get up and go", their commitment and sense of responsibility. All of these are important in developing an individual and meaningful life within the home community. Figure 2 illustrates how few people have high levels of conscientiousness, and those who do, are sometimes viewed by staff as interfering, and troublesome.

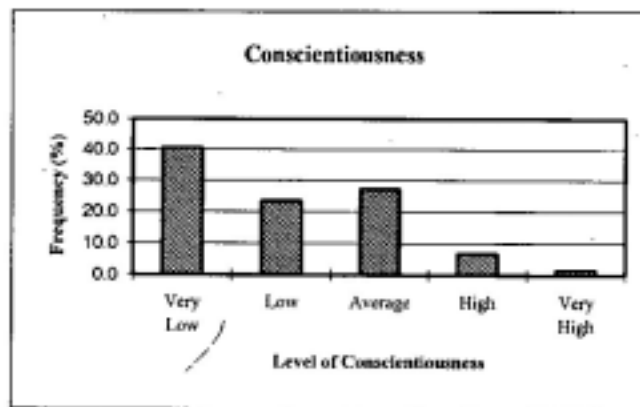


Figure 2

Relationships

Residents who were in close and regular daily contact with other residents had significantly higher levels of well-being than those who had only superficial relationships, (see Appendix I). Such contact was better than casual contact, regardless of whether it was close friendship or animosity. It seems, therefore that the crucial factor in maintaining well-being, is for people to have relationships which are felt to be significantly supporting. People who do not have such relationships need help in developing them, by staff and others.

Having someone close significantly increases the quality of a residents social life, (as measured by the DCM, see Appendix 1). Good relationships between residents are extremely effective in helping people have more sociable and enjoyable days. Encouraging people to form good relationships helps to create a setting in which well-being flourishes.

Quality of social contact

This research suggests that people who have any social contact, regardless of its quality, fare better than those who are isolated and ignored. The relationship between proportion of time in a '+3' state and well-being, not surprisingly, shows that people do have higher well-being if the contact is good. People with dementia need frequent, respectful and interesting contact, though of course it depends on the individual as to exactly what works best. A dangerous state to look out for is when people are doing nothing, or being involved in a fairly minimal way, but there seems to be nothing wrong, ('+1' state). This state is "well-being, alive but dying". In short, where there is well-being present, it should be promoted as far as possible. Keeping the person engaged will help promote well-being a great deal. Moreover, if this can

include good quality social interaction, there is a strong chance that the person will maintain or improve in their level of well-being.

Staff

Most staff described themselves as being motivated by caring, and pay was rarely cited as a cause of either satisfaction or dissatisfaction. Homes which had staff who had a personal concern for their work had residents with higher levels of well-being. Several such staff described how they were committed to dementia care, and believed that something could be done for people with dementia. They were willing to learn new ways of caring.

Achieving a high level of commitment and willingness to learn requires a lot of effort. Most importantly the effort comes from each member of staff. This will only happen when there is motivation. Money was rarely named as a major cause of dissatisfaction; however feelings of being restricted at work and lack of support frequently were. Some staff held very high standards for their work and were anxious that they were not performing well enough. They felt they needed more support in finding out how they were doing, and opportunities for personal development.

By improving staff motivation and morale, we can improve the well-being of the residents. To achieve this increase, staff and managers need to focus their attention on the needs of the residents, and managers need to reward good person-centred care. Several approaches to this are now common: Care plans, for instance, encourage personal responsibility and help structure care and the achievement of goals. Another example is personal supervision, which although still viewed with suspicion by many, is increasingly valued by staff.

Much, much more is needed to improve the well-being and morale of staff. If residential settings are to offer a special kind of care for people with dementia, then there should be full recognition that it is the staff who will make them special. Senior staff and management have a vital role in developing staff and making the role of carer fun, interesting and rewarding. Obviously, senior staff and management have similar needs for encouragement and motivation.

Physical setting

The data show that measures of physical environment had little relationship with well-being. However, there was a very mild effect relating to the physical amenities measure. The inference is that homes which had facilities such as adequate and accessible toilets, and a decent laundry were more able to enhance the well-being of residents.

No precise measure of lounge size was taken. However, it was evident that the design of the lounge had a considerable effect on the atmosphere in the home. Many lounges were large and public, which hushed conversation and inhibited friendships. In these instances there was a strong pressure to conform to group pressures. A few lounges were too cramped or were awkward, so that residents sat at strange angles, or back to back. Apathy, lack of communication and anger were more common in this type of lounge. The lounges which 'felt best' were only large enough to take everybody sitting facing each other, and have space for wheelchair access. The feeling was like having several friends round to your house and filling the lounge to capacity, but so that no one was cramped. This became impractical after about twelve people. Small group living settings were often designed to achieve this, although they could be too cramped. Occasionally, large communal settings were creatively arranged to create the small, friendly lounge feel.

FINDINGS RELATED TO ILL-BEING

This section, like the well-being section preceding, lists the conditions found to relate to the measure of ill-being. Again the findings are listed in an approximate order of statistical significance, and the actual results may be found in Appendix 1.

Social setting

One of the most important factors which led to increased ill-being was for people to be left unattended, showing signs of ill-being, for long periods of time. This lack of attention, once over thirty minutes, very significantly contributed toward a high state of ill-being. Apathy and loneliness were the most common forms of ill-being observable in those who were left unattended. These findings reinforce the need for frequent individual contact; a guideline would be at least every half hour, with a review to see if some change of activity would be beneficial. Well planned structuring of an individual's day should enable this to happen.

Some homes had a great deal of conflict and mutual disrespect amongst the residents. The statistics listed in Appendix 1 show that any strong relationships, good or poor will help promote well-being. So, having a row with another resident is better than nothing, but it will promote ill-being too; whereas good social contact will only promote well-being. Often the people with dementia are blamed for causing anger and fights. A common staff response in this situation is to try and get the person with dementia to keep out of the way, and not bother people. This can lead to difficulty in avoiding potential future conflict between the residents. Helping other residents to understand the person with dementia's inability to deal with certain situations could be a much more appropriate response. Promoting a good atmosphere and positive community is an essential part of minimizing ill-being.

Integration with the outside community helps keep ill-being to a minimum. Where there is integration, the home has a higher level of social interest and purpose; the residents feel less trapped, apathetic and abandoned.

There was less ill-being present when residents, as a whole, had more control and influence in the running of their home. The sense of being in control helped them deal with difficult emotional events, and feel more independent and able.

Home policies which encourage staff to leave residents to their own devices should be applied cautiously. It may be helpful to think in terms of two broad categories of people who would rather not be involved. The first are

those who like to be in the background of social situations. Such people often prefer to be able to watch interesting things happening. The second group are those who feel too unsafe to join in. This is often, in part, because the atmosphere is insufficiently welcoming and supportive. Staff need to develop skills in facilitating choice. Problems arise when staff offer too much choice, or use complicated language which further confuses the person. Also, each choice needs to be backed up by sufficient support to enable the person to carry out an action. In other words, the person with dementia can only make proper choices after their disabilities have been accounted for through the skill of the staff. Therefore, each person should be considered on an individual basis, and allowance made for differing social contact and dependency needs.

Dependency

Individual dependency varies greatly, and has a direct effect on the extent to which people can generate their own quality of social life. Physical dependency can be extremely crippling, and loss of sight, hearing and language places the individual at great risk of isolation, potentially leading to extreme anger, or withdrawal and despair.

Typically those who are extremely emotionally dependent, (that is needing emotional support from others), become alienated. This is often because others around them become intolerant. Staff intervention frequently takes the form of disaster limitation, keeping the person safe from physical harm. Emotional dependency is often the most reducible of the forms of dependency, but it is also the most time consuming.

Cognitive decline varies greatly in how it affects people. In general, the greater the loss of intellectual ability, the more dependent the person is on others to generate their quality of life. Whatever the nature of the dependency, the role of the staff and those around is to compensate for that dependency so that the person is living at their highest level of independence.

Personality

Neuroticism, agreeableness and conscientiousness were three dimensions of personality which discriminated well between high and low ill-being:

Neuroticism is a tendency to view things in a negative way. People who have high neuroticism scores tend to be more anxious, but also more sensitive and emotional. When, however, there is a setting in which good relationships and support are provided, these people have a great deal to offer; they are able to transcend their state of need and support others.

Agreeableness is basically how easy to get on with, and easy going a person is. Those who are easy to get on with tend to fare better in residential

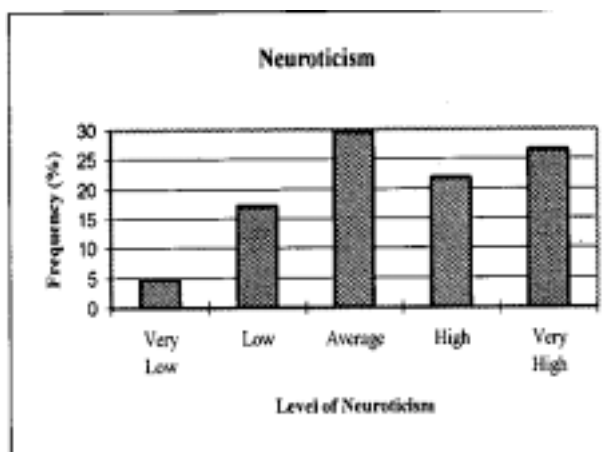


Figure 3

settings. People seen as 'disagreeable' are in fact those who are likely to manage and implement their own ideas⁽¹⁴⁾. In the residential setting, such people may find themselves in conflict with organizational rigidity with respect to staff and resident role. Accepting the needs for more control and a sense of responsibility may help reduce the ill-being of many 'disagreeable' people. For example, when arranging things to do, create opportunities for residents to take on some responsibility.

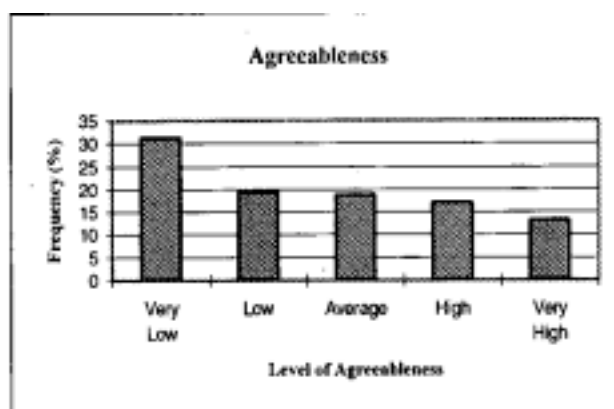


Figure 4

Conscientiousness was described above in the well-being section, and the distribution shown in figure 2. In the context of ill-being, the unconscientious person is at risk of sliding into a state of apathy, and may even want to! Such a person needs a great deal of motivating.

Relationships

The findings relating to relationships and ill-being are far from conclusive, however, by looking at the trends (see Appendix 1), some comment is

possible. The statistics suggest that lower levels of ill-being are found among those with good friendships with other residents. Those with frequent, poor quality contact with other residents are likely to have higher levels of ill-being. This finding is somewhat circular as well-being is likely help people develop friends, and ill-being can lead to interpersonal conflict.

The type of relationship a person has with their visitors may have some effect on their overall level of ill-being. Frequent, good quality contact will help promote well-being and minimize ill-being, albeit not significantly. Frequent, poor quality contact will promote ill-being to some extent. The recommendation is, therefore, for staff to promote maximum contact between residents and visitors, while helping with relationships which are distressing, (to the resident).

Staff

Higher levels of ill-being were observable where there was an emphasis on staff routines and procedures. Furthermore staff did not enjoy their work as much where these approaches were used. Where management encouraged staff to act flexibly and creatively in meeting the needs of residents, lower levels resident ill-being were observable, and staff had greater job satisfaction. One of the main difficulties staff encounter is in trying to meet the needs of residents, and finding themselves in conflict with the needs of routines and physical tasks. Many of these tasks were trivial and unimportant. This was mainly true for those staff who felt that spending time talking or being with residents was a very important part of their work.

Staff who lack confidence either personally or professionally often feel anxious in their work. This can lead leads to lack of action, sickness, avoidance of residents, and so on. Staff need to be supported in understanding that doing something, especially spending time talking to residents, is better than doing nothing, and that the main aim of their care is to develop good relationships. This approach requires commitment and a continuing willingness to improve. These attitudes are far more important than any formal training.

Physical setting

It is difficult to draw firm conclusions from the information relating to physical setting. This research, however, supports the view that physical design should be such as to enable independently living. Good lighting, easily accessible call systems, clearly marked toilets, etc. may all help to minimize ill-being.

