

Home from home

A report highlighting opportunities for improving standards of dementia care in care homes

Two thirds of people
living in care homes
have dementia

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Foreword



Taking the decision to move to a care home will never be an easy one, either for the person with dementia or their family. I know this all too well from my own personal experience. Until we have a major shift in priorities and particularly funding priorities we are not going to achieve the level of care that people with dementia deserve. The way we treat the elderly in our society remains a national disgrace.

This report presents a picture of the current state of dementia care in care homes. It tells us that there are no guarantees of the quality of care a person might receive. Some homes are clearly doing a fantastic job, but why is this not the case for all? The experiences of carers reported here also tell us that it is the people delivering that care that matter – so why are many so undertrained and underpaid? Providing good dementia care is a highly skilled job and should be treated as such.

The report looks at what needs to change if all care home residents who have dementia are to get the care they deserve. This starts with challenging our own expectations about the standard of care people with dementia, and the elderly in general, have the right to receive. People with dementia are not second-class citizens and should be entitled to first-class care. Anything less should no longer be acceptable to them or us. The care home system must be designed around high expectations, through improved inspection and regulation, resource allocation and support from other services. Alzheimer's Society has long campaigned for quality dementia care in all settings and will continue to do so. I welcome this call for action to improve the lives of the thousands of people with dementia living in care homes.



Executive summary

1 Summary of findings

Two thirds of care home residents have some form of dementia (244,000 people). This figure is likely to increase as people with lower level needs are supported to live at home.

Only 60% of these individuals will be in dementia-registered beds (which are targeted at people with a high level of specialist needs) therefore it is vital that the whole sector is geared up to provide good dementia care.

The excellent care provided by some homes makes a huge difference to their residents' quality of life. Carers hugely value the efforts of staff who provide this level of care. It must be provided consistently in all homes.

Many homes are still not providing the level of person centred care people with dementia deserve. Key problems include:

- 1 provision of activities and occupation
- 2 treating residents with dementia with dignity and respect
- 3 relationship between care home and relatives/friends.

The support from external specialist services, eg OPMH teams, is unacceptably variable.

Care staff responding to our survey enjoy their work, and would like more training opportunities and support to improve their skills as well as to be recognised for the important work they do in caring for some of the most vulnerable in our society.

2 Purpose of report

This report was produced as part of the Alzheimer's Society 'Putting care right' campaign with the aim of providing an up-to-date understanding of carers' perceptions of the quality of dementia care provided in care homes and recommending action to bring the quality of all homes up to that of the best.

3 Overarching issues relating to dementia care in care homes

- There must be recognition and response to the fact that the primary task of the care home sector is providing good quality care to people living with dementia.

- The expectations of the quality of life that can be experienced by people with dementia in care homes need to be much higher. The bar is set too low.
- Long-term care is about living one's life. Good care homes have a good atmosphere and warm relationships among residents, staff and relatives. Policy goals for residential care must reflect this by prioritising social needs alongside safety.

4 Frequently raised issues where carers were unhappy with the care provided

4.1 Lack of activities and occupation

- 54% of carers reported that their relative did not have enough to do.
- An Alzheimer's Society survey found that the typical person in a home spent only two minutes interacting with staff or other residents over a six-hour period of observation, excluding time spent on care tasks.
- This problem is particularly acute for people with severe dementia; a number of carers reported that their relative was left alone in their room for hours with no attempt from staff to engage with them.
- Many carers reported that their relative had no access to outside space or gardens.
- Research shows that availability of activities and opportunities for occupation is a major determinant of quality of life and affects mortality rates, depression, physical function and behavioural symptoms.
- Staff enjoy providing opportunities for activity and occupation and would like to be able to do more of this within their work.
- There is no shortage of types and levels of activity and occupation that have been developed and described for people with dementia. Applying occupation and activity as part of regular care practice poses the real challenge.

4.2 Failure to treat people with dementia with courtesy and respect

- Examples included care staff failing to offer privacy and talking about residents in a disparaging way.
- Standards of personal care provided in some homes were poor, for example lack of basic dental hygiene and bathing. Carers found this very upsetting and cited that their relative would be very unhappy that their standards of personal hygiene were not met.

- Assessment and care plans failed to recognise the unique histories and characteristics of individuals with dementia, therefore restricting the quality of person centred care provided.

4.3 Involvement of friends and families in the care home

- Almost one in four respondents were unsatisfied with the level of their involvement in decision making about the care of their relative.
- Over one in four carers felt they did not receive enough information and updates about the care and treatment of the person they cared for.
- A number of carers were unhappy that they were not informed when falls and injuries happened and that it was difficult to find out how injuries occurred.
- Maintaining good relationships between the relatives and the home and supporting the ongoing relationship between relatives and the person with dementia has important benefits for both parties, including carers' degree of stress, residents' quality of life and engagement in activity.
- Care staff can find this a difficult, yet rewarding, area of their work. It is essential that they are supported by management to maintain good relationships with families.
- Some carers are still reluctant to raise concerns with the home because of concerns for the implications for their relative. An independent route for complaints that is open to all is essential.

4.4 Support from specialist services

- One third of care home managers reported no support or very limited support from the local older people's mental health service.
- One quarter of care home managers listed accessing advice from external services as one of the top three challenges in providing good dementia care.
- This is despite government policy statements that care homes should receive good support from specialist services, through advice, support and training.
- Support from specialist dementia care services can improve the quality of care provided, reduce the use of harmful neuroleptic drugs and potentially reduce the number of hospital admissions.

4.5 Staffing

- Carers were clear that the care team were the basis for a home's success. We received many good reports of extremely hardworking and caring staff.

- The top three challenges to providing good dementia care from a care home manager's point of view relate to developing a staff team with the right attributes and skills and keeping them motivated.
- A well-supported, fulfilled workforce who are confident in their skills and motivated in their work will be better able to provide excellent care to residents with dementia.
- Training should help staff understand what a difference they can make to residents' quality of life by providing good quality person centred care. Staff need to be hopeful about what can be achieved with people with dementia and training should encourage positive attitudes to dementia when it is recognised or diagnosed.
- Training can reduce staff turnover and increase job satisfaction, and focused training interventions have been shown to reduce the use of neuroleptics and increase communication between staff and residents.
- To sustain the benefits of training it must be supported by a formal staff management and support programme, alongside positive reinforcement of good practice.

5 Recommendations for action

5.1 Training in dementia care must be mandatory for all care home staff

Training must:

- be supported by a commitment from government to provide adequate funding, through simple to access sources
- be recognised and supported by the regulation and inspection system.
- be supported by a career structure and linked to pay
- be supported by a programme of support and effective management to ensure implementation
- help care staff to understand what a difference the care they provide can make to the quality of life of residents' with dementia.

Development of the training programme should involve all stakeholders to ensure that it is widely accepted. The development of the National Dementia Strategy should provide an opportunity to produce workforce development plans.

5.2 Inspection and regulation systems should acknowledge that dementia care is the primary role of the sector

The inspection and regulation system must:

- focus on outcomes of most importance to people using the services. For people with dementia in care homes, this means that meeting residents' social needs must be a high priority
- ensure that residents have access to outside space and that those with severe dementia are supported to access gardens if it is appropriate for them.

5.3 Local authorities have an important role to play in improving the quality of care home provision in their local area, through commissioning for quality and negotiating a fair price for caring for people with dementia.

5.4 There is evidence that older people's mental health liaison services can potentially improve care in care homes and save costs, resources must be available to enable policy advocating these links to be implemented.

5.5 Systems for sharing good practice among care homes should be supported on a national basis.

5.6 The development of specialist assessment procedures that are systematic and standardised in approach should lead to more coherent care for people with dementia.

Standardised specialist assessment procedures for people with dementia that add to a proposed common assessment framework, should seek to improve liaison between primary and secondary care and care homes, reduce the variability in the quality of assessment and ensure ongoing monitoring.

6 Facts and figures

700,000 people in the UK have dementia. Over a third of people with dementia (244,000) live in care homes. (Alzheimer's Society, 2007)

Dementia is the strongest determinant of entry into residential care in over 65s. (Alzheimer's Society, 2007)

Two-thirds of care home residents in the UK have dementia. (Alzheimer's Society, 2007)

7 How was the information collected?

Three questionnaires were distributed among the following groups:

- carers – 1,859 responses received (estimated 79% response rate)
- care home managers – 772 responses received (24% response rate)
- care home staff – 1,503 responses received (16% response rate).

Personal experience

Visiting my dad

I enter into the foyer, squirt my hands with anti-bacterial liquid and sign in. I then go to the secured first floor, which is locked with a keypad, and begin the search for my dad. First I check his room. His name and photo are on the door, though this does not deter other residents from entering his room at times! One particular gentleman likes my dad's room so much he has been known to fall asleep there! To make dad's room more homely, we have brought some items from his flat, including his TV and VCR, old clock and pictures. He also has a radio and CD player, but this often migrates to one of the lounges! Alternatively odd things, like photos and glasses that don't belong to my dad, migrate into his room!

If dad's room is empty, then it's on to the lounge, where chairs are placed around the wall, so everyone can watch the telly, which is usually on or maybe a video is playing or music. There is not enough space to put the furniture any other way. The adjoining dining room has wooden tables and chairs but no carpet, which makes the floor easier to clean, but the room seems clinical and cold.