GENERAL ISSUES

Personality

In a perfect world we would like all people have the opportunity to fare well in residential care, regardless of personality. However, at present this is not the case. Attempting to understand the needs of different personalities may help in achieving a more ideal situation. The findings listed above show how certain personality characteristics, and the impact of different approaches in relation to individual personalities, enable some to fare better than others. Some aspects of personality are associated with greater resilience to ill-being, This section gives the results of the analysis of the combined five personality dimensions. The aim is to find common 'personality portraits' of people with dementia living in residential care. These portraits allow us to look at common sets of personality characteristics, and to find out if there are any groups of people who fare particularly well or poorly.

Preliminary findings from this work have been published¹⁸, and are updated here to include more people, from a greater variety of homes. A total of 112 people's personality profiles were gathered from mixed and specialist settings, and cluster analyzed. Six personality profiles emerge from this research. They can be expressed simply in terms of their personality dimensions, (see Appendix 1). Here we will express them in a more concrete way, in terms of six imaginary people.

Personality profiles (most common first)

Profile 1: "Agnes"

Agnes tends to see the negative side of things. She is a bit nervy and emotional, easily distressed and yet caring of others. She is fairly passive and content to let life pass her by. She seems to have lost her sense of purpose, and requires encouragement to join in with others. Agnes has moderate levels of both well-being and ill-being. Her well-being really comes to the fore when she is with people she likes, who give her encouragement. However she is often left alone, and that is when she becomes anxious.

Profile 2: "James"

James on first view seems a bit like Agnes, moderately content and quietly letting the world pass by. He is however, very different. First, he is emotionally quite stable, and is not easily upset. He likes his routines, familiar surroundings, and is quite conventional. He is quite friendly and

helpful. The main problem for James is that, providing nothing seriously provokes him, he slips away becoming apathetic and withdrawn. What James really likes is having friends around, and things going on to watch. He likes join in just now and again, often with a joke or comment. While James has a low level of ill-being, he also requires frequent human contact and stimulation to maintain his well-being. James needs good quality, low key friendship, and encouragement to stay involved.

Profile 3: "Hilda"

Hilda is 'fighting the system'. She frequently gets upset and angry, few people like her and she tends to avoid human contact. She is stubborn about doing what she does, walking, cleaning, going home, and so on, and staff find her very hard to relate to. Hilda seems to be fighting battles within herself too. Both her well-being and ill-being are moderately high. She feels at her best when those around her help her feel independent, respected and in control. However, when she finds herself in conflict she gets angry and sometimes violent.

Profile 4: "Eve"

Eve is one of the few who are faring the worst. She is easily upset and often very anxious. She does make friends with other people, and does not like to do anything at all. Staff find that most people like Eve are very difficult to relate to, however Eve has a vulnerability about her, and staff find that she appreciates their attempts to help her feel safe. Most of the time Eve is withdrawn into herself, and closed to all around. For people like Eve, staff find that it takes a great deal of gentle and sensitive emotional support, often over several months to bring them out of their withdrawn state.

Profile 5: "Ellen"

Ellen is a 'happy socialite'. She is emotionally stable, highly outward going, gets on very well with people around her and is almost always active. Sadly there are not too many like Ellen. Her well-being is high, and her ill-being is low. While Ellen is among some of the easiest and fun people to work with, it is important that people like her are not taken for granted, and that their positive, strong personality is encouraged. Such people often carry a lot of the other residents along with them, and are a great asset to the home.

Profile 6: "Edgar"

Edgar is highly anxious, and is seen as very difficult to relate to, however he is also highly outward going. Staff often become exasperated with Edgar as he demands a lot of attention, and is not easily satisfied. It seems that

ideally he would like one-to-one support all the time. Eventually staff find themselves avoiding him or brushing him off to save time and the emotional stress of talking with him. Perhaps it is surprising then is that of all profiles, people similar to Edgar often have among the highest levels of well-being. This suggests that if staff were able to channel and adequately support their emotional energy, then people fitting this profile would be able to maintain very high levels of well-being, and be a great asset to the home.

These profiles are intended to help staff identify individual needs, and not to put on fixed labels. By finding which profile, (if any) a person most suits, staff have additional information in helping decide how to help the person achieve a fulfilling life within the home. At the same time this information will help identify risk areas. Of the six profiles 84% of the residents came from just three: profiles 1, 2 and 3. Profiles 1 and 3, (56%), represent people whose personalities suggest a trend towards increasing ill-being. The main two things preventing these people joining the people in profile 4 are their own inner strength, and the input of their care and environment. Their inner strength is most likely to maintain when the care and environment promotes their well-being, and helps minimize their ill-being. This may shed light on why traditional approaches failed its residents and patients; profile 4 describes the traditional end of the line for people with dementia. We constantly need to remind ourselves that without sustained, good quality care 56% of residents are at risk of becoming vegetated.

What of the other 28% of people who are in profile 2, and have on average fairly low levels of ill-being? With the right kind of setting and friendships their well-being could be promoted into the higher levels. Therefore, the majority of people are at risk of developing high levels of ill-being, but still have inner strengths which can be maintained and promoted. This gives the person the ability to help themselves emotionally, which will probably be the most effective remedy. The remaining people have low levels of ill-being, allowing for the relatively easy task of helping them live fulfilling and interesting lives.

Staffing levels

The proportion of direct care staff on duty to residents varied from home to home, and was largely determined by the type of registration. In a mixed residential home, where the greatest range in staffing levels occurred, the quality of social life experienced by the residents varied according to the

number of staff available. The highest and most consistent quality of social life in mixed settings was achieved when there were between 8 and 9 residents per member of staff, (staffing level is an average of the number of direct care staff on duty over the 9am to 7pm period). Where there were fewer staff, the quality of social life lowered and became more variable. Where there were higher levels of staff there was a great variety in quality of social life, from the very best to some of the worst. It was not possible to take a specific look at staffing levels in nursing or specialist settings due to the similarity of staffing levels. However, there was a great variety in the quality of social life in these settings, despite similar levels of cognitive and physical dependency.

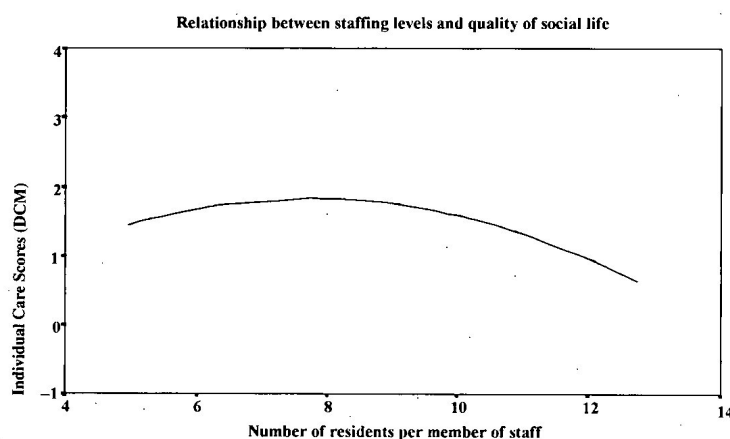


Figure 5

The main finding is that where there are more staff than necessary to achieve the basic levels of care, comfortably, there is a need for strong direction and leadership. Where these were not present the staff were unsure of what work needed doing, and more likely to believe that someone else was doing the work. Therefore, rather than just adding extra staff to improve care, the culture needs to be first oriented towards social care. Any extra staff need to come in with a clearly defined and supported role, with specific plans and goals for improving care, and individual residents' relative well-being.

Religion and spiritual needs

Religious ceremony has a great deal to offer people with dementia. The extent to which a person may benefit will, of course vary; it is rare, however, for

someone who is involved in a religious ritual seem to gain no benefit at all. These benefits exist in a full range of spiritual, personal, social, cognitive and physical facets. Beyond those things which are intangible, there are two main categories of benefit: security and companionship.

There are several forms of security available for the person with dementia who joins in a religious ritual. The first is the sense of familiarity. In a confused world, being part of a well-learned ritual can give respite from these feelings of confusion. In this situation the person with dementia knows what to expect, how to act, and so on. Security through faith is especially powerful for those who have spiritual faith. In other words, those who believe in God and continue to have a formal link with God may gain a sense of security through that link. This benefit helps promote the "basic trust"⁽²⁾, a feeling that, despite the many changes and difficulties in life - all will be well. A further form of security is that of continuation. The familiarity of practice, maintained over a period of time, means that the future will hold something predictable and safe.

The second main benefit, that of companionship, is available regardless of belief. Although in the case of religious ritual, the belief strengthens the sense of belonging. Without some belief on the part of some attendees other ways of promoting companionship would probably be more suitable. The religious ritual provides the opportunity for people to gather together and share. There is an expectation of kindness and community that can give a person with dementia a window into the social world of those around. Singing or praying together gives the sense of being with friends and being part of a group. These are two very important aspects for most people, and certainly help promote well-being. This form of companionship may be available elsewhere in homes where there is already a strong community atmosphere, but it is often, sadly, unavailable to many people with dementia.

Expression of personal faith was expressed in both positive and negative ways. On the negative side, some people were very distressed, crying out to God to help them. Others were very angry with God for placing them in their position. Some very religious people expressed their ill-being as despair or anger toward God. Most people in these situations still had reasonably good self-awareness, and were aware of their deficits. Some residents were observed receiving pastoral visits from clergy, or friends whom they recognised from their church community. These visits often seemed valuable and reassuring. On the other hand, one extreme example of ill-being in the religious context was that of a lady being told by ex-church friends that her dementia was a punishment from God. Needless to say she found this extremely distressing.

On the other hand, there were some who had what seemed to be absolute trust and faith in God. These people, regardless of their cognitive ability, tended to have positive attitudes about their lives and situations, and were often popular in the home.

There was almost no opportunity to look beyond the Christian context, and so these findings are best applied only to Christianity and English residential settings. There is, however, every reason to suppose that very similar considerations would apply to people of other faiths. Further research is needed on this topic.

Private and not-for-profit homes

This study included a total of 6 private homes, so obviously generalisations about the private sector are not possible. The homes that were included in this study had residents with equivalent levels of both well-being and ill-being in comparison with the not-for-profit homes. The variability of quality of care within the private sector is notorious. This study does show that where there is a high level of commitment to relationships and staff development the private sector is able to achieve a good quality of care. This applies to both mixed and specialist care.

Medication

It is interesting that there was no noticeable relationship between medication and either well-being or ill-being. Many homes had policies to keep medication to a minimum, and to take people off psychoactive and tranquilizing medication wherever possible. The majority of medication which was in use related to heart, urinary or arthritic conditions. It was fairly rare for people to be on psychoactive medication, especially during the day. High levels of well-being were observed in people with a whole range of cognitive impairment, and this challenges views that dementing conditions require the use of psychoactive and tranquilizing medication.

TWO EXAMPLES

The following two examples, Yellow Place and Blue Lodge are fictional examples, or caricatures of homes and observations relating to the care for people with dementia. Yellow Place represents the low end of care, where little care takes place and people are left to live or suffer as they will. It is characterised by a lack of concern for people, and rigid adherence to routines. However, it is important to realize that it is staffed by any normal group of staff. Blue Lodge has taken a different approach to care. Foremost is a commitment to the social nature of caring. Personal development of staff and residents is encouraged and expected, and the home is organized to facilitate people in having fun and interesting lives.

Yellow Place

Yellow Place is a large Victorian house, converted into a residential home, and set in quarter of an acre of land. The living areas are large and public, while bedrooms are burrowed away down long dark corridors. Toilets are cramped and difficult to find, and bathrooms are large with centrally placed baths for "all round access". The conservatory and spare lounge are full of stored furniture and wheelchairs, and are quite uninhabitable. Through the windows an uninteresting garden is visible, access to which is through a locked conservatory door, or through the front door which is also kept locked. The view from the upper storeys is restricted by tall hedges, and large trees.

The home is run on a strict hotel model, where the priorities include perfectly made beds by ten, 'prompt' service at meal times, and keeping up to date with the laundry. There is a common pool of clothing and bedding. There are set times at which residents are woken, helped to bed if necessary, given meals, and bathed. During the day, the residents are expected to live their own lives and organize their own entertainment, and no account is taken of each individual's ability to make choices. Residents are free to go on holidays or outings provided they, or a relative, make the arrangements. The staff, however, are discouraged from taking residents out from the home due to safety and staffing reasons. Contact with relatives is minimal and professional, and although the management recognizes that the relatives may need support, the staff do not have time to be counsellors to everyone. The staff believe that the relatives are interfering and creating more work, while the relatives feel like they are unwelcome and are a nuisance.

Many of the able residents sit around complaining about each other all day, and arguing; as a whole, they tend to see the negative side of things. They

seem to be more interested in telling people what to do, than doing anything themselves. One frustration for the staff is that the residents will never use the tape player or television; rather, they wait until a member of staff turns it on. Another frustration for the staff is in trying to make the lounge more sociable. Each time staff move the chairs from the edges of the lounge, the residents move them back, and complain bitterly about the interference.

There are a few people in the home with memory problems. In general they are shunned by the other residents, and get what little support they may from brief moments shared with staff. The staff see dementia as a sad and pitiable state, where nothing can be done and every "dementia" needs treating like a baby. The person is no longer considered as an individual and the notions of personality, quality of life and need for choice are forgotten, as they are thought to apply no longer. Some staff would like to spend more time with these people, but it would mean additional staff to keep up to date with all the duties. Also, other staff would be critical of them sitting around with residents.

The able residents tolerate the person with dementia, only if the dementia sufferer is quiet, does not move around, interfere too much, or keep repeating questions. However should that person become demanding, the residents get up in arms, gossip and cruelly isolate them. The manager is petitioned to have the sufferer moved out. One resident with memory problems has poor vision, and is entirely dependent on others for direction when going from place to place. Most of the time he is slumped asleep in his chair. However on occasions he gets up and urinates in the corner of the lounge. The residents want him out too. A couple of others with memory problems stay in their rooms all day, watching television, asleep or sitting alone. The staff encourage them to join in, but they refuse and become very anxious if moved down.

Blue Lodge

Blue Lodge is a large Victorian house, converted into a residential home, and set in quarter of an acre of land. There has been a great deal of conversion and decoration resulting in a light, open feel. The home conveys a feeling of spaciousness, and homeliness, and the decoration is warm and cheerful. The main lounge is small and intimate, allowing just enough space so that people are not cramped, and that a wheelchair may manoeuvre safely. There are plenty of windows allowing natural light in and giving a view over interesting and varied gardens containing a conservatory and garden seating. The gardens are secure and residents have free access to them. The home itself is well equipped with modern facilities including single rooms en suite, and clearly

labeled, spacious toilets that lie near to the lounge and dining areas. There are a few twin rooms for couples, or those who wish to share. There is a large laundry, as well as a smaller one for residents to use. Kitchenettes are available for residents to be involved in making meals or snack preparations, as they choose. The main kitchen lies next to the dining room to allow prompt receipt of meals. Most importantly there is a variety of easily accessible public spaces including a main lounge, dining area, quiet lounge with facilities for religious services, activity room with good storage and seating in the hall ways.

The residents with dementia have a clear structure to the day, but guided by their choice. They are able to get up and go to bed when they want, and have meals when and where they want. At least one member of staff is continually available to facilitate a variety of activities. These include one-to-one or group based activities such as physical exercise, craft, worship, music, cooking, gardening, socializing, intellectual stimulation, household chores, and relaxing. Other residents in the home have an active role in supporting this programme, and are themselves supported in developing the skills and attitudes necessary when working with people with dementia. Residents, (with or without dementia), who do not wish to take a direct part are able to stay and watch the goings on, or find their own things to do. Often, these people like to be somewhere near to other people, where there is plenty to watch. Many people lack the confidence to join an established group, and so careful one-to-one support is given, and people are made welcome if they do join in. One member of staff has responsibility for the overall organization of activity; this person has a deep personal commitment to dementia care. However, the work load is shared out among all the staff, residents and relatives who are interested in the care of people with dementia.

The residents are encouraged to explore and try out new things, to continue with old interests, and to make friends. Staying active through the day is important, but not necessarily in a physical sense, more in a mindful sense: the person is awake, aware and interested; they are not asleep, withdrawn, and uninterested. Where difficulties arise, the staff and relatives attempt to identify the nature of the problem and what may be causing it.

The home takes an active role in supporting the relatives and friends of their residents. Where possible, visitors are encouraged to join in and help as much as they can. A solid three-way partnership exists between relative, resident and staff, and everybody feels that they are a valuable member of a small community. People with dementia are viewed as needing a special type of emotional and physical support, which takes into account the great variety in personality, ability and dependency.

The home actively supports its staff. Members of staff are encouraged to develop their communication and interpersonal skills. Personal development is understood as necessary in achieving better quality dementia care, and job satisfaction is seen as important. Above all, an open attitude exists where staff freely discuss their feelings and ideas for the home.

SUMMARY POINTS

- Whatever the physical design of the home, make sure that the physical environment is varied and interesting.
- Make sure the garden has safe and easy access from the house, and that exits from the garden are secure.
- Make the lounge space cosy, informal and homely; encourage friendship and communication.
- Ensure facilities are available so that residents may continue to live independently.
- Especially for the dementia sufferers, have an individually planned, yet flexible structure to the whole day, every day.
- Ensure that there is at least one member of staff with responsibility for coordinating the structuring and organizing of each day.
- Ensure that all members of staff (who are interested in dementia care) spend time developing relationships with residents, and help provide a varied and interesting day.
- Be creative and encourage residents to explore and try out new things, if something works repeat it, and find out more things so that the person does not get bored. If something does not work, try something different, or try again in a different way.
- Be committed and willing to learn more, every day, not just "facts" but also about yourself.
- Stay active in developing opportunities for each person, rather than only responding to crises and things going wrong.
- Promote friendships between residents, relatives, staff and community.
- Provide maximum support for staff, in their care work, in training, in supervision, in time out and in enjoying their work.

CONCLUSIONS

This research has taken a broad overview of individuals with dementia in residential settings. It is clear from the findings that a whole range of personal and environmental influences combine to promote or minimize a person's well-being and ill-being. The discussion has focused on creating a balance in these influences so that each person may continue to fare well, and have their needs met in an appropriate way.

Residential care has a clear and crucial role to play in society's support for people with dementia. The staff of these settings, when given sufficient support and motivation, have a great opportunity to enable people with dementia to live fulfilling lives. The particular challenges in achieving this are for staff to develop the commitment and personal involvement of being a 'dementia carer'; to be creative and resourceful - never giving up; and to be responsive to the variety of individuals found in any residential setting.

PART III: Dementia AND SHELTERED HOUSING

INTRODUCTION

Current literature on sheltered housing provides no published work detailing research into the lives of tenants with dementia. This study, aimed to be the first to focus upon this important issue.

Major changes have occurred over recent years, both in the age structure of sheltered housing and in the form and availability of good alternative provision for older people. Using Anchor sheltered housing as an example, in 1984 only 10% of tenants were aged over 85 years, whereas by 1993 this figure had risen to 21%⁽²¹⁾. This is the age-group most likely to have dementia. Alongside this ageing tenant population the availability of local authority residential accommodation for those with extra care needs has declined under the government's community care policy⁽²²⁾. Increasingly sheltered housing is being discussed as a resource for those in greater need of support, rather than as a luxury for fit, newly retired people⁽²³⁻²⁴⁾. These factors have combined to create a situation where increasing numbers of those in the early stages of dementia move into sheltered housing, while decreasing numbers of those with developed dementia move on into full-time care. Consequently concern about the best way to move ahead has grown among those working in sheltered housing.

This study had four aims. The first was to examine whether there was any one clear indicator, for example a cognitive test score, which would show when a person with dementia was unable to be maintained in sheltered housing. The second was to investigate factors which affect the well-being of tenants with dementia, their wardens, and the other tenants in the scheme. The third was to look at three issues relevant to people with dementia living in the community, which are: having a spouse alive, ability to control finances and making use of community care resources. Finally, the research aimed to investigate the effect of training wardens about dementia. This looked at the effects both on the warden and consequently on the scheme.

METHODS

The study was conducted in fifty-one sheltered housing schemes throughout the Midlands and North of England. Forty-five of the schemes (88%) were owned by Anchor Housing Association, 5 schemes (10%) by Methodist Homes (50% of their schemes in the region covered), and 1 scheme (2%) by Hanover Housing.

Inclusion of participants

Wardens were asked to identify any tenant or tenants in their scheme who may have dementia. Each tenant suggested then participated in the mini-mental-state-examination, MMSE⁽¹⁰⁾. This scale assesses the person's orientation, registration, attention and calculation, recall and language abilities, resulting in a total score out of thirty. The authors of the scale have shown that a score under twenty reliably discriminates between those older people who do or do not have dementia. All tenants included in the study scored under twenty points correct. Table 9 shows the distribution of MMSE scores of the participants in the study.

Table 9: Distribution of MMSE scores

Under 10 correct	10-15 correct	15-20 correct
15%	39%	46%

Participants

Ninety-two tenants with dementia were included in the study. Table 10 gives information on the participants.

Table 10: Participants in the study

	MALE	FEMALE
Number in study (total 92)	13 (16%)	79 (84%)
Average age (range 69- 95 years)	84 years	83 years
total with spouse alive (total 12 - 13%)	7 (58%)	5 (42%)
average MMSE score (range 2 - 20 correct)	14.6	13.8

Measures

Table 11 gives information on each measure used in the study. These measures are divided into four categories. Three measures give specific information

about the tenant with dementia. Two measures investigate effects on the warden of having a person with dementia in the scheme. One measure investigates effects on a representative selection of other tenants. Finally, six measures investigate scheme specific factors that may have effects on a person with dementia.

Table 11: Measures used in the study

	Scale	Source/ Developed by	Ref	Completed by
Tenant with Dementia	Mini-mental-state Examination	Folstein, Folstein & McHugh 1975	10	Researcher rating
	Well-being scale	Bradford Dementia Group, 1994 (unpublished)		Warden rating
	Activities of daily living scale	Petre, 1994 (unpublished)		Warden rating
Warden	Ability to cope practically	Petre, 1994 (unpublished)		Warden rating
	Ability to cope emotionally	Petre, 1994 (unpublished)		Warden rating
Other Tenants	Disruption index	Petre, 1994 (unpublished)		Three tenant interviews
Scheme Factors	Number of social visitors	Petre, 1994 (unpublished)		Warden rating
	Warden's experience of dementia	Petre, 1994 (unpublished)		Warden rating
	Warden's social support	Petre, 1994 (unpublished)		Warden rating
	Warden's job satisfaction	Petre, 1994, based on Willcocksetal 1987	6	Warden rating
	Amount of home care	Petre, 1994 (unpublished)		Warden with main home carer
	Physical environment	Petre, 1994, based on Moos , 1984		Researcher with warden

Well-being in sheltered housing

A main question of this research was whether sheltered housing is a suitable environment in which people with dementia can live. Equal consideration needs to be given to three groups; those with dementia, the warden, and the remainder of the tenants. Each of these groups is equally important and each has a major impact on the lives of the others. Therefore, sheltered housing can only successfully accommodate those with dementia if, for each group of people, well-being can be maintained and problems solved. Four questionnaires were used to investigate the well-being and problems of each group.

1. **Well-being of tenants with dementia.** This was assessed each week for three weeks by their warden. A form listed ten behavioural states from which well-being can be inferred. The well-being indicators used were discussed in detail on pages 12 and 13 of this report. The warden was asked to indicate the frequency and intensity of each behaviour in their tenant with dementia over the preceding week.
2. **Warden's ability to cope practically.** This scale investigated any practical difficulties the warden had in coping with the behaviour of the tenant with dementia.
3. **Warden's ability to cope emotionally.** This scale investigated the presence of any emotional stress placed on the warden directly attributable to having the person with dementia in the scheme.
4. **Disruption index.** This investigated any problems caused to other tenants by the person with dementia. For each person with dementia three randomly chosen tenants were interviewed individually in their flat. Questions did not refer directly to the person with dementia, but did ask specifically about experience of problems typically expected in dementia. For example, tenants were asked whether they had ever been woken at night or bothered at their flat door, or whether they had experienced fire in the building. Any disruptions reported by tenants were coded as being either a minor, an intermediate, or a major disruption, depending on the effects they reported.

Three criteria were identified which must be met if sheltered housing is to be suitable for people with dementia: tenants with dementia must show evidence of moderate or high well-being, wardens must experience few practical and emotional problems attributable to those with dementia and, finally other tenants must experience few problems caused by those with dementia.

The findings section discusses the factors which are important if these criteria are to be met.

Training

The study involved giving detailed training on dementia to wardens. The main benefits and effects of the training were investigated three months later. The training consisted of four special features:

1. **Training packs.** Each warden was given a pack of literature discussing many aspects of dementia. It was intended that they could take this away

and read it at leisure, looking up parts specific to their situation at different points in time.

2. **Cross-organization training.** The training courses were held on four occasions. Wardens from both Anchor Housing Association and Methodist Homes attended each training. Wardens worked together and were encouraged to share advice and experience from their different organizations.
3. **Focus on social needs and tolerance.** Throughout the training the main focus was on the needs of those with dementia for sensitive human contact. People who have dementia suffer if isolated and ostracized. Wardens were encouraged to be sensitive both to this need for social contact and for the need to prevent criticism by other tenants.
4. **Dealing with specific problems.** Wardens were encouraged to discuss with each other specific problems they were having with dementia in their schemes. Everyone worked together to attempt to suggest ways to resolve the problems of other wardens.

The findings section will discuss the effects of this training on the schemes and the tenants with dementia.