As I make my way down the long corridor, where pictures of flowers, landscapes and photo collections of residents decorate the walls, I greet other residents as I go. I find my dad in the other lounge, the telly is on but he's not watching it. This time he is sitting on his own, but sometimes he is in a room full of people where the staff sit with the residents.

Depending how my dad responds (he has Lewy-Body Dementia, which fluctuates greatly) we either sit and talk, or walk along to the conservatory, which is much better since they built a decking area outside of it, where residents can sit, but only when staff are available to accompany them. Sometimes we go back to his room, listen to music or watch a video, interrupted at times by residents wandering in and out. But on other occasions, my dad just sleeps irrespective of what is going on around him. So what does my dad do when I'm not around?

I still wonder about the staff ratio and just how much time is spent doing activities with the residents. And whether the staff are overwhelmed by the volume of work when helping residents with their physical needs, especially when residents have bladder problems? And what about the staff? How are they trained and supported for caring for the elderly, with or without dementia, is one of the most demanding jobs on the planet! Anyway, moving on -

My visit lasts for 1-1½ hours and I leave when tea begins and that's when my guilt begins. Sometimes my dad wants to come with me or he wants me to stay. It's especially difficult when his conversation is lucid and I think, 'what is my dad doing in a care home?' Other times he is quite happy to go with the carers. In this residential care home, people with dementia live in the upstairs secure section of the building. I've often wondered if the residents with less severe dementia are made worse by living with those with severe dementia.

Although my dad's care home is a modern, purpose built institution, not in any sense of the word a home, and not the most ideal place, the staff make-up for it, as I can see they care for my dad and treat him kindly, with much affection and that's what's important. Also my recent visit, where I had a chat with the new Assistant manager, was most encouraging. Reassuring me that it was not always easy to change food stained or other stained clothing, as some of the residents put up quite a fight. We also talked about the welfare of my dad and trying to make where he lives as homely as possible, along with his continued care. She also stated that not only was she there as a support for my dad, but for me also, where upon I was able to share some of my feelings of fear of not doing enough and guilt. This was most helpful and reassuring and surprising, for caring for the elderly is often a lonely road to walk. It's good to have someone on your side.

Introduction

KEY FACTS

- 700,000 people in the UK have dementia. Over a third of people with dementia (244,000) live in care homes (Alzheimer's Society, 2007).
- At least two-thirds of care home residents in the UK have dementia (244,000 people) (Alzheimer's Society, 2007).
- 40% of people with dementia in care homes are not in dementia-registered beds (see Table A.3, Appendix A).
- 45% of care home residents have moderately severe to very severe cognitive impairment (Darton *et al.*, 2006)

Alzheimer's Society has compiled this report as part of its campaign to raise the quality of care provided to people with dementia. We aimed to bring together information from different sources, including a large survey, to provide us with an informed perspective to drive forward a campaign for better quality care. The thousands of reports we receive each year from people with dementia and their carers demonstrate the unacceptable variation in standards of care around England, Wales and Northern Ireland, ranging from excellent to mediocre to disturbingly neglectful. These are supported by national reports which paint a picture of services, many of which are in clear need of improvement (Healthcare Commission, 2006 and National Audit Office, 2007).

700,000 people in the UK have dementia and residential care provides a home for one-third of these individuals. We know that good quality care improves the lives of care home residents with dementia and it is therefore essential to address the current quality of dementia care in care homes and the challenges to ensuring excellent outcomes for all.

This report presents the current state of dementia care in residential and nursing home facilities from the perspective of carers. It also highlights some of the key challenges in providing good dementia care from the point of view of care staff and care home managers. The perspectives of carers are different from those of people with dementia resident in the care home but both are valid. Carers are in a unique position through knowing the person with dementia prior to their dementia and also experiencing care homes as a service user might. They are often able to articulate views that their relatives may not be able to do on their own behalf. The Commission for Social Care Inspection

(CSCI)'s report of its thematic inspection into dementia care in care homes expected in Spring 2008 will provide a very useful insight into the experience of care home residents with dementia.

To gather the views of carers, three focus groups were held and we collected the views of nearly 2,000 carers with recent experience of care homes via a questionnaire. We also sent questionnaires to care homes and received responses from nearly 800 care home managers and over 1,500 care staff.

Carers' questionnaire

The questionnaire was sent to the entire Alzheimer's Society membership via the newsletter. This represents 26,000 people of whom the last membership survey revealed about 9% (2,340) are caring for someone in a care home.

- 1,859 responses were received (an estimated 79% response rate).

Relationship to care home resident:

- 820 spouse or partner
- 54 friend
- 791 son or daughter
- 183 'other'.

The following numbers of carers had experience of the different types of home (some had experience of more than one type of home):

- care home only: 424 people
- care home with nursing: 577 people
- specialist dementia care home: 925 people.

Care home managers questionnaire

The questionnaire was sent to 3,230 care home managers randomly selected from a database of all care homes with at least one dementia registered bed in England, Wales and Northern Ireland.

- 772 responses were received (24% response rate).

The spread of managers across each care home types was as follows:

- care home only: 366
- care home with nursing: 148
- specialist dementia care home: 388.

Care staff questionnaire

Three copies of the care staff questionnaire were sent with each care home manager questionnaire with a request to distribute them to staff. This represents 9,690 questionnaires.

- 1,503 responses were received (16% response rate)

The spread of care staff across each care home types was as follows

- care home only: 546
- care home with nursing: 453
- specialist dementia care home: 673.

We know much more now about how to provide good quality, person-centred dementia care and why it is important to ensure services are working to these high standards. But the current system does not enable or support consistent high quality care. Alzheimer's Society believes that this can in part be explained by endemic ageism, but also 'dementia-ism' whereby people experience prejudice because of their cognitive decline. As Dawn Brooker describes in her very welcome book 'Person-centred dementia care: making services better' (2007) this discrimination is evident in service provision, resource allocation, policy priorities and professional training. As a society, we need to reassess how we value those of us who have dementia and the expectations about the quality of life we deserve. There must be a commitment from all who have a part to play in dementia care that low standards are no longer acceptable.

1 Dementia care in care homes

KEY POINTS

- The impact of dementia in each individual is profound. Care staff perceive communication problems as one of the biggest challenges in providing good dementia care.
- The majority of carers were positive about the dementia care provided to their relatives, but many people reported key problems including poor standards of dignity and respect, dementia becoming a label and a lack of knowledge or skill in how to respond to the symptoms of dementia.
- As only 60% of the people with dementia in care homes are in dementia-registered beds, standards of dementia care across the whole sector must be improved to ensure the needs of all residents with dementia are met.

‘I cannot speak highly enough about this home. My mother is 93 and lived in isolation alone at home. She loves company and every time I visit her she tells me how happy she is there. It is just one year since she moved there and I do not detect any deterioration in her condition.’

People with dementia dominate the care home population. But is the care home sector currently meeting the needs of their biggest proportion of residents? This chapter looks at some of the broad issues relating to how care homes respond to the needs of people with dementia. It addresses:

- how dementia symptoms impact on an individual’s needs in a care home
- the problem of under recognition of dementia in homes
- carers’ views of homes’ response to the symptoms of dementia.

1.1 Impact of dementia and the challenges it creates for staff

The impact of dementia in each individual is profound. Dementia can affect a person’s memory, speech, and ability to complete activities of daily living. Problems with eating are common and in the later stages people may experience urinary and faecal incontinence. In time dementia leads to

Table 1.1

What do care staff find most difficult about caring for people with dementia?

Things that care staff find most difficult about caring for people with dementia	Proportion of staff (%)
Communication / not being about to get through to residents	18
Dealing with aggressive/violent/abusive behaviour	17
Understanding residents' behaviour/difficulties/frustrations	10
The relatives / demanding families / their lack of understanding	7
Challenging behaviour / behaviour problems (unspecified)	7
Not enough time / unable to spend quality time with residents	7
Memory loss / asking for people who have passed away	5
Emotional reaction of residents / families / carers	5
Repetition / repeating yourself/themselves / being asked the same thing	5
Demanding/stressful work	5

increased disability and possibly immobility, making the use of hoists necessary for safe transfer. Good skin care is also vital to prevent pressure sores. People with dementia may also experience hallucinations and delusions. Most dementias are progressive and so staff, carers and people with dementia are coping with a changing pattern of abilities over time. Also people with dementia are very vulnerable to physical illness which may lead to heightened confusion and delirium that can go unrecognised as people often think this is just part of the dementia.

Communication problems can be a particular challenge in the care home setting, and many people with dementia communicate through behaviour that may be seen as challenging, for example hitting out. This can and often does lead to overuse of sedatives. Communication problems make a person with dementia increasingly vulnerable to exclusion and isolation and make it difficult for them to form relationships. As a result, people with dementia are at risk of being neglected and ignored if care staff do not have the skills to communicate effectively. In addition, people with dementia may be over-represented in the group that care staff find the least rewarding to care for, or whom they find most difficult.

Given the range and seriousness of the symptoms of dementia, it is clear that caring for residents with dementia is a highly skilled task. We asked care home staff to tell us about what they found challenging about providing good dementia care and a wide variety of aspects of care were raised (Table 1.1)

Many of the responses were concerned with communication. Understanding the challenges as perceived by care staff helps us understand the issues upon which training should focus as well as how to improve care by teaching strategies to deal with particular issues such as repetitive questioning.