SHELTERED HOUSING AND COGNITIVE IMPAIRMENT

Sheltered housing consists of individual flats. Tenants have access to cooking facilities, external doors are never locked to them, and often there are many physically frail tenants living in close proximity to each other. This means that there are a number of potentially dangerous situations that could arise when a person with dementia lives in a scheme. Those with dementia could, for example, burn their kitchens; eat rotting food and develop food poisoning; be aggressive to physically frail neighbours; or wander out of the scheme and become lost at night.

However the overall results of this research point to a positive conclusion. In the 51 schemes visited, 276 tenants, (neighbours of those with dementia) were interviewed. Of these the majority, 57%, indicated they had never experienced any problem with any tenant with dementia in their scheme (159 out of 276).

In the case of wardens, 35% claimed to have experienced no practical problems whatsoever in supporting a tenant or tenants with dementia (18 out of 51). 60% of those with dementia had rarely or never woken their warden at night (55 out of 92 tenants). In all 92% of the tenants with dementia were judged by their wardens as being able to remain in the scheme for the next six months without any major problems (85 out of 92 tenants).

It is important to note that in one or two schemes crisis point had been reached with wardens and neighbours suffering under intolerable strain from a person with dementia who had attacked others physically and/or verbally, or caused fires, or allowed access to burglars. Although these were rare occurrences the problems experienced by these people should not be undervalued. Overall though the research would suggest that at present there is no widespread crisis in sheltered housing due to the presence of those with dementia.

A very important finding from the research was that the problems that are caused to wardens and other tenants are not correlated directly with the cognitive severity of a person's dementia. No justification was found for suggesting that there may be a cut off point of cognitive ability below which a person would definitely need to move into residential care. The results show that problems caused by a person are much more strongly related to a mix of individual differences rather than score on one global measurement. For example, the findings of the parallel study would suggest that the personality of the person with dementia is a very important variable.

Sheltered housing providers need to start taking steps now to ensure that a crisis does not develop as the proportion of those with dementia in sheltered housing increases. The following sections will discuss how this can be achieved. The statistical method and results relating to these findings are in Appendix 2.

FINDINGS RELATED TO WELL-BEING IN SHELTERED HOUSING

The tenant with dementia and the warden

The research found that well-being in the warden and his or her tenant with dementia is very closely linked. Factors that affect one also affect the other. The well-being of both was found to be encouragingly high, as can be seen in tables 12 and 13.

Table 12: Distribution of well-being in tenants with dementia

	Low (score 0-30)	Moderate (score 31-60)	High (score 60+)
Tenant with dementia's well-being (total score possible = 90)	23%	68%	9%

Table 12 clearly shows that the majority of those included in the study showed evidence of moderate or high well-being (77%). Only a small proportion (23%) were judged as having low well-being.

Table 13: Distribution on scales measuring warden well-being

	Low	Moderate	High
Wardens ability to cope practically	3%	40%	57%
Wardens ability to cope emotionally	0	23%	77%

As can be seen from table 13, according to the measures used in the study the majority of the wardens had high work related well-being.

The tenant with dementia's cognitive state

Overall analysis showed that a tenant was more likely to have higher well-being when their dementia was less developed (as measured by the MMSE). This would suggest that people who have their cognitive abilities largely intact can create and support their own well-being and it is when a person starts to lose this ability that their well-being is easily damaged. The implication of this is that those with advanced dementia need high levels of sensitive interpersonal contact to ensure that their well-being is maintained. The research found a number of examples of this happening in practice. People with very low cognitive ability were found who showed signs of considerable happiness and well-being- These people were socially well supported within their schemes. The strongest evidence for this is that the highest well-being

score in the study was obtained by a person who scored only 6 on the mini-mental-state examination - a very low score. Five of the people in the study who had above average well-being had scored below 10 on the mini-mental state examination, a score known to distinguish those with severe dementia. The results would suggest therefore that sensitive human contact can maintain well-being even in those who are very severely demented.

Obviously personality is an issue. Part II of the report discussed in detail the differing personalities of people with dementia. The person in the current study with a very low cognitive score together with high well-being fits into the personality profile described as 'Ellen' - a happy socialite (see page 28). However, this is not to say that people with less agreeable personalities cannot also have their well-being maintained in sheltered housing. It simply means that extra effort is required of wardens to find what maintains the well-being of such individuals.

There is a mutual dependence between the well-being of wardens and tenants. The study found that those tenants who had the highest well-being tended to cause fewer practical problems for, and place less emotional strain on, their wardens. Wardens need to spend time forming a bond with their tenants with dementia, and to help them develop a fulfilling social life. As well-being is enhanced in the tenant, wardens themselves will experience positive effects.

Gender of the tenant with dementia

The study found that male tenants with dementia showed higher well-being than the females with dementia. Qualitative findings suggest this is mainly due to sheltered housing demography, that is, very few men live in sheltered housing, (approximately 23% of tenants are male, [21]). It was found that men tended to be treated more leniently and positively by others. This was due largely to the inherent role expectations of this age group, in combination with men being largely a novelty in sheltered housing. If a male attempted any cooking for himself for example, other (female) tenants commented, 'that poor man manages by himself without a wife to look after him'. Often males in the study had an affectionate bond with their female warden, and a number had at least one female in the scheme who specifically helped them.

It may also be the case that well-being is damaged by a series of losses that are less pronounced for men in sheltered housing. This would reflect literature which suggests that entering residential care is a qualitatively different experience for men and women^(25,26). This literature suggests that men perceive no major threat in receiving domestic and physical care from

predominantly female staff. In contrast women have accumulated experience of offering care to others rather than receiving it and thus receiving care from others depletes female identity and self-esteem. Sheltered flats provide a home domain. In the age group who are presently living in sheltered housing it is likely that women will have run the home domain while men will have had their main power outside the home. It may be that when these people need additional care, for example with cleaning and cooking, that men are more able to relax into allowing someone to take over these tasks. However women, who will have been used to running the household, are more negatively affected when someone takes over from them.

These two points would suggest that changes in attitude can help improve the well-being of women in sheltered housing. Wardens should be aware of the need for everyone - themselves, tenants and visitors - to be positive and lenient towards people with dementia whatever their gender. In addition any home care given to people with dementia, especially women, needs to be sensitive to vulnerable self-esteem. Tenants with dementia can be encouraged to say how they prefer housework, shopping and cooking to be done. Home care staff need to respect their preferences and to help them to feel that they are still participating in these tasks.

Warden's job satisfaction

One part of the research dealt with wardens rating of their job satisfaction with reference to aspects unrelated to dementia. Questions asked for example, about their satisfaction with the physical state of the building, the wage, job security, and management of the organization. Hence this scale gave an indication of the warden's global job satisfaction largely unaffected by whether there was anyone with dementia in the scheme. Wardens were found to have moderate to high satisfaction with their jobs. Table 14 shows the distribution of warden job satisfaction.

Table 14: Distribution of warden job satisfaction

Total possible score = 60	Low satisfaction (<25)	Moderate satisfaction (26-50)	High satisfaction (50+)
	2%	60%	38%

Global job satisfaction was closely linked to the well-being of the warden and also to their perceptions of the tenant with dementia's well-being. Wardens with the lowest job satisfaction tended to perceive more practical and emotional strain on themselves due to those with dementia. Tenants with

dementia who lived in schemes with wardens who were unhappy in their job were rated as having lower well-being. Wardens unhappy in their job are much less likely to support and put in extra time with a person with dementia.

These findings have implications for providers of sheltered housing who need to ensure a high level of job satisfaction in wardens. Depression and burnout will occur in wardens who are unhappy, together with subsequent ill-being for those with dementia. In order to avoid this providers can take a number of steps. The organization needs to recognise the changing role of the warden, making it explicit that they may have to accommodate tenants with dementia. What is important is that the organisation demonstrates to its wardens recognition that the job has changed. Wardens should be given working terms and conditions with which they are happy. Very importantly, organizations need to move towards the formation of a support network for wardens to gain advice and support whenever they need it, particularly when dealing with unfamiliar problems raised by tenants with dementia.

The other tenants

This section will examine factors found to be present in schemes where well-being of tenants is adversely affected by the presence of tenants with dementia.

Physical environment

Two aspects of the physical environment were found to be important. The first was how difficult it was for a person to find their way around a scheme. For example, whether all floors were identical, all doors were clearly numbered, or whether there were guiding signs at decision points. The second aspect was how stimulating the physical environment of the flat was. For example, whether the person with dementia had a large window overlooking interesting daily activity or a view onto a brick wall. Statistical analysis found that in • schemes where the view from the flat is unstimulating and the layout of the scheme is confusing, a person with dementia is more likely to cause disruption to other tenants. Those with dementia leave their flat due to boredom, go out into the scheme, and are then unable to re-find their flat. In this situation they will ask other tenants to help them to their flat, or, walk into someone else's flat thinking it is their own.

The implications for providers of sheltered housing are threefold. In the planning of new schemes building should incorporate orientation aids. The tradition of building sheltered housing in quiet areas so tenants will not be disturbed should be reviewed. Finally, when schemes already built come to be re-decorated attention should be paid to increasing the clarity.

Social events

In schemes where a lot of socialising between tenants occurs, (for example, luncheon clubs, religious services, close links with local schools), tenants report more disruption from those with dementia. This is mostly due to increased encounters; in a scheme without social events everyone stays separated in their own flats or they go out of the scheme to socialise. In such schemes no-one spends time with their neighbours and therefore cannot see their problems or be disrupted by them.

A stimulating social life in a scheme is essential. Tenants both with and without dementia need to have as much social stimulation as suits their personality. In order to reduce the perception of being harassed by others, especially those with dementia, tenants need to be encouraged to be flexible and tolerant with each other.

The importance of social dynamics within the tenant group will be expanded upon in detail in the following section.

Gender and intolerance

The study found that women with dementia are more likely to be perceived by other tenants as creating problems. This is probably linked to the finding discussed earlier that the men in the study tended to be better supported and thus have higher well-being. People with high well-being create few problems for others and are happier, therefore it is pleasant to spend time with them. When men make mistakes they are more likely than women to be looked after and be treated sympathetically. Additionally, gossip in schemes is common among women about other women, regardless of mental state. Hence women with dementia are at the extreme of scheme gossip.

The main implication is that a culture needs to be developed in which tolerance and not gossip is the norm. Reasons for this not being the case and ways in which it can be achieved will be discussed in the following section.

FINDINGS RELATED TO SOCIAL DYNAMICS

This section deals with the most important finding from the study. All other factors- physical clarity, warden's job satisfaction, availability of services-although all extremely important, are all of secondary importance to one main factor : the social dynamics within a scheme. There will be difficulties and ill-being for all concerned if there is an unsupportive culture for those with dementia.

The move into the scheme

There are two ways in which a person with dementia may come to be living in a scheme. They may live there for a while and then develop dementia, or they may move into the scheme while already having dementia. A large difference was observed between these two situations.

In schemes where a person had lived in the scheme and developed dementia slowly other tenants were found to be more supportive. The person with dementia had many friends within the scheme who know his or her hobbies and tastes. As dementia developed these friends tended to slowly accommodate and make allowances for strange behaviour. Therefore the tenant with dementia was likely to receive practical help and still be included in social activity.

In schemes where an unknown person moved in to the scheme with dementia they were 'that new tenant who's a bit funny'. Every new person who moves into a scheme is initially 'that new tenant'. Most people in this position however are able to use their social skills to become part of the group. In a person with diminished social skills due to dementia there is less likelihood of becoming part of the group and more likelihood of remaining isolated.

Wardens need to know in advance when those with dementia will be moving into a scheme. Extra effort is needed to help the person with dementia become part of the social group.

Growth of resentment

The most damaging situation for a person with dementia in sheltered housing occurs when a core of bad feeling against the person builds up in other tenants. It was found that in many cases a tenant with dementia had become ostracized, criticised and blamed for anything that was wrong in the scheme, often with no obvious justification in their behaviour. Two examples are; a bedfast person with dementia was blamed for ringing doorbells at night two

floors above her own: a person with dementia who had all of her laundry done by home care was blamed for breaking the washing machine. Where bad feelings build up everyone suffers. The person with dementia is isolated and treated poorly and thus their well-being is damaged. The warden faces great pressure and complaints from tenants. Finally the tenants convince themselves they are being hard done to and therefore are less happy with their lives.

The research found three avoidable reasons why a core of bad feeling builds up. First, tenants believe sheltered housing is not designed for those with dementia. Usually they were not told when they applied for a flat that people with dementia may be their neighbours and have never been told subsequently that this is policy now and could happen. This results in the comment, 'their sort shouldn't be here', as a global statement regardless of whether the person with dementia can cope or not.