1.2 Under-recognition of dementia

Recognising that a person has developed dementia is the first step towards developing a care plan that meets their needs (MacDonald and Carpenter, 2003). Sometimes people do not want the label of a diagnosis of dementia because of the stigma that goes along with it. However, it is helpful for people to be properly diagnosed. It allows access to appropriate agencies and support networks and means people can plan for the future. Diagnosis can also allow for therapeutic interventions, such as structured group cognitive stimulation programmes, which can support the maintenance of cognitive ability.

The level of under-recognition of dementia is an important barrier to providing good dementia care. Firstly, newly admitted residents may have undiagnosed dementia and secondly, residents may develop dementia while in the home, which is not recognised.

Challis *et al.* (2000) found that 85% of people newly admitted to a care home and with a Mini Mental State Examination (MMSE) score of below 9 had no diagnosis of dementia, neurological disorder or other psychiatric phenomenon, despite their severe cognitive impairment. Given that only a third of people with dementia receive a diagnosis (National Audit Office, 2007) it is not surprising that many people with dementia enter a care home with no formal diagnosis. The significant number of carers who reported that it became clear the home could not meet the individual's needs soon after admission highlights the need for a good pre-admission assessment. This can be neglected particularly when there is pressure to find a care home place for that individual. Poor pre-admission assessment and recognition of needs resulting in inappropriate placements and moves is extremely unhelpful and adds stress to an already difficult situation. Being moved was most frequently the case amongst residents who were still physically active.

'My husband went into care in January of this year. He was there for four weeks when we were told he would have to leave. He was a bit too much trouble for them. Wasn't prepared to sit in his chair and watch TV all day. He was one who was walking around and opening doors, one thing or another'

Rates of recognition of dementia among existing residents have been found to be as low as 34% in non-specialist nursing homes (MacDonald and Carpenter, 2003). This must improve with the support of local specialist services. Early diagnosis of individuals already resident in a care home allows them to input

Table 1.2

How satisfied are carers with the care provided to their relative/friend?

Rating	Overall satisfaction with quality of care provided at the home (% of respondents giving that score)	How well the home understands the needs of people with dementia (% of respondents giving that score)
1 very unsatisfied	3	4
2	3	5
3	9	10
4	22	22
5	37	30
6 very satisfied	25	29

into decisions around future care and make arrangements for finance and other matters. Recognition of dementia must be followed by thorough assessment, with specialist input, and the development of appropriate care strategies based on the assessment.

1.3 How do homes respond to the needs of people with dementia?

Reports from carers who are happy with the care provided to their relatives help us understand what outcomes are important to them. The staff team are key – what really matters to carers is whether their friend/relative is cared for by someone who cares about them. It is so important that staff teams interact with residents and encourage social interaction between residents. Care homes should be a home from home, where residents are supported to maintain their skills and interests and are treated with respect and care. Of course nice decoration is valued, but a pleasant atmosphere is often regarded as more important than a plush environment. The relationship between staff and carers is also important.

Carers were asked to rate on a scale of 1–6 (with six being very satisfied) how satisfied they were with the overall quality of care provided to their relative and how well the home met the needs of people with dementia. The results are shown in Table 1.2.

On the one hand the results seem to show that the majority of people are happy with the care provided, but when questioned further it becomes clear

that people have very serious concerns, for example in relation to activities. Alzheimer's Society is concerned that many people hold low expectations. 54% of respondents said that their relative did not have enough to do during the day. 68% of this group nonetheless rated their satisfaction with how well the care home understands the needs of people with dementia as between 4–6.

The comments below from carers who have had good experiences reflect how much they value the care provided to their friend/relative. We need to understand how to harness and support consistent provision of this level of care.

'I could not wish for a better home for my husband. All visitors are treated wonderfully and patients treated with respect and dignity. As if they were their own family, well done.'

'I think it is a perfect care home. I live 130 miles away and visit every week. I have lunch there with my Mother and am treated like one of the family. Nothing is too much trouble and all the young care workers treat the residents with respect and great care. It is a pleasure to visit.'

1.3.1 Key problems reported by carers

Much has been written, in government policy and organisations' goals, about the importance of person-centred care but our research demonstrates that the care provided to many people with dementia falls far short of this. Key problems reported by carers included:

- Basic standards of courtesy and respect being ignored when working with people with dementia.
- Dementia becoming a label behind which other needs were lost.
- A lack of knowledge or skill in how to respond to the symptoms of dementia.

1.3.1.1 A diagnosis of dementia can mean basic standards of courtesy and respect are ignored

'Would not recommend the home to dementia sufferers, as staff would sometimes see residents as a bit of a nuisance.'

There were worrying reports about the lack of respect shown by some staff members to residents with dementia, for example making fun of residents and talking about them in a disparaging way. Other carers reported that residents were treated like objects while personal care tasks were carried out.

'I don't like the way the staff talk about the patient's problems in front of them. It is upsetting for the patient as they find it difficult or impossible to reply.'

‘I don’t like to see them sneering at people. I see a lot of that. You know rising them up and I don’t like that you know... I’ve had to say a few times. You don’t do that to people.’

A number of carers complained that there was no attempt to support the individual with dementia to have freedom of choice over their lives – when to have a drink, what to wear, when to go to bed for example.

‘Somebody had asked for a cup of tea and they had said ‘oh no you can have it later’. If it was anywhere else that somebody said ‘you would have to wait till later’, they probably wouldn’t have said it to anybody else. Because its ok and time doesn’t mean much to them but that’s taken everything away from them.’

‘I feel that ‘holistic’ care is abandoned because the clients have a dementing illness, for example, choices should still be given to the client on what they would like to eat, what they would like to wear, what they would like to do with their day etc. Spiritual/religious beliefs should also be catered for.’

Standards of personal care provided to people with dementia were also of concern to many carers. Many highlighted that their friend or family member had always had very high standards of personal hygiene and would be very unhappy with the one bath a week that they now received or the lack of teeth cleaning.

‘My husband still has his own teeth at the age of 91! Unless I go to the home he is not reminded to clean them – which seems a small thing I know, but it matters to me as he always took care of them previously.’

Residents not having their own clothes was another issue in relation to the standards of dignity and respect shown to residents. Glasses and teeth going missing were also frequently reported. Many homes manage to avoid this problem. One carer reported to us that she was pleased with how the home avoided this problem and provided some choice about what to wear:

‘The care home put two sets of clothing out for the client to choose from in the morning. Once the decision is made the other items are locked back in the wardrobe.’

1.3.1.2 Dementia becoming a label behind which other needs were lost

The needs of people with dementia living in long-term care are many and varied. People have unique histories and will react to their situation in many different ways. Some of these reactions will be due to dementia, others will not. Some carers had experience of everything being put down to their relative’s dementia and were understandably concerned that other needs would be missed because of this. This highlights the importance of individualised assessment and analysis. Person-centred care plans and interventions should

be based on this assessment, to enhance well-being by appropriately matching activity and occupation to persons with dementia, or reducing disturbed mood or behaviour (Cheston, 1998; Verkaik, Van Weert and Francke, 2005).

‘I think there should be people there for me to talk to. For me to be able to go over to a nurse and say “look, how is my mum today”. All that I get out of them is ‘well, you know it’s the dementia.’ You know that’s their answer to everything...’

Carers were often frustrated that particular behaviour was dismissed as just a symptom of dementia rather than the communication of frustration, pain or another feeling or need. Carers have experienced the person they care for being labelled ‘difficult’:

‘(the social worker) listened to everything the manager said and the staff and they talked about my mother as very ... like ... they couldn’t cope with my mum, she is very difficult, that is how she was labelled. I thought what about the approach, my mother is not a horrible person and it is your approach towards her maybe why she behaves that way. And there is no one listening. I tried to explain to them how to cope with her, maybe that would help, and they didn’t want to know...’

1.3.1.3 A lack of knowledge or skill in how to respond to the symptoms of dementia

‘And I think my other concern is ... that often people go into a care home, the care homes are registered and they say that they can provide the care that the person needs and they clearly can’t, and you’re dealing with a situation where people are being moved on all the time, not through any fault of theirs but because the care homes haven’t got the qualified staff to deal with the issues that come up with dementia. And if you are registered as a care home for dementia care then you should be able to provide care.’

Caring for people with dementia demands a high level of skill. Lack of staff knowledge or skills is often highlighted as a reason for interventions not achieving positive results (Ballard *et al.*, 2002; Turner, 2005). The value systems, knowledge and skills of staff are fundamental to providing good quality care for people with dementia. It is important that staff understand what a difference good quality care can make to the wellbeing of people with dementia. It is unacceptable that some people with dementia are still experiencing very poor care and little understanding of their symptoms. Carers reported a range of problems homes had in responding to the needs of people with dementia. One example is a home that always served a woman who required puréed food last at mealtimes. The carer explained:

‘They had to blend her food for her but she was always served last and she cried every day. And they just said “she’s crying again, she knows every day

she's going to get her food." Now anyone would put it on her table first to stop her getting distressed everyday.'

A number of carers reported that while the home was registered to take people with dementia, it had not been able to cope with individuals with dementia who are active. There must be more places well-equipped and able to support those who remain physically active – some of whom will be younger people.

'They can't cope with people who don't conform and sit still. My father was constantly falling and ended up in hospital – where he remained in a specialist dementia ward and where they understood his needs. I don't think any standard nursing home is capable of this. There needs to be more specialist training.'

1.4 Dementia-registered beds

Two-thirds of care home residents have dementia and 40% of these individuals are not in dementia-registered beds. CSCI guidance states that many people with dementia will be in the general care home sector and dementia-registered beds are for individuals' whose needs cannot be met by general care homes. However, if this is the case there must be mandatory requirements to ensure the general care home sector is trained and supported to meet the needs of people with dementia. In particular the care home workforce require skills in communication and engagement to reduce the risk of isolation among those residents with dementia who are quiet and withdrawn and maybe unlikely to be in specialist care (which may focus on those who display so-called challenging behaviour).

The National Audit Office was concerned that the low number of specialist dementia beds inhibits diagnosis and leads to a 'lack of visibility of the need for dementia training in care home settings (National Audit Office, 2007).' There must be wide understanding of the fact that a person with dementia can be placed in a general care home if it meets their needs. Standards which resulted in the care home sector as a whole being able to meet the needs of people with dementia would help to avoid reluctance to diagnose.

In addition to driving up dementia care standards across the sector there must be increased provision of places that are well-equipped and able to support those who are most distressed, restless and physically active – some of whom will be younger people. Specialist homes would be well-placed to act as a resource for other homes, providing support and advice.

1.5 Summary and conclusions

The high-quality dementia care provided by some homes demonstrates that excellence can be achieved and provides an incentive for all homes to reach the standards of the best. Alzheimer's Society calls for:

1.5.1 A vital step forward in improving dementia care is to acknowledge that dementia care is a key task of the care home sector

- The system must be designed accordingly, including mandatory dementia care training.

1.5.2 Training staff in recognition of dementia

- Under-recognition of dementia in care homes highlights the need for the implementation of the NICE recommendation that all staff working with people with dementia receive appropriate training – which for care home staff would include recognition of dementia.
- The English Department of Health national dementia strategy will also focus on raising awareness and improving early diagnosis. Supporting care home staff to play their part in early recognition will be an important part of the strategy.

Further information and guidance

Alzheimer's Society Quality Care Programme produces a range of publications promoting excellence in dementia care and runs an extensive training programme to complement the publications. Publications include:

- Quality dementia care in care homes: person-centred standards – helps managers and staff focus on the needs of people with dementia.
- Featherhead DVD – looks at the experience of people with dementia and the people closest to them. The accompanying notes suggest how to facilitate learning from the film.
- Alzheimer's Society guide to the Dementia Care Environment – provides instrumental guidance on simple design rules and principles.
- Yesterday, today, tomorrow video/DVD training package, with training manual – helps staff gain a greater understanding of dementia and become more confident in supporting the people in their care

For more information on training materials and courses available please go to www.alzheimers.org.uk/working_with_people_with_dementia

Other information

Brooker D, 2006, Person-centred dementia care: making services better – gives fresh definition to the important ideas behind and the implementation of person-centred care for people with dementia. It contains a tool for care providers to use to assess how well they think they are doing at providing person-centred care. Available from: www.jkp.com

2 Activities, engagement and occupation

KEY POINTS

- Opportunities for activity and engagement have a huge impact on quality of life and affect important outcomes including mortality, yet over half of carers felt the person they cared for did not have enough to do during the day in the home.
- This supports previous research. For example, a survey of 12 homes found that over a six-hour period the median resident spent less than two minutes in conversation (or other forms of communication) with staff or other residents, outside of care tasks.
- People in the later stages of dementia are particularly at risk of isolation and lack of stimulation.
- Many people with dementia, particularly those in the later stages, are not able to access outside space.

‘I never saw evidence of any entertainments at the first home my mother was in, while all sorts of things have been done at the one she is in now. There are annual summer and Christmas parties for clients and their families with staff and their families. It’s really nice to see young children so cheerfully involved. Such a lot of effort and planning goes into these and it’s lovely to participate in the party atmosphere with my Mum.’

2.1 Introduction

Mary Marshall noted in 2001 that ‘only relatively recently have we understood that people with dementia need to be more than clean, warm, and comfortable.’ The National Minimum Care Standards for Care Homes for Older People (Department of Health, 2003) states that service users, particularly those with dementia, should have opportunities for stimulation through leisure and recreational activities which suits their needs, preferences and capacities. The findings presented here suggest that many homes have not moved on a great deal since then. Over half of survey respondents said their relative did not have enough to do during the day.

‘Care seems to be wash them, change them and feed them with very little else. For someone with early onset dementia it is a bleak existence.’

2.2 What does research tell us about occupation/engagement?

Having something meaningful to do is an important part of quality of life (Ball *et al.*, 2000) and this is as true for people with dementia in care homes as it is for the rest of the population. Occupation need not necessarily be a formal, structured activity. Laying a table, cleaning or folding laundry are all examples of everyday activities that people may enjoy. Pleasant interaction between staff and residents while carrying out care tasks and other times is also essential.

2.2.1 The importance of occupation

Opportunities for occupation and pleasure in care homes significantly affect outcomes for residents. Those people who obtain little pleasure from things they do in the home are more likely to die and more likely to be depressed after nine months (Mozley, Sutcliffe, Bagley *et al.*, 2004). Inactivity and low levels of engagement also contribute to loss of physical function, social isolation, behavioural symptoms and poor quality of life (Mor, Branco, Fleishman *et al.*, 1995; Alessi, Yoon, Schnelle *et al.*, 1999). A study which explored the meaning of activity from the perspective of individuals with dementia in the community found that taking part in a variety of everyday activities, including housework, social involvements and recreational activities, provided meaning and supported their sense of self (Phinney, Chaudhury and O’Connor, 2007).

Elaine Murphy points out that good homes are those ‘where there is a satisfying bustle, where staff are engaged in conversation and daily mutual banter with residents, where even the most disabled person is brought into an exercise or music group and included in outings, where the televisions are kept out of sight in residents private rooms’ (Murphy in Mozley, Sutcliffe, Bagley *et al.*, 2004). This highlights the need for stimulation through interaction with others. Kitwood highlights that ‘doing activity’ is only one way of creating engagement. He notes ‘All that is required for engagement is that the person’s mind is consciously active, or mindful’ (Kitwood, Buckland and Petre, 1995). The uniqueness of each individual with dementia means that activities and occupation need to be tailored to their individual needs.

There is an increasing number of structured or therapeutic activity-based interventions that have been utilised with people with dementia, on both group and individual bases, with a wide range of aims. These include reality orientation (Spector *et al.*, 2000a, 2000b); cognitive stimulation therapy (Orrell *et al.*, 2005); reminiscence and life review (Spector *et al.*, 2000c; McKee *et al.*, 2005); music therapy (Aldridge, 2000; Sherratt *et al.*, 2004a); art, writing, dance and movement

(Allan and Killick, 2000; Coaten, 2001); drama (Batson, 1998; Chaudhury, 2003); aromatherapy and sensory stimulation (Ballard, O'Brien *et al.*, 2002; Holmes *et al.*, 2002; Smallwood *et al.*, 2001); Snoozelen (Baker *et al.*, 2003); intergenerational programmes (Jarrott and Bruno, 2003); Montessori-based methods (Camp and Skrajner 2004); doll therapy (James *et al.*, 2005); the SPECAL approach (Garner, 2004); emotion-oriented care (Finnema *et al.*, 2000, 2005); horticultural therapy (Gigliotti *et al.*, 2004) and woodlands therapy (Pulsford, 2000).

In summary, there is no shortage of types and levels of activity and occupation that have been described for people with dementia. Developing a firm evidence base of what works for whom, when and in what setting is a difficult task. Given the heterogeneity of this population, the varied skill level of staff, the enormous variety of settings where activities take place alongside the problems of finding suitable outcome measures, it is not surprising that the research evidence for most of these activities is lacking (see reviews by Beck, 2001; Cohen-Mansfield, 2005; Gitlin *et al.*, 2003; Marshall and Hutchinson 2001; Sherratt *et al.*, 2004b; Thorgrimsen *et al.*, 2004 Verkaik *et al.*, 2005). Nonetheless, from a practice perspective, seeing someone light up with delight when engaged in an activity that has meaning for them, is evidence enough that this is a worthwhile endeavour. It is applying occupation and activity as part of regular care practice that poses the real challenge.

Unfortunately, the questionnaire results confirms previous research findings that activity and engagement is an unmet need. 54% of people said that their relative did not have enough to do during the day. Comments include:

'My wife has not been there for very long but complains of nothing to occupy her time on most days.'

'The problem in that care home is the lack of stimulation and lack of activities for the residents. They don't seem to do very much at all, other than sit around and watch TV, or listen to music. And that's what I would like to see changed.'

'The biggest problem appears to be conflict between short-term physical needs and long-term mental needs. My Mother is allowed to stay in bed and in her room too often this means she forgets the patterns required to keep her mentally stimulated and active. She has a happy personality and is easily coaxed!'

'I found my Father's files full of trite observations, minute detail of his bad language etc, but never found staff sitting with him or holding his hand...'

Previous studies have produced similar findings (Hancock, Woods, Challis *et al.*, 2006; Ballard *et al.*, 2001). An Alzheimer's Society survey of twelve nursing homes, using Dementia Care Mapping to understand the quality of care, found that over the six hour daytime period of observation, people spent more than 69 minutes (19.2%) asleep, but less than 29 minutes (7.7%) talking (or communicating in other ways) with staff or other residents, outside of care tasks. In addition, this

latter figure is skewed by a small proportion of residents with more active social interaction, and the median resident spent less than two minutes engaged in social interaction.