Secondly, because tenants have little knowledge of dementia it frightens them and causes them to worry about their own future. We live in an ageist society which believes that older people cannot benefit from, or change, as a result of receiving education. It makes sense that some tenants in sheltered housing who have been perhaps professionals, nurses, and caring mothers, can be educated about the needs of those with dementia. A simple programme which underlines three topics needs to be developed. These are:

- 1) only a minority of people will ever develop dementia,
- 2) dementia is not a disease which can be caught from someone with it,
- 3) people with dementia benefit greatly from social contact.

It is a general experience of life that tolerance increases as people become better known and understood.

The final basis of bad feeling is small rumblings being allowed to escalate. A very small proportion of tenants, probably only one, may initially make a complaint about a tenant with dementia. However, this is usually ignored by the warden and others who don't agree. They hope that if they ignore the complaint it will go away. In actuality the complainers then convince more and more people of what they say (even if it is wildly exaggerated) and bad feeling spreads. Wardens need to stop rumours as soon as they are initiated. It is usually policy that wardens should not discuss one tenant with other tenants as this causes a person to become stigmatised. However a policy of confidentiality should not be used as an excuse for being powerless against the growth of harassment. In schemes in which bad feeling has arisen wardens need to be encouraged to meet with tenants to discuss general issues around dementia and to work on a one-to-one basis with individual tenants to discuss the needs and difficulties of the tenant with

dementia. We should not underestimate the ability of sheltered housing tenants to understand and act humanely. However, responsibility for dealing with bitterness towards those with dementia should not fall fully on a scheme warden. Organizations need to be aware that those with dementia often face harassment from other tenants purely because of their disability, rather than because of any specific behaviour. This equates to harassment people face purely because of skin colour or religious practice. Therefore, discrimination due to dementia needs to be written into organization policy on harassment.

GENERAL ISSUES

When there is a spouse

When a person with dementia has a spouse alive the spouse will be old themselves and possibly physically frail. In the study only 67% of couples where one partner had dementia were receiving services, compared to 76% of the single people with dementia in the study. The average score on the activities of daily living scale for those with a spouse alive was only 27, compared to the total average of 44 (a higher score indicates the person is better able to look after themselves). This would indicate that those with a spouse alive are in most need of external services but are less likely to receive them - the burden of this situation falling on to an elderly spouse.

Additional problems occur for this group if the spouse dies or needs to be hospitalised. As there is insufficient additional care in place, or possibly none, it is believed that the person with dementia cannot remain in the scheme without the spouse. Seventy six percent of wardens whose tenant with dementia had a spouse alive claimed that if the spouse was removed the person with dementia could not remain. However an examination of the whole group shows this is unfair as single people were being supported with much lower ability to look after themselves than some of those with a spouse. Twelve single people without a spouse had an activities of daily living score lower than the average for those with a spouse. These people had social services care packages in place because there was no expectation of a spouse caring. If these twelve people could be supported then those with a spouse who dies could also be supported.

These findings suggest two important pointers. First, even when a spouse is alive the warden should assess and refer the person with dementia to relevant care agencies as they would with a single person with dementia. Second, the death of a spouse should never be the reason for a person with dementia being moved out of a scheme. Facilities to support them should be set in place while a spouse is alive. At present little is known about the effects of bereavement on people with dementia. However, it can be expected that a recently bereaved person with dementia will need additional help, both with the practical and emotional aspects of adjusting to the loss. If relevant care agencies are already in contact with the person when he or she is part of a couple their help can be stepped up when the person is alone. What is essential is that the warden has the confidence to deal with a bereaved tenant with dementia in the scheme. Wardens will need support, encouragement and advice from their housing managers and organizations in order to achieve this confidence.

Control of finances

While a social services care team can dress a person and do housework, can a person who cannot handle bills and pay rent feasibly live in sheltered housing? In the current study this issue was found to be of less importance than was initially envisaged as the majority of participants had family support. The research found that someone had often taken over the person's finances when they first showed signs of dementia: usually one of their children or a sibling. Obviously it is not necessary for a person to live close by, visit regularly or give up their job, in order to arrange someone's finances. It can be done very successfully from a distance with re-directed bills and direct debit. Therefore, while it may be thought that finances could provide a reason for a person not remaining in sheltered housing this was not found to be the case in this study.

However, the issue of finances is exceedingly complex. This study found few problems for those with supportive relatives, but it did not collect data on how many tenants do need to move from sheltered housing due to inability to control their finances.

What is important is that when a person begins to show signs of being unable to cope with finances, steps should be taken to ensure that someone responsible sensitively takes control. With such an important issue as finance, guidelines which wardens can refer to and follow need to be drawn up by the organization.

Sheltered housing as a community care resource

In recent years tenants living in sheltered housing have become older and consequently frailer⁽²¹⁾. The current study found an average of nearly two people with dementia in each scheme. It is inevitable when a person has dementia that their ability to carry out tasks of daily living will decline. This study examined in detail people with dementia at two points in time, three months apart. The most significant change in people after three months was their decline in ability to look after themselves. The growth of dementia in sheltered housing therefore has major implications for housing and care policies.

The aim of current government policy is to provide community-based support to enable those who cannot live independently, (which includes many of those with dementia), to remain in their own home rather than moving into hospital or residential care. Government directives clearly encourage the use of sheltered housing as a community care resource and see it as the preferred option for frail older people. The government's White Paper on community care⁽²⁷⁾, recognizes sheltered housing as a vital component of

community care and as a key for many people to independent living. It suggests, 'a move to more suitable accommodation, which may be sheltered or very sheltered housing, together with the provision of social services support'.

Thus as a result of community care policies, sheltered housing is in the process of switching roles. It originally provided accommodation for fit, newly-retired people. It is now needed to provide accommodation for those in greater need, to support tenants if they become very frail, and preferably to house them until they die. Throughout this process of change it must be ensured that tenants with dementia in sheltered housing receive maximum support from statutory services and that the burden of direct care does not fall on to wardens. The emphasis on community care and away from institutional care has considerable implications for the role of wardens, who now need to have a thorough understanding of the services available, and how to access them for their tenants. The quality of social services support will determine in many respects the success of sheltered housing as a community care resource for people with dementia.

The findings of the current study suggest that wardens are becoming very proficient at understanding what their tenants are entitled to and how to ensure they receive it. While some wardens are struggling in chronically under-funded areas, to a large extent those with dementia in sheltered housing are receiving support. Seventy six percent of the tenants in the study were gaining some help from statutory services. This ranged from meals-on-wheels to very comprehensive packages including dressing, shopping and meal provision. In 13% of the cases where tenants were receiving no help this was due to their refusing to accept services which had been offered. Overall the findings suggest that the principles of community care are beginning to work for those with dementia in sheltered housing. Many people, who would require residential care if alone, are being supported to remain in their own flats.

There are however three main factors which undermine this success.

The principal reason is a shortage of suitable services with the result that home based care packages are often less than optimal for each individual. The likelihood of an older person gaining an adequate package of support is dependent upon local authority resource constraints, political differences and traditions of service organization and delivery. Consequently, people in schemes in one area may gain comprehensive care while those in different areas with similar needs may be left without help. If there are no locally available home care teams or day centres, the tenant cannot receive services even if they are in great need. Government funding and local government practice needs to support community care promises.

The second reason, more directly controllable by housing providers, is poor communication and cooperation between the warden and social services. Sheltered housing providers can take a number of steps to alleviate this problem. A first step involves promoting the warden's professional role to all social services departments. This should emphasize the key elements of the job as identifying problems and needs, making referrals, acting as key worker, and providing direct care only for short term emergencies. A second step is to provide all wardens with quality training to give knowledge of the services available, and the methods of case recording, referral and key working. Finally, close involvement can lead to sheltered housing schemes and social services producing joint care policy statements which foster a partnership approach in allocating flats and providing care. This has been attempted with success by Anchor in a number of areas⁽²⁸⁾.

The third reason for failure of community care is tenants refusing to accept help. This is common for a variety of reasons, especially when there is a spouse still alive. Again an important issue here is the confidence of wardens to guide and encourage their tenants in gaining services. Wardens need advice, guidance and support from their organization and housing manager in being assertive in advising tenants of the help they need.

Sheltered housing can only be feasible for those with dementia if good supporting services are available. If these services are well designed and implemented a successful environment for the community care of those with dementia is possible.

FINDINGS RELATED TO WARDEN TRAINING

The training on dementia given to wardens was found to be very beneficial in raising the confidence of wardens to work with tenants with dementia. In the current study housing managers were not given training. However, in order to support and advise wardens in their work it is increasingly essential that housing managers have a knowledge of dementia. This section will discuss the main effects of the training given in the study on both wardens and their tenants. Wardens completed a follow-up evaluation of the benefits of the training. The figures given in brackets in the paragraphs below refer to the percentage of wardens who stated each point discussed as being important.

What is most useful in training?

Wardens valued a number of aspects of training on dementia: in particular information packs which could be taken away for reference when needed (25%), looking positively at problems (13%), and finally, sharing experiences with other wardens (25%). There is a clear need for wardens to come together regularly for training, discussion, and sharing of problems and ideas. Housing associations and local authorities need to look closely at the possibilities for inter-provider links, in order that all wardens no matter how geographically separate from others in their organization, can have the benefit of social support.

Do wardens use ideas/suggestions in practice?

Sixty nine percent of the wardens who completed a training evaluation form stated that they had put some aspect of the training into practice, in one of three main ways.

The most important of these was increased contact for the person with dementia (45%). The second practical outcome was that other tenants were encouraged to be more tolerant (36%). This had worked, tenants were reported by wardens to be acting with more tolerance towards the person with dementia. Thirdly the training had helped wardens to solve specific problems (27%).

Does the training produce actual effects on the tenants with dementia?

Again results are extremely positive and encouraging. Thirty one percent of wardens had noticed a change in their tenant with dementia.

Wardens reported that their tenants with dementia now appeared less confused (13%), observably happier (13%), and more willing to be involved socially (19%). This is obviously very beneficial, as willing participation in social activities by a person with dementia is likely to enhance greatly their well-being.

Overall the results show that training on dementia can have very beneficial effects on all concerned. Wardens feel more confident in working with those with dementia, there is more tolerance in other tenants and there is increased happiness and possibly even reduced confusion in those with dementia.

A selection of comments from warden feedback

What was the most useful part of the training?

'literature to read through and refer to at a later date'

'talking as a group as I learnt new ideas from members in the group'

'looking positively at problems'

Did you put any of the practical advice into practice?

'have involved other tenants in helping to ensure my tenant with dementia is involved in social activities'

'helping the other tenants to be more tolerant'

Have you noticed any changes in your tenant with dementia due to this?

'... she has a busy life now with lots of social contact. Her periods of confusion seem to be a lot less'

'she is calmer and happier. She is keen to be involved if reminded that something is going on'

'other tenants are more tolerant'

'we still have very confused states but not as often'

THE LIMITS OF SHELTERED HOUSING

The principal findings have shown that at the present time sheltered housing under certain conditions is successfully able to support people with dementia. The aim of sheltered housing should be to support its tenants until they die. This is very important for tenants with dementia. Recent work suggests that personal security is a crucial factor in enabling people with dementia to maintain well-being, and even, in some circumstances, to undergo positive change⁽²⁹⁾. It has been argued that it is important for those with dementia to know that there is not going to be further change and disruption in their lives, and ideally, that their current home is a haven for the rest of their lives⁽³⁰⁾.

However, in a minority of cases there may be good reason for a move to residential care. The current research would suggest that when the following three factors occur in combination, the warden, together with their housing manager, may need to discuss the possibility of residential care.

1. Those who have, in addition to dementia, a severe physical illness which needs intensive nursing care.
2. Those who have no support from family and friends in the local community or in the scheme.
3. Those who live in schemes where the possibility of access to social services is limited.

TWO EXAMPLES

The following two composite examples, Red Court and White Court, are intended to give an overview of the findings of the study. Red Court represents sheltered housing which is not supportive of people with dementia. It is characterized by a lack of tolerance from both the warden and other tenants. White Court represents schemes which are supportive of those with dementia. The warden and other tenants do their utmost to facilitate people with dementia maintaining their well-being.

Red Court

Red Court is a six year old sheltered scheme. It has three floors, each of which are identical in layout. All three floors have plain cream walls with no visual differences outside the lifts or at the stairs.

There is one tenant with dementia in Red Court. Mrs. D is eighty and has shown signs of dementia for ten months, she is now very disoriented in time and within the scheme. She frequently mistakes other flats as her own. As her difficulties with finding her way around the scheme have increased, Mrs. D has stopped leaving her flat as often as she did in the past. At one time she was a socially active person but now she has no confidence to find the communal lounge, which has rendered her isolated.