However, some carers reported that they were very pleased with the level of occupation and stimulation provided to their relatives. This quality of care must be extended to all homes:

‘We have recent experience of an event tailored to engage us and my brother-in-law and another resident. We all walked to the local pub in the company of the activities organiser. Three hours invested in two residents! Excellent.’

‘You can see the care put into this home with lots of activities and outings for residents. I feel content that my mother is being well cared for by the excellent staff.’

2.2.2 Engagement in the later stages of dementia

It is particularly important that care homes proactively address the needs of people with late stage dementia for occupation. These individuals are especially vulnerable to becoming isolated and starved of attention from staff and are likely to be very reliant on others to provide opportunities for engagement. It can be more challenging, require more skills and be more time consuming for staff to provide opportunities for stimulation and to interact with people who can no longer communicate verbally, particularly if training is inadequate and staffing levels do not allow for the time required. This is also true for people who display behaviour that some find challenging. However, over recent years, there has been a much greater recognition that it is possible to engage with people in later dementia and maintain quality of life and that it is important to do so.

Methods of engaging with individuals with severe dementia should be based on their needs as an individual. There is a range of guidance available to dementia-care providers to support the engagement of people in all stages of dementia in meaningful activities. One example is ‘The Pool Activity Level (PAL) Instrument for Occupational Profiling’ (Pool, 2002).

Carers reported a wide range of experience in terms of occupation and engagement for people with severe dementia, ranging from excellent to very poor. Many were concerned that staff spent time with the more able residents to the detriment of those with more severe cognitive impairment:

‘They always chat to Mum and squeeze her hand even though she can’t respond, they treat her as if she understands everything. Visitors are treated as family, they seem to love my Mum. I totally trust them with her.’

‘One Christmas they had one [party] downstairs in the garden and they had one in the activities room on the first floor. But the thing is, I took Bob to those and that time they had that guy who sang and he was quite a singer ...

I would always take him there at least to have a look at it. To get him out of the atmosphere of the unit. But the thing was the people in the unit who had no-one to take them or weren't able to get there under their own steam ... well they lost out completely. You know and that didn't seem fair to me ... It's easy to arrange activities for people who are not gone too far down the road as it were. It's harder for people who have gone well down the path. But nevertheless I don't think they try hard enough!

'Mum is bed-ridden and can no longer communicate and they tend to spend more time with the mobile residents and those who make a fuss. Mum's non-verbal are quite good if they would just spend a bit more time with her, especially at meal times.'

This corresponds with previous research findings which has found staff are more able to meet the occupational needs of less impaired residents who were more able to communicate and respond (Bruce, Surr and Tibbs, 2002). Residents with more severe cognitive impairment had their physical needs attended to but little time was left for social, emotional or occupational needs. Ballard *et al.* (2001) reported that more severe dependency was associated with less time engaged in activities and the authors stressed the need for measures to improve staff interaction with more cognitively impaired individuals. As the population of care homes is likely to become more dependent in the future the workforce must be equipped with the necessary skills to support activity and engagement for this group.

Research also illustrates that evaluation of a care home's standards of providing engagement and occupation should involve observation of activity sessions rather than counting the number of activities available – attendance does not necessarily lead to engagement (Kolanowski *et al.*, 2006). One study found that only 6.5% of residents at five care homes received appropriate activities despite high attendance at activity sessions (Buettner and Fitzsimmons, 2003).

2.2.3 Access to gardens

Access to outside areas is something carers hugely value as an opportunity for their relative to continue their hobby of gardening, or to benefit from taking exercise or being in the fresh air. A number of homes described their plans for sensory gardens. The Alzheimer's Society guide to the dementia care environment (2007) lists the therapeutic benefits of access to outdoor spaces as including:

- exposure to natural light and a range of temperatures
- increased personal space
- engagement in familiar activities
- exercise
- relaxation.

The benefits of a garden can change through the stages of dementia, at first providing opportunities for gardening activities and later promoting stimulation

of the senses and awareness outside of the self (National Institute for Health and Clinical Excellence / Social Care Institute for Excellence, 2007).

Unfortunately, carers of people with more severe dementia frequently reported that the gardens were completely off limits to their relative/friend because there were no care staff to accompany them to the garden.

‘The en-suite was rather lovely, but there was no garden so they couldn’t go out anywhere except to sit on a ramp. Now, if it was lovely weather, he couldn’t go into the car park, he couldn’t go into the lovely conservatory, because it would have had to be a carer to go in and look after him and there was not a carer to go in and look after him. I just wonder when they get planning permission to build these homes why they take up every inch of land to build more rooms to put people in, as that was a lovely old house but they had gone right up to the end of their ground around that house. So there was nowhere for them to go and walk. They just all sat around the rooms and no activity. The government lays down some laws about how these homes should be used, so why is it not that they miss out a couple of rooms so they get a small corner somewhere for a garden, and an activity person.’

‘They have a lovely garden which because the nursing floors are usually only staffed to the “minimum requirement”, those with severe dementia have no chance to enjoy unless brought down by relatives.’

‘I was impressed by a brochure of the home showing patients and staff enjoying the sunshine in their pleasant gardens. I asked If I could sit outside with Mother several times and on one occasion they could not find the key. It appeared the gardens were never used by patients.’

The NICE dementia clinical guidelines note that although there are few studies looking at the therapeutic benefit of access to gardens and the best design of gardens for people with dementia, some features of a residential home environment are arguably ‘inalienable rights’. Alzheimer’s Society strongly supports the guideline’s conclusion that it might be considered that all people with dementia in residential care should have the option to spend time in a safe outdoor environment.

2.3 Care home staff perspective on occupation

Staff report that engaging with residents with dementia and providing them with opportunities for occupation brings great job satisfaction. 70% said that helping residents with dementia be occupied through activities or just chatting was something they really enjoyed about their job. Care staff talked about how they enjoyed working with families to determine the best activities for people with advanced dementia. They were frequently concerned that staffing levels did not

allow them to provide the level of stimulation and engagement that they would like.

When asked what would bring more job satisfaction many raised greater availability of activities and more time to spend chatting and interacting with residents. Responses included:

‘Having more time to become involved in setting up one-to-one chats/activity therapy sessions.’

‘More allowance to do activities – more courses for staff to teach them options on activities beneficial to people with dementia.’

When asked what things they found most difficult about caring for people, comments included:

‘Not having enough time to sit and talk with residents about the memories they still have.’

‘You are not able to spend enough quality time with the more dependent residents.’

2.4 Summary and conclusions

The good experiences of many carers demonstrate that it is possible to provide a stimulating atmosphere that provides quality of life for people in all stages of dementia. This is what all homes should be aiming for. Higher expectations about the life that care home residents with dementia should be able to expect are essential, accompanied by a commitment to delivering these expectations.

2.4.1 Higher expectations

- It is important that people with dementia themselves and their carers know they should not have to accept hours spent in front of the television or no access to gardens. Their expectations can be a driver for change.
- Many care home groups are already committed to ensuring residents have a range of activities available to them and that staff work to avoid apathy amongst residents, but this needs to be extended to all.
- To support care homes to provide this type of care local and central government must also be working to the same high level of expectation in terms of the standards required, training, funding and support provided.

2.4.2 Staffing levels and skills

- Many carers felt the numbers of staff simply did not allow them to spend time interacting with residents. Others felt that staff did not have the skills to

use opportunities such as support with dressing and eating to engage with residents with dementia.

- As important as an adequate number of staff is ensuring staff know what they should be doing to support occupation and stimulation. Good leadership is needed for this, particularly to emphasise to staff that activities are not solely the task of the activities coordinator and to ensure staff understand that pleasant interactions with residents is as an important part of their job as personal care tasks for example.

2.4.3 Care plans

- Alzheimer's Society believes the care plan should contain details of activities based on the needs, preferences and abilities of the individual and that this should be regularly reviewed. Communication needs should be included in a care plan as improving communication can support engagement.
- Including this within the care plan will support staffs' understanding of how to engage with and provide meaningful activity for residents, enable families to understand how their relative is being supported in this respect and also provide additional evidence for CSCI. Given the need for occupation to be individually based, it is not sufficient for a home just to outline the type of activities available in the brochure.
- Alzheimer's Society South Tyneside branch reported that a local home developed activities files for each resident, which supported good communication between staff and enabled relatives to see at a glance what their relation is doing.
- Jackie Pool writes that given that most care staff are not able to spend a long time with each resident, activities that are most important to the individual should be prioritised. She provides the example of a resident to whom fashion and personal appearance has always been important. Staff should prioritise spending time supporting this resident to put outfits together and ensure hair and nails are tidy (Pool, 2002).

2.4.4 Implementing research into practice

- A number of studies have developed service models that ensure care is provided in a way that promotes activity, achievement and well-being, for example, the 'Enriched Opportunities Programme' demonstrates a method of promoting well-being through an activity-based model of care (Brooker and Woolley, 2007). It recommends that five key elements are needed to work together to bring about a sustainable activity-based model of care. These elements are: specialist psycho-social dementia expertise; individualised assessment and case work; an activity and occupation programme; staff training; and management and leadership.