The warden of Red Court feels that housing someone with dementia in the scheme is not part of the job she applied for. The warden is very caring and competent but feels bitter at her housing association who have introduced a policy to house those with dementia without consulting wardens about their opinions. The warden has been given no training on dementia and does not feel confident working with Mrs. D. This has contributed to resentment of Mrs. D being in the scheme. The warden has no interest in inviting Mrs. D to join in with social events and makes no attempts to encourage other tenants to do so. The tenants never tell Mrs. D if things are happening in the lounge and if she comes to events by chance they 'tut-tut' and shake their heads when she makes mistakes or repeats questions. The warden openly agrees with tenants when they complain about Mrs. D wandering or repeatedly questioning people. Everyone seems to agree that Mrs. D should not live in Red Court.

As a result of the warden being shy and social services personnel being overworked, Mrs. D is not receiving the home care to which she is entitled. Social services assume the role of the warden is to provide some direct care for tenants, and they are uncooperative if she phones to request help. Because

Mrs. D is not receiving the help she requires, there are a number of avoidable problems affecting the warden and tenants, increasing bad feelings in the scheme. As Mrs. D is still attempting to cook meals she occasionally forgets to check food which is cooking and so sets off the fire alarm. She has also begun to go out to the shops leaving the windows and door of her flat open. As her flat is on the ground floor this has caused concern to neighbours afraid of burglary. Neighbours and the warden have begun to nag Mrs. D. This is causing arguments, and considerable worry and ill-being for everyone.

A number of factors in this scheme have contributed to ill-being in Mrs. D. Mrs. D was a sociable person who enjoyed the company of others. A combination of poor physical design, intolerance by others and insufficient support, has resulted in her becoming withdrawn, anxious and depressed.

White Court

White Court is a six year old sheltered scheme. It has three floors each of which are identical in layout. The decoration has been chosen with the possible orientation difficulties of older people in mind. Each floor has walls and carpets different in colour to the other two, as well as clearly numbered doors.

There is one tenant with dementia in White Court. Mrs. A is eighty and was diagnosed as having dementia ten months ago. She is very disoriented in time and repetitive in conversation, but seems to have few orientation problems within the scheme. She often walks along to a seating area on her corridor and watches children playing in the nearby school; this is something she really enjoys. When she is tired she can find her way back to her flat which has her name and a pot plant outside. Other tenants in the scheme have never experienced Mrs. A mistake their door for her own.

The warden of White Court is interested in memory problems and has a positive attitude to people with dementia. This interest was developed during and after training on dementia which the warden attended as part of her induction to the job. A close affectionate bond has developed between Mrs. A and the warden: they hug and make conversation together easily. The warden actively encourages tenants who were old friends of Mrs. A to spend time with her and make allowances for her. Whenever a tenant makes a negative comment about Mrs. A she attempts to speak to that person alone later and find out the root of their complaint and whether it can be dealt with. Because of this extra effort by the warden the majority of tenants in White Court are accepting and supportive of Mrs. A.

When she moved to the scheme Mrs. A played cards and dominoes each

afternoon with a group of other tenants. She now has difficulty in following the games, but can still join in if given prompting and extra time. The tenants have developed a system whereby they meet in the lounge at their usual time and play a few games. About half way through their get-together one of the group goes to Mrs. A's flat and invites her to join them. They then spend the last half of their afternoon playing at a slower pace to accommodate Mrs. A. In this way everyone can still enjoy the games and Mrs. A is able to gain great pleasure from company and stimulation each day.

The warden has established strong links with social services, explaining clearly that her role is not to provide direct care. She now has a good working relationship with social services staff. They, for their part, know who she is when she phones with requests, and treat her as a fellow professional. The warden and social services have put together a care package that ensures Mrs. A has her meals cooked or delivered and her housework done. Consequently Mrs. A causes few problems for the warden, who feels that the work she is actually doing matches her job description.

A number of factors in the scheme have contributed to Mrs. A's well-being. Support and encouragement have resulted in her being able to maintain social contact and engage in activities that she enjoys. This is reflected in her ability to feel comfortable in the scheme and to enjoy a joke and chat with others: above all else this is an environment in which she can feel safe.

SUMMARY POINTS

Warden

- Ensure a clear physical design and decor to help the orientation of tenants with dementia.
- Spend time developing a relationship with tenants with dementia, find out about them, their past and their interests.
- Be creative and encourage tenants to explore and try out new things, if something works repeat it. If something does not work, try something different, or try again in a different way.
- Stay active in developing opportunities for each person with dementia, rather than only responding to crises and things going wrong.
- Be committed and willing to learn more about dementia.
- Promote friendships between tenants, relatives and members of the community.
- Develop close and strong links with social services.

Organisation

- Provide maximum support for staff in their work, in training and in supervision.
- Promote wardens as key-workers in designing and constantly re-assessing the package of care for each tenant.
- Provide training for wardens and housing managers specifically focused on dementia in sheltered housing.
- Provide policy guidelines for wardens on harassment of tenants with dementia.
- Provide policy guidelines for wardens on assistance with finances.
- Provide support for wardens when deciding on the limits of sheltered housing.

CONCLUSION

This study has resulted in a number of important findings for the future of sheltered housing. It has shown that severity of dementia, as measured by cognitive test scores, is not directly correlated with crises or unhappiness in schemes. The research found that a complex mix of social dynamics, personality, physical environment, warden job satisfaction and training and service availability, creates the ability or inability for people to remain in schemes. Additionally it was found that well-being can be maintained, even in those with severe cognitive decline, by sensitive interaction; also that tenants can be encouraged to be more tolerant of those with dementia and give them the human contact that they need. Thus, as the role of sheltered housing changes to support those with dementia, both wardens and tenants need to be treated as mindful adults and be given information and advice on how to accept and assist with the difficulties of those with dementia.

Overall the research has shown that we need to look afresh, and positively so, at the role of sheltered housing. The research shows that there are grounds for optimism. Sheltered housing has been found to be a successful environment in which those with dementia can live with well-being. What is important in maintaining this success is that wardens are fully supported in their work with tenants with dementia. While some problems are being encountered at present, the research has shown that steps can be taken to enable sheltered housing to take its place as one of the main options for the community care of older people with dementia.

PART IV: LOOKING TO THE FUTURE

The studies described in parts II and III give us many insights into the possibilities for enabling those who have dementia to live fully human lives. One of the strongest messages is that there is no need either for government or providers to panic about an 'epidemic of dementia'. We can make a reliable estimate of the present requirement for different kinds of provision, and we can be reasonably sure about how this will change during the next 20 years or so. Also we are beginning to understand many of the key issues in providing care for those who have dementia. Best practice can be a guide and inspiration; research gives us a larger picture, enriched with more systematic knowledge. The task now is to learn the lessons, to be clear about priorities, and to develop a balanced plan for the development of different types of provision. Ideally, this will be guided both by knowledge and by human values; although informed by financial reality, it will not be finance-driven. The purpose of the last part of this report is to draw out some of the general messages from the research.

THE NEEDS OF PERSONS WITH DEMENTIA

We have now moved a long way on from that older view of dementia, which created dreadful images of negativity and doom. High levels of well-being are possible for many people who have dementia, even when their cognitive impairments are severe. Although, undoubtedly, there will be ill-being (as with every one of us), it can be greatly reduced. Also, while general health is of very great importance, dementia itself is not, fundamentally, a medical issue, but a human one; the task is the maintenance of personhood.

Caring positively.

Both studies highlight the necessity for an active approach to caring for those who have dementia. In the old culture of care the general emphasis was on meeting physical needs, on providing conditions of safety, on reducing risk, and on the control of troublesome behaviour. It is clear now that this is not enough. Wherever there is something that a person cannot do, and which would enhance the quality of their life, positive action is needed to make up for what is missing. If we compare the examples of success with those of failure, again and again we find that it is not the cognitive impairment in itself that was the problem. Rather, it was the response of other people; whether they helped and enabled, or whether they were critical, gossiped, and excluded that person from their company.

The uniqueness of each person

The research has gone deep in its engagement with the lives of those who have dementia, both by observing their manner of life in detail and by meeting them personally. Here the uniqueness of each individual comes sharply into focus. The formal diagnosis of dementia fades into the background; far more significant is what each person brings as a result of his or her history, relationships, interests and personality. Thus two people might have identical diagnoses, from a medical standpoint, but what is required to enrich the quality of their lives may be radically different. One might be greatly enlivened by boisterous activity, while the other values quietness; one might be liable to constant fatigue, while the other is immensely energetic.

The need for 'structure'

Whatever the setting, be it sheltered housing or some form of residential care, people with dementia generally need some degree of 'given' structure to their

day. The reason for this is clear. Those of us who have all our mental faculties intact can cope with change, and with events that are sudden or unexpected, because of steady ideas, memories and plans that we carry within ourselves. In dementia much of that inner stabilisation is taken away, and a person can very easily become confused or bewildered. It is necessary, then, to provide more stability, more of a sense of a continuing rhythm in daily life, if a person with dementia is to feel secure. This is a particular challenge in making sound provision for people in sheltered housing who are living alone, the insecurity of whose lives is partly hidden behind their front door.

Maintaining contact

There is a vital need for human contact; dementia can be an extremely lonely business, even when a person is living with others in a residential or nursing home. The type of contact that is most helpful will vary from person to person; the need for it seems to be universal. Those who are strongly extravert in disposition may well enjoy much laughter, banter, and the sense of being at a party. Others, however, will need quieter, less obvious and more sensitive forms of contact. Of particular concern are those who might be termed 'anxious introverts', who may account for about 30% of all who are in residential settings. For these are the persons who seem to be less attractive and loveable, and some make very few demands on the people around them. Maintaining contact with them is one of the biggest challenges in dementia care.

Spirituality and dementia

It is not common for research to be concerned with the needs that we might term spiritual, but we have at least ventured into this domain. The issues here go far beyond the fairly straightforward matter of enabling the continuance of religious practice for those who have engaged in it in the past (important though that is). Spirituality, in the broader sense, is concerned with a person having a place in the whole order of living beings, of having significance even in the vastness of the cosmos, and of a brief life having some kind of meaning. In dementia, even for those who are or were 'religious', these forms of awareness will largely be maintained through the sensitivity and love offered by other human beings. We have encountered some for whom this has indeed been the case; but also others who, abandoned by human beings, felt abandoned by God also.

THE PHYSICAL AND SOCIAL ENVIRONMENT

We turn away now from the individual with dementia to some broader issues concerning the place where they are living. Providers need to be concerned both about the physical surroundings and about the nature of human relationships that are found there. If any one general point emerges, it is that the quality of the inter-personal environment is of far greater importance than the physical. There are no simple 'technical fixes'. Some old and seemingly unsuitable places are centres of excellence, because of what the people there are doing; newly built and specifically designed places do not necessarily turn out well, because of the limits set by what people can do.

A place with 'clarity' and homeliness

In relation to the physical environment, three factors do stand out from this research as being important for the quality of life of those who have dementia. The first is 'clarity', as we have termed it. That is, there should be clear signs to enable people with dementia to find their way around; confusing signals, such as different floors having identical layouts or decor, should be avoided; above all there should be sufficient cues to enable those with moderately severe dementia to get back to their own 'base' - their flat or their own room. The second factor is that of 'homeliness'. A place should convey feelings of familiarity and comfort, rather than of clinical austerity or technical efficiency. Lounges should have an atmosphere of harmony and intimacy, and not be bare and barn-like. The third factor is 'interest'. Some environments visited during this research were bleak and institutional, as if very little imagination and care had gone into making them like a real home; others have been very successful. A general guideline would seem to be this: wherever a person might sit down in the areas that are shared, there should be a range of different things to attract the eye: a view, plants, pictures, objects, textures, a sense of space. A person who rested there for a little while would not get bored.

The suitability of different environments

The research has explored the life of people with dementia in four types of setting: sheltered housing, 'mixed' residential homes, 'specialist' residential homes and nursing homes. Of these, the last two are in a minority, so we must be more cautious in generalising. Nevertheless, something can be said about the suitability of each type of place for those who have dementia. Sheltered housing seems to work best for persons whose physical health is sound, who are

sociable by disposition, and who are well-supported by friends and family both within the housing scheme and in the community. The prospects for those living with their spouse are better than for those living alone. In 'mixed' residential homes similar considerations apply. The conditions are most favourable when the proportion of persons with dementia is fairly low (say up to 20%), and when special provision is made to create an interesting, structured day for those with dementia. Specialist residential homes are needed in addition, particularly for those who have more severe cognitive impairments and who show consistently higher levels of distress. Such homes can develop their own kind of culture, in which the residents seem to be able to recognise and accept each others' disabilities. Nursing homes are most suitable for those requiring general nursing care, and whose dementia is a relatively small part of their disability. For the time being, it is unlikely that the specific needs associated with dementia will be high on the priorities for care in nursing homes.