- Further work is required to establish how to implement these models outside of research studies and how the benefits can be sustained over the long term (Brooker, Woolley and Lee, 2007).

2.4.5 Inspection process

- Because it is such a key determinant of quality of life, levels of engagement and availability of occupation and activities for people with dementia should be given considerable weight within the inspection process. The merger of CSCI with the Healthcare Commission should provide an opportunity to review standards around occupation and activities in England. The new observational SOFI tool (Brooker, May, Walton *et al.*, 2007) being implemented by CSCI will enable inspectors to better understand whether people are engaged by activities provided, and whether residents are provided with opportunities for stimulation outside of structured activities.
- The provision of engagement and occupation for any residents with severe dementia should be given particular focus as evidence demonstrates that this group is most often overlooked and at risk of isolation.

Further information and guidance on provision of activities

- Alzheimer's Society Book of Activities – contains tried and tested ideas and explains how to set up an activities programme.
- Alzheimer's Society, Memories are made of this: Reminiscence activities for person-centred care.
- NAPA, the National Association of Providers of Activities for Older People – provides a range of good practice guidance and training programmes to support care homes in providing activities. These include Guides for activities planners such as 'Starting out and and keeping it up' and 'Developing team spirit and cooperation'.
- Therapeutic Activities and Older People in Care Settings: A Guide in Good Practice provides a statement of good practice and a benchmark against which activity provision can be measured and evaluated.

These guides and other information are available from www.napa-activities.co.uk

Jackie Pool, 2002, The Pool Activity Level (PAL) Instrument for Occupational Profiling, A Practical Resource for Carers of People with Cognitive Impairment Available from www.jackie-pool-associates.co.uk

Relatives and Residents Association, 1999, Gardening in homes Available from www.relres.org

3 Involvement of friends and families in the care home

KEY POINTS

The transition to residential care is a major event for both the family and the new resident. Maintaining good relationships between relatives and the care home, and supporting the ongoing relationship between relatives and the person with dementia, has important benefits for both parties.

The relationship between home and relatives is a problem for many carers:

- 22% were unsatisfied with the level of their involvement in decision making
- 29% felt they did not receive enough information and updates about the care and treatment of the person they cared for.

This relationship is also a difficult area for care home staff. Good management is important in supporting staff in this area.

‘She’s in a home now where the staff are entirely different and they are friendly. She’s forever moving furniture and what not, but that’s part and parcel of the illness. And I just love to start dancing with her to take her mind of things like that and I find that very, very helpful to me. I still go every day to feed her, as they have a job getting her to sit down to eat her breakfast in the mornings... She’s alright now.’

3.1 Introduction

The transition to full-time care is a major life event for the carer as well as the individual with dementia. It is vital that support is provided to the family carer at the time of transition and that they are supported to continue their relationship once the person is in the home. Ideally, the future care of residents with dementia should be a partnership between that individual, their carers, the care home staff and other professionals involved in their care.

Woods, Keady and Seddon, in their comprehensive book *Involving families in care homes* (2007), describes the 'dementia care triangle' which illustrates the relationship between the person with dementia, relatives and care home staff (see Figure 3.1). They describe how the relationship between the person with dementia and family and friends is important in terms of their journey through life and their relationship with staff is important in terms of meeting their day-to-day needs. The relationship between family and staff underpins those two relationships and they are affected by the quality of the family/staff relationship.

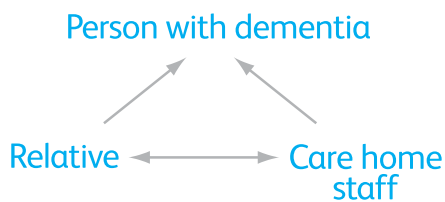


Figure 3.1

The dementia care triangle (reproduced from Woods, Keady and Seddon (2007) with kind permission of Jessica Kingsley Publishers).

This chapter looks briefly at existing research around involvement of families in care homes and at what we found about carers' views of their relationship with the home and what changes they would like to see. It also looks at the perspective of care home staff on staff/relative relationship and ways in which it can be improved.

3.2 What does research tell us about the involvement of families in care homes?

The research literature around the relationship between families and care homes confirms that the transition from home to care home is a very difficult time for carers and much of the distress is related to guilt (Woods, Keady and Seddon, 2007). It can also be difficult for carers to cope with the change from having many care staff visiting the home during the course of the week, particularly if they have become isolated from friends and families due to their caring responsibilities. Admission to a home can be a very difficult time for the person with dementia, particularly when the individual cannot remember how or why they are now living in such a place.

Families like to be involved in the care home in a variety of ways. For example, some liked to continue providing hands-on care while others identified a preference to support their relative to take part in activities. Woods writes that the new roles taken on by relatives include:

- monitoring the care provided
- personalising the care received
- offering their knowledge and experience of the person with dementia to the staff.

3.2.1 Benefits of involvement

The vast majority of carers still want to be involved in the care of their relative after they have moved to the home. Being involved in the home and maintaining good relationships between relatives and homes plays an important role in residents' well-being (Bauer, 2006). Family involvement may be linked to important outcomes for the person with dementia, including quality of life and engagement in activity (Zimmerman *et al.*, 2005; Dobbs *et al.*, 2005). Furthermore, carers' degree of strain and ability to cope with the burden of post-nursing home placement is enhanced by positive interactions with nursing staff and other significant persons, including other residents (Almberg *et al.*, 2000; Garity, 2006).

Our research highlighted how important it was to carers to have a good relationship with the home and maintain a role in the individuals' care. Carers clearly valued homes that supported a partnership approach to care.

'All the staff encourage and welcome input from residents families and at no time are you made to feel that you shouldn't be there or are getting in the way. I am so grateful that my husband was allocated a place in such an excellently run care home.'

'The home opened about six months ago. It has improved steadily over time and I am fully involved in my wife's care, visiting every day. It is close to my home and I am as happy as one can be in the situation.'

Good homes worked in a way that recognised and supported the ongoing relationship between residents and their family and friends. It is important that homes recognise that carers benefit from this as well as the person who has moved to the home.

'I go every day for four hours, I need him more than he needs me.'

'And it's acknowledging that this carer loves the person that's in there, and still wants the very best for them.'

3.3 Relatives can assist care staff

Many homes value the contribution of carers as partners in care and in assisting them in helping care staff understand how best to support the individual. In particular, where residents communicated their anxiety through their behaviour, carers were able to give advice on how to approach and reassure them. Also, carers are invaluable at providing additional information about a resident's personal history to support care staff's understanding of the person as an individual and provide person-centred care.

‘They said he won’t co-operate. So I said ok, well you give him a bath tomorrow and I’ll arrange to be here and perhaps just seeing me will calm him down a bit. And anyway we did that and that worked fine.’

‘I think it’s listening to the carers as well, the staff listening and finding out information on how the carers deal with difficulty because they know their relatives more than anything else. They go through the different periods/ moods of dementia. But sometimes there’s activities they could use as a distraction when behaviour gets more difficult. Having information on what their life is like’

A number of carers also carried on providing personal care to the resident, although this was sometimes because they felt the home did not have time to do so.

Unfortunately research to date suggests that in many cases involvement is not encouraged (Davies and Nolan, 2006).

3.4 What have we found about the relationship between care homes and families?

Unfortunately, in some homes relationships between staff and families could be improved. Understandably this was a source of much distress. Specific problems included:

- Concerns around involvement in decision-making and not being kept up-to-date.
- Not being told immediately of falls and other events.
- Perceived difficulties in raising concerns with the home.

3.4.1 Concerns around involvement in decision-making and not being kept up-to-date

Responses to our survey of carers showed that while many were happy with the level of involvement in decisions they had a significant proportion were not happy (Table 3.1). The relative’s unique knowledge of the person with dementia means their input is extremely valuable in the provision of good person-centred care and should be actively sought out.

In addition, nearly a third of carers (29%) said that they did not get enough information and updates from the home about their relative/friend/partner’s medical condition and treatment.

‘I think not even once a week, or once a fortnight, we should have a meeting to see how John’s going on, to see how he’s progressing, different things but there’s nothing like that. I just feel like going every day you are just in limbo. That’s all the future will be, but as I say 75% of the staff are really good and

Table 3.1

How happy are carers with the amount of involvement they have?

Rating	How satisfied are you with the amount of involvement you have in decisions around the care home and treatment of your relative/friend/partner? (% of carers giving each rating)
1 very unsatisfied	5
2	6
3	11
4	24
5	26
6 very satisfied	25

really nice, and with me going every day I know them well, and they are very good to me.'

These findings are similar to those of Woods and Matthison's postal survey (1996) which found a quarter of the 153 respondents felt that staff did not pay sufficient attention to the family member's views and that staff made decisions that they would have preferred to make, as family members. In addition, nearly two fifths wanted more contact with staff.

3.4.2 Not being told immediately of falls and other events

Carers highlighted that, should their relative or friend have a fall or become injured in another way, they would like to be told promptly and in sufficient detail to understand how it happened. They did not express this in a way that inferred that they were necessarily blaming the home for the fall or injury, but it is understandable that they would wish to know what had happened to their loved one. Upon finding the person with dementia with bruising, carers were faced with an uphill struggle to find out what happened and also found the incident forms lacked sufficient detail to shed any light. This is unacceptable and some carers compared it unfavourably to what would be expected standards in a nursery looking after young children.

'They came to change his clothes, and I noticed he was very badly bruised over down his left side. I said "What's this? Is it pressure sores?". "Oh he had fallen out of bed on Tuesday". Now this was Sunday, and I never had been informed. "Oh, he was checked over, and he was alright", but I still insist that I am told of any falls.'

‘This is the second care home she has been in. The first one she was there for six weeks, and it proved to be a catalogue of disasters from day to day. One typical example is my mother had fallen one day and broken her glasses. I got a phone call to come over with replacement glasses. Picked my dad up on the way, took him to see my mother who was covered in bruises. A young care assistant came in, and my dad as you would expect, said to the carer “oh, did you see this happen?” The next thing I knew there was a knock at the door and I was asked to the manager’s office, this was a frequent event. The manager told me he was upset, because a member of staff was upset, because we had asked her a question, and she thought we were trying to trick her. That was the very typical example of the management of the care home.’

3.4.3 Perceived difficulties in raising concerns with the home

The reluctance of some families to raise issues about which they are unhappy or would like to question has been widely reported. A previous Alzheimer’s Society survey found that while 94% of respondents said that they would consider making a complaint, many expressed concern that a complaint would either result in the person with dementia being asked to leave, or would lead to poor care or abuse (Alzheimer’s Society, 2004). In addition, carers were acutely aware of the shortage of alternative beds available and did not want to jeopardise the place in the care home by ‘causing trouble’.

We received a number of reports in our current survey which highlighted that fear of complaining is an ongoing problem in some homes. It is not possible to determine the degree to which carers’ fears are justified, but the high level anxiety in itself is of grave concern. In addition, we are concerned by the number of people who had actually been asked to leave after their representative had made a complaint about poor care standards. These issues need to be taken extremely seriously.

‘So many relatives have experienced the traumatic difficulty of finding a suitable nursing home place where their loved ones would be accepted; and of having to change from one home to another before finding satisfaction and relative piece of mind. There is always the threat, the fear, real or perceived, that in speaking out we may lose what we have, and our loved ones suffer the consequence.’

‘They weren’t concerned about my mother as a person and the treatment she was getting although at one stage I wasn’t telling anyone because I was scared of the knock-on effect for my mum. So you’re kind of putting off saying things and I got to the stage where I thought “no, this is not fair for anyone”. Care means care and this person is suffering you know and if I could talk to someone regarding my mother it would help other people who were in the same experience or worse. But it wasn’t taken on board.’

‘If I complained. I got that ... I sort of started to withdraw myself from complaining. It was simple little things like I used to say to her give it to me I’ll do it myself I’ll do it. You know that to me is terrible if you can’t sit and have a conversation with somebody about your mum. You know. You sort of got to... ‘cos you are frightened ‘cos you know they are talking about, oh here she is, she’s moaning again. Like I used to say I’m not moaning I’m just working with them! If they were to be ... I’d do the job myself if they’d let me....’

Carers reported that because of fear of the repercussions, they waited to complain until their relative had moved to another home or had died. One carer explained that she had raised concerns with the local CSCI office but was too scared to complain officially. The CSCI inspector sympathised, but hoped she would change her mind as without an official complaint it was much more difficult for them to take action.

3.4.3.1 Complaints procedures

The recent report by the Joint Committee on Human Rights (2007) noted the unsatisfactory situation in relation to complaints, whereby CSCI do not have the power to investigate specific complaints and instead refer the complainant back to the home. As we have found, many individuals do not want to pursue a complaint with the home with which they are unhappy. Furthermore, CSCI reported to the Committee that although residents placed in care homes by local authorities have access to the local authorities complaints procedures and eventually the Ombudsman, self-funders do not. This creates an unacceptable two-tier system.

The Joint Committee note the disparity between this system and that within the NHS whereby the Healthcare Commission can investigate complaints directly. They hoped that the approach of the Healthcare Commission would prevail once the two inspectorates were merged in England. Alzheimer’s Society would very much support this.

The consultation document also supports access to advocates for all who may need support in having their voice heard. Alzheimer’s Society fully supports this. This is particularly important for care home residents with dementia who do not have relatives or friends. However, this group are particularly at risk of exclusion from services, and advocacy and support systems need to be set up so that vulnerable individuals who may require their services can be identified. It should be possible for a range of people to make referrals, for example, care home workers and voluntary sector organisations. A number of carers who responded to our survey were concerned about residents with dementia who did not have visitors and it was suggested there should be consistent provision of ‘official visitors’.

3.5 Staff perspective on the involvement of families in care homes

The relationship between care home staff and family is a complex one and staff can find it difficult as well. It is clear that in some homes both care home staff and relatives would like to see the relationship improve.

However, positive feelings towards relatives also exist. Staff were asked to rate how much they enjoyed different aspects of their jobs and many enjoyed working with friends and families (Table 3.2).

The European study described in Woods, Keady and Seddon (2007) supports our finding that staff had negative and positive perceptions of relatives. UK staff saw relatives as a resource for staff as well as for the person with dementia. Relatives helped with tasks such as activities and were also seen as an important source of information. However, relatives were also seen as disrupting routines and creating an additional burden. Some staff felt relatives could be overly critical and not understanding of the staff's attempts to provide autonomy and independence. There was also a feeling among staff that relatives' poor understanding of dementia could lead the relative to be frustrated. However, staff were understanding of the difficulties faced by relatives, for example guilt, coping with all their commitments and grief, particularly when the individual with dementia no longer recognised

Table 3.2

How much do staff enjoy working with families/friends?

Rating	How much do you enjoy working with families/friends of residents with dementia (% of care staff)
1 (not something you particularly like)	1
2	1
3	4
4	14
5	24
6 (something you really like)	53

them or showed difficult behaviour. Carers do appreciate the support and understanding shown to them by staff in these difficult situations:

‘My brother found it very hard to cope with my mother in the home. He did not enjoy visiting and hated the smell. A nurse gave me a very useful piece of advice, which was to remember that he would be my brother for the rest of my life, and my Mum’s life was nearing its end. Mum would not want to be the reason for animosity between us and so the best thing for me to do was to accept that he could not visit and support in that way. When I did that, I found it all much easier to cope with and we are closer now than before.’

3.6 How to improve relationships

‘I currently visit 2-3 times a week, but would like to be more involved with carers and other relatives. As my father withdraws from me due to his illness I would like more exchange with the staff about him.’

A policy to support family participation was introduced in Dutch nursing homes in the 1990s (Dijkstra, 2007). An evaluation of the policy found that the following conditions are important to its success:

- abolishing visiting hours
- establishing good communication between family and staff
- offering support and guidance to the family
- clarifying who does what and when.

Most homes in the UK have unrestricted visiting hours and this is very much appreciated by carers:

‘My husband has always received great kindness from all the staff and I can visit him whenever I choose.’

‘I can visit any time, even at 7pm. The staff are exceedingly kind to the patients (and visitors). Everything is in apple pie order and pretty. My husband says he is happy. Good atmosphere.’

3.6.1 Respecting lifestyles and choices

Carers from the lesbian, gay, bisexual and transgender (LGBT) community can face particular problems if the care home does not respect LGBT lifestyles and choices. Many LGBT carers are fearful of revealing their sexual identity at the home and expressing their ongoing love for their partner for fear of prejudice and abuse. Visitors must be able to express their ongoing love and maintain their relationship with privacy and without threat.

The recruitment and training of staff should ensure that they are sensitive and respectful of all residents and partners/friends/relatives, regardless of sexuality.

The rights of same-sex partners as next of kin must be recognised and acted upon, with involvement in all discussions relating to care and treatment.

3.6.2 Relatives groups

Many carers see relatives groups as an important way of supporting their involvement in the home and improving communication. Garity (2006) found that participation in monthly support groups, run by the nursing home, provided a forum for significant interaction and increased carers' coping through shared perspectives and comparing their experiences.

44% of homes surveyed reported that they had a relatives/friends group, although this varied slightly across type of home (37% care home only, 59% nursing homes and 47% specialist dementia care homes). Care home managers were asked to list the benefits of such groups and the top ten answers were:

- 1 support from others in the same situation
- 2 sharing of information/experience/ideas
- 3 feeling of involvement / being involved in decision making
- 4 able to communicate/discuss things openly / get feedback
- 5 gives an understanding of the difficulties faced / care being provided
- 6 make friends / interact with other families or residents
- 7 keeps them updated / knowing what's happening in the home
- 8 express any worries/concerns
- 9 help with client/care/activities
- 10 fundraising.

Some homes reported that they had tried to set up such groups, but none of the families chose to come along for various reasons. Indeed relatives groups are not appropriate for all and they require good local leadership to encourage people to attend and to sustain attendance. However, Alzheimer's Society would like to see the expansion of these groups as they do encourage the sharing of information and the development of relationships. They could also be used as a forum for individuals to raise issues in a supportive environment. Some relatives might find it easier to raise issues in a group environment, particularly if they are able to talk to other relatives and find they are not alone.

'The matron said that every six weeks you see the care staff and then she has a surgery every couple of months, and I thought I have never heard of that and it sounds like such a good idea, so the carers can go and have a chat with the matron, whether it's like a support group because sometimes you do need that extra support when somebody goes into care. I had never heard that before and I thought it was good.'