Recognizing relationships

Both pieces of research have shown, in their different ways, the vital importance of the relationships between the people for whom the accommodation is being provided, and the crucial part that can be played by a generally accepting and supportive culture. In our view, this has been recognised far too little, either in general policy or in training. Thus staff, hitherto, have been inclined to take too much upon themselves, perhaps assuming that the only really important relationships are the ones which they create. This view places too great a burden upon them, and it also downplays the real abilities of older people - including the abilities of those who have dementia. Members of staff (and increasingly, wardens of sheltered housing) should see themselves in part as facilitators - helping bonds and relationships to develop, and de-fusing dissension and quarrels. Very little training of staff addresses these issues at present. Also, it is remarkable how many older people are open to learning about how to help look after those who live close to them and whose mental powers are failing. All too often they have simply been viewed as passive receivers of care.

The importance of consistent standards

At present there is great inconsistency in the quality of provision for those who have dementia. This point applies generally; it does also to the contribution made by each of the sponsors of this research. We have encountered places where persons with dementia have fared remarkably well -

far better than we might have anticipated on the basic abilities assessed by cognitive tests. Also, and even more surprising in view of the many critical voices that have been heard of late, there are some sheltered housing schemes where community care is working really well. All this gives great encouragement in envisaging what might be achieved. On the other hand, the research has also involved being in places where the needs of those with dementia are very far from being adequately met. The proper conclusion seems to be that at present too much depends on random factors, such as the presence of highly talented and committed individuals, or a fortunate 'mix' of clients, or being specially favoured in terms of resources. Any major provider that seeks to be in the forefront should develop ways of minimising inconsistency, and set up reliable and enduring forms of quality control.

STAFF AND THEIR NEEDS

In an ideal world, there would be a close match between what a job actually requires, the stated job specification, and the competence of those who are employed. During the course of the research it has become clear to us that in many instances this is far from being the case. Often it is as if staff had been prepared for a set of circumstances that are now irrelevant, and for a culture of care that is now outmoded. This serious mismatch cannot be rectified by a few small 'shots in the arm'; it requires a more thorough overhaul.

Training and development

In all the settings visited in this research, without exception, there were signs of staff not being properly equipped for their work. In some residential settings, staff have had no preparation at all for dementia. In virtually every sheltered housing scheme the warden had received no training to deal with the needs of tenants who have dementia; they have simply had to learn by trial and error. Even the relatively small amount of training given to some wardens during the course of the research was very much appreciated. It is essential, then, that providers develop a comprehensive training strategy in order to equip staff for the new situation that they will encounter during the next few years; for the proportion of people with dementia in all kinds of residential setting and sheltered housing is likely to increase. The strategy should include induction, in-service training, and the possibility for staff to receive accreditation - for example through the NVQ CARE programme, or the Bradford Certificate in Dementia Care.

Providing support

Wardens of sheltered housing schemes and managers of residential settings carry very heavy responsibilities. It is often assumed that they have boundless energy and resourcefulness. The research would suggest that a number of people in these positions see themselves as isolated and unsupported; they feel that few people really understand the burdens that they carry. In the case of wardens, there are still residues of the idea that their job is a kind of hobby; even if that had some truth at one time, it is far from being the case now. The design of these senior positions need to be re-examined, with a much clearer recognition of the range of responsibilities, and much more careful preparation of those who will take them on. Also, any organisation involved in this kind of provision should set up better systems of support; it is noteworthy how even meeting with colleagues from different places for half a day, and sharing ideas

and problems, seems to have given wardens considerable increase in morale and sense of efficacy.

Respecting the personhood of staff

Whereas some providers have tended to treat direct care staff as an expendable resource, accepting very high rates of turnover, Anchor Housing and Methodist Homes for the Aged have set a fine example of good practice. Providers of all kinds might follow this example in the difficult years ahead, and not be enticed by short-term ideas of so-called cost-effectiveness. Staffing policy needs to be directed towards ensuring quality and commitment. Supervision arrangements should be in place in every setting, with clear goals and procedures. In 'mixed' residential settings, where a member of staff has a special desire to work with those who have dementia, this should be encouraged and supported. Caring for persons with dementia deserves to be valued highly, as a form of work that requires special insight and expertise. If there is a general principle here that applies to all settings, it is this; the delivery of person-centred care to those who have dementia requires that staff, too, are treated in a person-centred way.

Managers and their role

The informal observations made during this research, together with experience more generally, suggest that the best pattern in dementia care is to have a 'flat management' style, with knowledge and skill well-distributed throughout the different levels, and with senior staff taking on, to some extent, the role of exemplary practitioner. The research revealed some excellent examples of this, but also some instances where the manager was relatively remote and preoccupied. It is vital that bureaucratic procedures be kept to the minimum that is necessary, and that wardens and managers are protected from an overload of unrewarding paperwork. To do this is to go against one of the general tendencies of the present time, one which has brought about tremendous stress and, in some cases, burn-out.

COMMUNITY AND COMMUNITY CARE

The day of the asylum - the place where people with 'abnormal' behaviour were locked away, out of sight and out of mind - is almost over. Whatever may have been the prime motive for the changes that led to the NHS and Community Care act, there is now the possibility for a profound re-humanisation of the mental disabilities of old age, including dementia. Warnings have been given, however, that Britain might simply re-create the worst features of the asylum in smaller and dispersed units, and even that people living in their own homes, awaiting their 'packages of care', might fare little better than those who lived in the large institutions. There are, then, many issues to be faced regarding the larger context of sheltered housing and residential care.

Being part of the community

The most successful locations visited during the course of this research were well-integrated into the local community. On the one hand, people from that community were able to visit freely, without the sense of having to cross institutional barriers. This applied to family and friends, but also to visitors from churches and schools, and other volunteer helpers. On the other hand, persons with dementia were enabled to take some part in the life of the wider community, visiting shops, the local park, the pub, or attending church services. This kind of fluidity, where the barriers are low, seems to be ideal. Besides what it does for those who have dementia, it may in the long term enable a much deeper acceptance of their presence in society at large.

Collaboration in providing care

As an extension of the previous point, there were some instances where staff and relatives had moved forward to a genuine collaboration in helping a person with dementia to live well. This is no small achievement, because staff sometimes feel resentment towards relatives who seem to be intruding, and relatives may feel critical if the provision is less than they had hoped. From both sides, there are areas of great sensitivity, and many possibilities for hurt. The ideal to work for seems to be one of 'shared care', in which staff and relatives fully co-operate in care planning, deciding on issues of risk, and consulting in all times of change or crisis.

Relations with social services and the voluntary sector

Under the NHS and Community Care act, Social Services have the major responsibility for the 'care management' of those who are living in their own

homes. At present the arrangements made in different areas show enormous variation; the success of collaboration from the point of view of sheltered housing schemes and residential settings, has been variable also. As things settle during the next few years, major providers would do well to provide a set of guidelines to wardens and managers for their negotiations with Social Services, and to include this as an item for training. It is also the case that voluntary associations such as the Alzheimer's Disease Society are developed to very different degrees in the various regions. Whatever form has emerged, it is important to ensure the fullest possible level of co-operation.

TOWARDS A NEW CULTURE OF CARE

The research reported here represents a time of transition. If it serves its purpose well, the lessons will have been learned by five to ten years' time. At present we are living with many of the remains of the old culture of care, with its gloomy outlook, its low aspirations, and its over-readiness to control people's behaviour through the use of drugs. None of the homes visited during this research now represent that old culture, which is a profoundly encouraging sign. Also, despite the lack of proper preparation, most of the sheltered housing schemes have adopted a positive approach to having a few of their tenants with dementia. Thus we have glimpses - and that is all that can be said at present - of a new culture coming into being.

There are 'resource implications', of course, if the quality of life of those who have dementia is to improve. However, these are not so great as many — particularly in the profit-making sector - have feared. On the whole, few improvements will come about by 'throwing dollars at problems', to use the American phrase. It is much more a matter of carefully and thoughtfully creating the conditions for good living: developing skill and awareness at all levels, and setting up the necessary structures even when these go against the current fashion. Here job design, staff support and development, training and supervision are paramount. In all of this, the task of transformation is a vast one, but there is no reason why it should not be undertaken. Without miracle solutions or magic bullets, the human solutions are within our grasp.

APPENDIX 1: STATISTICAL FINDINGS - RESIDENTIAL CARE SECTION

STATISTICAL METHODS

1. The WAIBS was analyzed using multiple regression. Observation scores were regressed against the researchers' ratings of global well-being and global ill-being. Having found the behaviours which significantly related to the global measures, further analysis was carried out to assess the accuracy of the regression model in predicting global well-being and global ill-being.
2. All the data variables were cluster analyzed, including the predicted well-being and ill-being scores. Three main clusters were identified. The first set of variables were in the same cluster as the well-being variable, the second set were in the same group as the ill-being variable, and the third set had variables which were in neither of the other two clusters.
3. Discriminant analysis was carried out using the variables identified by the cluster analysis as follows: To discriminate between high and low well-being, variables were taken from the first and third clusters. To discriminate between high and low ill-being, variables were taken from the second and third clusters. Discriminant analysis identifies which of the variables have a reliable and significant ability to separate participants into the correct group.
4. The information gathered relating to quantity and quality of contact from visitors, and residents in the home was analyzed using the Kruskal-Wallis one-way anova procedure. This allowed comparisons of three groups, those with daily high quality contact, those with daily distressing contact or conflict, and those who had less contact than this.
5. A specific look was taken at how the staffing levels in mixed residential settings affected the quality of social life. Measures were based on the

average number of direct care staff on duty over the ten or more hours of mapping.

6. An overall analysis of personality was carried out, again using cluster analysis. In this instance individuals were clustered on the basis of having similar personality scores on all five personality dimensions.

STATISTICAL FINDINGS

The discriminant analyses

The two tables represent the results of the discriminant analysis. The scores from the variables listed statistically and reliably distinguish between people in a high state or low state of either well-being or ill-being. The numbers listed in the discriminant function column represent the power the variable has to discriminate. The nearer the score is to 1 or -1, the more powerful it is. A discriminant function of 0 therefore means it has no ability to discriminate. One example is that of engagement. The function is 0.52, means that people who spent more time engaged had higher levels of well-being. If the function is negative it means that less of one variable leads to higher levels in the other. Choice, for example has a negative function, -0.17. This means that where there was a strong policy of giving choice, levels of well-being were lower.

The correlation shows how closely one score varies alongside another. So a high correlation, near 1, shows that a high score on variable would predict a high score on another. Therefore, variables with both a large discriminant function, and a large correlation are powerful and reliable discriminators. Correlations above approximately 0.24 are significant at the 5% level.

The combined information from the table of measures relating to well-being classify 79% of participants into the correct state, ($\text{Chi}^2 = 60.1, \text{df} = 10$,

Table 15: Measures which significantly discriminate between high and low levels of well-being

Measures	Description	Discriminant function	Correlation
Engagement	Time engaged through the day	0.52	0.73
Care Value +3	Proportion of time in +3 state (Dementia Care Mapping)	0.33	0.72
MMSE	Cognitive Ability	0.31	0.56
Openness	Level of openness to experience	0.28	0.24
Choice (Wilcocks measure)	Residents ability to set routine	-0.25	-0.17
Worry about work	General anxiety about how things are going at work	0.22	0.05
Conscientiousness	Level of conscientiousness	0.17	0.22
Care value +1	Proportion of time in +1 state (Dementia Care Mapping)	-0.14	-0.14
Visual problems	Level of Blindness	-0.14	-0.12
Physical environment	e.g.: Noise, Light & Condition	0.05	0.20

P<0.0001). This means that the information gathered in this study gives roughly 79% of the necessary information for deciding whether people will be in a high state of well-being or not. The measures are listed in terms of statistical strength.

The table below is similar in all respects to the one above, with the exception that it shows the results for ill-being. Different variables were chosen by the statistics to discriminate high-low well-being from those chosen for ill-being, with one exception, worry about work. This goes to show that well-being and ill-being are not two ends of a dimension, and that different individual and environmental influences effect the promotion or maintenance of each state. The combination of measures below classifies 83% of

Table 16: Measures which significantly discriminate between high and low levels of ill-being

Measures	Description	Discriminant function	Correlation
Neuroticism	Level of neuroticism	0.51	0.36
Care value -3	Proportion of time in -3 state (Dementia Care Mapping)	0.41	0.42
Worry about work	General anxiety about how things are going at work	0.51.	0.15
Staff oriented policy	Extent to which home policies are oriented towards staff	0.37	0.30
Social disruptiveness	Individual disruptiveness to others	0.31	0.23
Safety features	Provision of safety features	-0.30	-0.23
Segregation *	Separation from the outside community	0.24	0.37
Privacy (Booth Measure) *	Freedom of privacy	-0.23	-0.24
Conscientiousness	Level of conscientiousness	-0.25	-0.18
Care value -1	Proportion of time in -1 state (Dementia Care Mapping)	0.18	0.35
Care value -5	Proportion of time in -5 state (Dementia Care Mapping)	0.17	0.31
Agreeableness	Level of agreeableness	-0.11	-0.34
Resident conflict	Amount of conflict between all residents	0.18	0.06
Participation*	Amount of participation in the running of the home	0.08	0.34

* These scales have inverted scores, so more segregation, more privacy and less participation all contribute to the increasing ill-being (see discussion below).

STATISTICAL FINDINGS - RESIDENTIAL CARE SECTION

participants into the correct state, either high ill-being or low ill-being, ($\text{Chi}^2 = 77.0, \text{df} = 14, P < 0.0001$).

Analysis of relationships in residential care

The relationships in residential care scale covered two main aspects. The first is that of an individual resident's visitors. Included is information about the number of visitors, the frequency and the quality of visits. The second part related to close friendships or 'enemies' within the home. For this part, number of people, proportion of the day spent together and the quality of the relationship were all recorded. In the main this scale was very subjective, and largely qualitative. Therefore the researcher used the information to define extreme ends, and to compare them alongside those who did not have such obvious levels of close contact. The results are listed below.

Each table gives information about the proportion of people in each group, (based on the total sample of 132 participants). The tables also give the total ranks and the statistics based on these ranks. The procedure involves ordering every participants well-being, (or ill-being), scores and assigning a rank from 1 to 132. These ranks are then averaged. If there are no differences between the groups, then the scores will be randomly distributed, and the average ranks will all be similar. The greater the difference between the average ranks, the more likely it is that the difference does not occur by chance. The two tables of particular interest are the ill-being results for relatives and visitors, and the well-being results for friends and enemies in the home.

Table 17: Well-being and relatives and visitors to the home

Group	People	Rank	Result	
1 - daily distressing / conflict contact	11%	75	Chi ²	1.08
2 - no remarkable contact	73%	65	df	2
3 - daily good contact	17%	69	P=	0.58
A low rank equals low well-being. (Lowest well-being in group 2)				

Table 18: Ill-being and relatives and visitors to the home

Group	People	Rank	Result	
1 - daily distressing / conflict contact	11%	76	Chi ²	2.84
2 - no remarkable contact	73%	68	df	2
3 - daily good contact	17%	55	P=	0.24
A low rank equals low ill-being. (Lowest ill group 3)				

Table 19: Well-being and friends and enemies in the home

Group	People	Rank	Result	
1 - daily distressing / conflict contact	10%	83	Chi ²	8.91
2 - no remarkable contact	78%	61	df	2
3 - daily good contact	12%	87	P =	0.01

A low rank equals low well-being. (Lowest well-being in group 2)

Table 20: Ill-being and friends and enemies in the home

Group	People	Rank	Result	
1 - daily distressing / conflict contact	10%	72	Chi ²	0.63
2 - no remarkable contact	78%	67	df	2
3 - daily good contact	12%	61	P =	0.73

A low rank equals low ill-being. (Lowest ill being in group 3)

Table 21: Friends and enemies in the home and quality of social life

Group	People	Rank	Result	
1 -daily distressing / conflict contact	10%	77	Chi ²	11.90
2 – no remarkable contact	78%	61	df	2
3 -daily good contact	12%	94	P =	0.003

A low rank equals low quality of social life. (Lowest quality in group 2)

Analysis of staffing levels

A quadratic regression analysis of average quality of social life, (individual care scores from the DCM), and staffing level. A linear analysis was also carried out, but was found to be much less significant. The results shown in figure 5 in the main text have the following statistics: $F_{58} = 4.04$ $P=0.023$, $r^2 = 0.122$ meaning that 11% of the quality of social life scores is explainable in terms of staffing levels, and the rest is dependent on other factors.

Analysis of personality

The results of the cluster analysis of the five personality dimensions are listed on page 85. The words high, low, v.low (very low), v.high (very high) and avg. (average) all refer to how the mean score for each cluster compared with a set of standardized results for a *normal* population of adults. In other words this set of personality data are considering the people with dementia's personalities alongside those of any group of adults. The blanks in the table refer to average

scores, and these have been left out to improve the clarity of the table. For a full description of these personality dimensions, the reader should refer to the manual, reference 18.

Table 22: Personality characteristics of each personality profile

Dimension	Profile 1 "Agnes"	Profile 2 "James"	Profile 3 "Hilda"	Profile 4 "Eve"	Profile 5 "Ellen"	Profile 6 "Edgar"
Neuroticism	High	Low	High	High	Low	V.High
Extraversion			Low	V.Low	V.High	V.High
Openness		Low	Low	V.Low		
Agreeableness		High	V.Low	V.Low or Avg.	High	V.Low
Conscientiousness	Low	Risk of V.Low	Low	V.Low	High	
Number(%)	34(30%)	31(28)	29(26%)	9(8%)	5(4%)	4(4%)
Mean well-being*	5.56	5.06	5.55	4.78	7.00	7.25
Mean ill-being*	5.26	4.29	5.55	6.33	4.20	4.50

* Well-being and ill-being were given an overall score of between around 1 to 10, with the score of 5.5 being the cut off between a high state and a low state.

APPENDIX 2: STATISTICAL FINDINGS - SHELTERED HOUSING SECTION

STATISTICAL METHOD

Initially the data was organized into groups of statistically associated measures using cluster analysis. This identified measures which were associated with: tenant with dementia well-being (and therefore warden well-being as the two were found to be closely related), and other tenant (neighbours of those with dementia) well-being.

Discriminant analysis was then used to analyze the ability of these relevant measures to predict high or low tenant with dementia well-being and other tenant well-being.

STATISTICAL FINDINGS

Tables 1 and 2 show the measures which were found to discriminate between high and low levels of, tenant with dementia well-being (table 1), and other tenant well-being (table 2).

The tables give two pieces of information about each measure.

1. The discriminant function reflects the measures power to predict high or low states of the factor being analysed. A positive score (see for example warden job satisfaction = 0.58) shows that increased levels of this measure increase the factor being analysed. So therefore, the tenant with dementia had higher well-being when their warden had higher job satisfaction. Conversely, a negative score (see for example social environment = -0.46) shows that increased levels of this measure decrease the factor being analysed. So therefore, other tenants had lower well-being when the number of social visitors to the scheme was higher.
2. The correlation shows the size of the relationship between the measure and high and low states of the factor being analyzed. The larger the correlation the more powerful and reliable the discriminator. Correlation's above approximately 0.50 are significant at the 5% level.

Table 23: Measures which discriminate between high and low levels of tenant with dementia well- being

Measures	Description	Discriminant	
		Function	Correlation
Job Satisfaction	Wardens general job satisfaction	0.58	0.59
MMSE	Cognitive ability	0.24	0.53
ADL	Tenant with dementia's ability to look after themselves	0.37	0.45
Gender		-0.57	-0.30

Table 24: Measures which discriminate between high and low levels of other tenant well-being

Measures	Description	Discriminant	
		Function	Correlation
Physical Environment	e.g. attractiveness, interest, clarity.	0.64	0.64
Social Environment	Amount of visitors to a scheme	-0.46	-0.62
Gender		0.47	0.59

RECOMMENDED FURTHER READING

Kitwood, T & Bredin, K (1992) *Person to Person; A guide to the care of those with failing mental powers* (2nd ed). Gale Centre Publications: Essex.

Kitwood, T. & Benson, S. eds. (1995) *The New Culture of Dementia Care*. Hawker Publication: London.

Mace, N.L (1985) *The 36 Hour Day* (2nd ed). Age Concern: England.

Stokes, G & Goudie, F (1990) *Working With Dementia*. Winslow Press: England

Archibald, C (1990) *Activities*. Dementia Services Development Centre.

Archibald, C (1993) *Activities //*. Dementia Services Development Centre.

Ongoing reading

Journal of Dementia Care. Hawker Publications.

REFERENCES

1. Kitwood, T. & Benson, S. eds. (1995) *The New Culture of Dementia Care*. Hawker Publications: London
2. See, for example: Kitwood, T. & Bredin, K. (1992) Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*, 12, 269-287
3. Kitwood, T. (1995) Positive long term changes in dementia: some preliminary observations, *journal of Mental Health* (forthcoming).
4. McKeith, I. (1995) Preliminary findings of the Newcastle Prevalence Study. University of Newcastle.
5. Ineichen, B. (1987) Measuring the rising tide: how many dementia cases will there be by 2001?, *British Journal of Psychiatry*, 150, 195-200
6. Willcocks, D. et al (1987). *Private Lives In Public Places*. Tavistock Publications : London.
7. Moos, R.H. & Lemke, S. (1984) *Multiphasic Environmental Assessment Procedure (MEAP) Manual*. Social Ecology Laboratory. Stanford University. Palo Alto California.
8. Moos, R.H. & Lemke, S. (1992) *Sheltered Care Environment Scale Manual*, Centre for Health Care Evaluation, Department of Veterans Affairs and Stanford University Medical Centres, Palo Alto, California.
9. Booth, T. (1985) *Home Truths; Old people's homes and the outcome of care*. Gower Publishing Company: England
10. Folstien, M.F. et al (1975) 'Mini-Mental State': a practical method for grading the cognitive state of patients for the clinician. *Journal Psychiatr Res.* 12, 189-198
11. Kitwood, T. & Bredin, K. (1993) *Evaluating Dementia Care: The DCM Method*. 6th Edition Bradford Dementia Group.
12. Pattie, A. & Gilleard, C. (1979) *Manual of the Clifton assessment Procedures for Elderly (CAPE)*, Hodder & Stoughton, London.

13. Jitapunkel, S. et al (1991) *The abbreviated mental test: Its use and validity*. *Age & Ageing*, 20, 332-236
14. Costa, P.T. & McCrae, R.R. (1985) *NEO PI-R Professional Manual* Psychological Assessment Resources, Inc. Florida.
15. Bradburn, N.M. (1969) *The Structure of Psychological Well-Being*. Aldine Publishing Company: Chicago.
16. Cook, M. (1990) *Levels of Personality* (2nd ed.). Holt, Rinehart & Winston: London.
17. Kitwood, T. (1993) Person and process in dementia. *Int. Journal of Geriatric Psychiatry*, 8, 7, 541-546
18. Buckland, S. (1995) *Well-Being and Personality in Residential Care*, in Kitwood, T. & Benson, S. eds. (1995) *The New Culture of Dementia Care*. Hawker Publication: London.
19. Felce, D. & Jenkins, J. (1978) *Measuring client engagement in residential settings for the elderly*. Research report no. 120. Wessex RHA.
20. Felce, D. & Jenkins, J. (1979) Engagement in activities by old people in residential care, *Health and Social Services Journal*, 2, November.
21. Riseborough, M. & Niner, P. (1994) *I Didn't Know You Cared; A Survey of Anchors Sheltered Rousing Tenants*. Anchor Housing Trust: Oxford.
22. Rolfe, S. Mackintosh, S. & Leather, P. (1994) *Age File '93*. Anchor Housing Trust: Oxford.
23. Centre for Housing Research. A comparison of sheltered and amenity housing for older people. University of Glasgow. Scottish Office. 1988.
24. Fletcher, P. (1991) *The Future of Sheltered Housing- Who cares?* Policy Report. London: National Federation of Housing Associations
25. Willcocks (1983a) *Gender and the care of elderly people in Part III accommodation*. Paper presented at BSG conference.
26. Adamson (1981) *Old women- The experience of ageing and implications for a feminist social work practice*. Unpublished MA dissertation. University of Warwick.
27. *Caring for people: Community Care in the next decade and beyond*. HMSO. Cmnd 8490. 1989
28. Fletcher, P. & Gillie (1991) *The Future of Sheltered Housing - Who Cares?* Practice Guide. Anchor Housing Trust: Oxford.
29. Kitwood, T. (1995) Positive long-term changes in dementia: Some preliminary observations. *Journal of Mental Health*, 4, 133-144
30. Watson, R. (1994) Towards a Compassionate Model of Care. *Journal of Dementia Care*, 1(6), 18-19

ABOUT THE RESEARCH

This is a time when, as never before, the needs of those who have dementia have become a matter of serious and general concern. It is clear now that the old culture of care was often ignorant and heartless; many people were sentenced to a futile and loveless existence in their declining years, and deprived of the personal respect that is their birthright. Now, however, we are beginning to see dementia in a more positive light, and standards for care practice are rising.

The issue of care provision is an urgent one. As the population in societies such as ours has grown older, the number of people with dementia has risen steadily. In the United Kingdom now the total is probably between half and one million, and by 2010 the numbers will almost certainly have risen further. So the question about 'Brighter Futures' is one that has to be faced.

The research reported here has been funded equally by Anchor Housing Trust, Methodist Homes, and Bradford Dementia Group. It consists of two parallel studies; one related to residential and nursing care, and the other to sheltered housing.

Both studies are concerned with identifying the conditions most likely to promote the well-being of people who have dementia. Both studies lead to the conclusion that there are grounds for optimism about the future, if the right kind of action is taken now.

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