3.6.3 Simple strategies for improving relationships

Woods, Keaty and Seddon (2007) provide comprehensive guidance about how to support family involvement in care homes and make visiting easier. Advice includes relatively simple ideas such as:

- suggestion boxes for staff and relatives
- staff pictures on the wall with names and roles
- key workers who are accessible to relatives
- effective sharing of information between the care team
- quiet areas in which relatives can spend time with residents as frequently noted by respondents to our carer survey.

‘The TV – always on and loud – makes visiting difficult and bedroom too small to use instead.’

3.6.4 Addressing the issue as early as possible

It is clear that efforts to ensure a good relationship should be started as early as possible. Although families frequently want to be involved in care they can be reticent about taking the initiative. Care home staff need to proactively address how the relative would like the relationship to work and to establish the roles of family/friends and care staff.

It is also important that there are early and ongoing discussions around parameters of individual risk-taking with agreement reached between the resident (wherever possible), the care staff and carers. For example, the family might support their family member’s decision to keep on going out by themselves. A risk assessment should be carried out and plans developed to ensure the individual was as safe as possible while still maintaining activities important to them. The care home should ensure that staff are aware of such agreements so that the levels of risk acceptable to the different parties are understood.

3.6.5 Supporting staff

It is important to address how to support care staff in this complex area of their work. It should be addressed in training programmes and ongoing supervision. Clarity around relatives’ expectations would be helpful for staff as well as families. In addition, helping relatives understand some of the challenges faced by staff, for example staffing levels, should help in better mutual understanding.

It was frequently noted by carers how important care home managers are in setting the ethos of the home and giving care staff the confidence and skills required to work well with relatives.

‘Like most organisations the tone of a home is set by the people at the top. The overall change of the whole complex is due to the matron in charge of the dementia unit, she sets and expects high standards. She’s also approachable for advice and help. You can approach her like a friend.’

‘The matron in particular sets the tone and acts well above the normal call of duty especially when easing people into the home and keeping me well informed.’

‘My Mum was in her home from December 2001 to January 2006 when she died. I felt the staff were often overstretched but the matron who took over in the last year or so improved relationships between staff and visitors. I should say that although overstretched the staff did their best.’

3.7 Summary and recommendations

In the best homes there is a confident and beneficial relationship between family, friends and care staff. This can help the family enormously. As many of our carers pointed out, their relationship with the person with dementia is as important as ever and they want to be involved in their care. Carers, with their unique knowledge of the individual, can also be a useful resource for care staff in providing good person-centred care.

3.7.1 It is vital that the care home system supports good communication between relatives and the home, as well as ongoing involvement in care.

This could be achieved through:

- Effective leadership which sets the tone of the home and supports good relationships between the care team and relatives.
- An inspection system that assesses whether recognised good practice in this area is implemented and supports homes in achieving good communication and family involvement, for example with regular meetings and the creation of a suitable environment.
- Provision of ongoing training for care staff in how best to involve partners/families in care and support relationships between residents and their friends and families.
- Recruitment and training should ensure the care home workforce are sensitive and responsive to the needs of people with dementia and their carers from the lesbian, gay, bisexual and transgender community.

3.7.2 The planned revision of the complaints procedure in England must provide better support for residents and their families who have concerns or complaints about a care home.

- Relatives and residents must have the option of taking complaints to an independent body if they are not happy to complain directly to the home or if they find the home does not satisfactorily resolve the issue.
- A two-tier system whereby self-funders are excluded from an independent procedure must be avoided.

Further information and guidance

- Woods, B., Keady, J. and Seddon, D., 2007. *Involving Families in Care Homes: a relationship centred approach*, Jessica Kingsley Publishers – provides background information and practical guidance on how care homes can help families to become partners in the caring process.
Available from www.jkp.com
- Relatives and Residents Association, 2001, *Involving Relatives and Friends: A good practice guide for homes for older people* – aims to spread understanding of how to enable the family and friendship relationships which residents have built up over a lifetime to continue to flourish so that relatives and friends remain involved in the care.
Available from www.relres.org
- Relatives and Residents Association, 1996, *Setting Up Relatives Groups in Homes: puts forward step-by-step pointers for setting up and running a relatives group in a care home*. Useful for relatives and friends as well as managers and staff of a home.
Available from www.relres.org

4 Challenges in providing good dementia care

KEY POINTS

The big challenges identified by care home managers relate to attracting and motivating staff and ensuring they have the right skills. It is vital to support and motivate care home staff by:

- Acknowledging that dementia care is a skilled area of work and valuing, training and rewarding staff accordingly.
- Providing a comprehensive training programme that is linked to career and reward structure and supported by ongoing supervision, positive reinforcement of good practice and effective leadership.

Despite government policy making it clear that liaison between dementia specialists and care homes should happen, provision of support to care homes is extremely variable. Liaison work between OPMH teams and care homes can improve care and reduce costs. Many OPMH teams would like to do more of this type of work.

Improved coordination between care homes and hospitals would improve the care provided to people with dementia. There must be greater recognition that care homes are part of the local health care provision.

We asked care home staff and care home managers about the challenges and difficulties they experienced in caring for people with dementia. The commitment to provide a good quality of life for residents with dementia was clear, but getting all the elements of a good dementia care home in place is no easy task. This chapter looks at the key issues in dementia care from the perspective of care home staff and managers.

4.1 Biggest challenges

Care home managers were provided with a list of challenges and asked to select the three they considered to be the biggest challenges in providing good dementia care in care homes. Table 4.1 gives the results.

Table 4.1

The biggest challenges in providing good dementia, from the point of view of care home managers

Challenge	Proportion of managers listing it as one of the top three challenges (%)
Attracting care staff with the right skills	60
Funding training	46
Maintaining staff morale and motivation	44
Accessing advice from services	26
Physical design of building	26
Finding info re sources of funding	26
Finding info re type of dem care training to provide	20
Turnover of staff	18
Finding information about how to access dementia care training	15
Consistent quality of agency staff	3

4.2 Staffing issues

The top three challenges from a care home managers point of view relate to developing a staff team with the right attributes and skills and keeping them motivated. This resonates with carers' views that the staff team is the key to a good dementia care home. Furthermore, we know turnover is very high (a 2001 report found 30% in nine months in some care facilities, (Margallo-Lana, Reichelt, Hayes *et al.*, 2001)) creating problems for continuity of care and development of skills. It is important therefore, to look at what more could be done to improve skills, provide support and encourage care staff to stay and develop within the field. A well-supported, fulfilled workforce who are confident in their skills and understand how quality of life can be improved by good care will be better able to provide excellent care to residents with dementia.

We asked care staff an open question about what could be done to improve their job satisfaction. We also asked care home managers what they thought

Table 4.2

How could care staff's job satisfaction be improved?

How job satisfaction could be improved	Proportion of care home staff giving this answer (%)
More training, better courses that are more relevant to job	22
Higher salary	21
Adequate number of staff	12
More time to spend with residents	11
Availability of activities	5

Table 4.3

What do care home managers think could be done to improve staff's job satisfaction?

How job satisfaction could be improved	Proportion of care home managers giving this answer (%)
Higher wages	23
Improve training in dementia care	17
Employ more staff	12
Respect appreciation from all	8
Higher private fees/funding	6

would improve care staff's job satisfaction. Responses were coded and the top five answers of each are given in Tables 4.2 and 4.3.

It is important to note that 8% of care home staff said that their job was fine as it was.

4.2.1 Attracting and keeping the right staff

There are many issues that need to be addressed in order to attract and motivate good staff to stay within the sector. These include:

- status and reward

- training and career development
- good management and support
- staffing levels.

4.2.1.1 Status and reward

The low status our society accords people who are doing this work will inevitably be a reason why it is so difficult to attract staff. It is clear from reports from carers who have experience of excellent care being provided to their friend or family member with dementia greatly value those staff members and the job that they do. Unfortunately, appreciation of the hard work of many care home staff is not widespread. Raising public awareness of the level of skill and dedication in care teams is a necessary morale boost to those working hard to promote quality of life for residents with dementia. Carers' comments included:

'The only comment that is appropriate for the home is for me to express my deepest feeling of gratitude for the care and dedication the staff has willingly bestowed on Joyce.'

'I see her every night and I can tell as soon as the staff walk through the door her face lights up and she can't talk but she makes signs to say she understands what's going on ... I think staff are the secret to the home's success.'

The status given to people working with people with dementia is reflected in the level of pay and reward. Working in residential dementia care is stressful and emotionally and physically demanding work and there are many other opportunities open to them which are less stressful and pay a similar wage, for example working in a supermarket. A comprehensive, standardised training programme that is linked to pay and a career structure for those that want it must be part of the change required in dementia care. Dawn Brooker (2007) writes that: 'unless we let those in power know that this is a skilled area of work that cannot be done successfully on the cheap by staff with no training, then we are devaluing the lives of those we care for. If we devalue a person, this is not person-centred care.'

'I wish salaries paid to care staff could be increased, this would provide a more settled staff level and better job satisfaction. Therefore end result happier residents.'

4.2.1.2 Training and career development

While some of the personal skills required for good dementia care cannot be taught, good induction and ongoing training are needed to develop a good staff team and have important benefits for both staff and residents. Chapter 1 highlighted that many carers felt the care home staff's knowledge of dementia care needed much improvement.

Table 4.4

What would care staff like to do to improve their skills in caring for people with dementia?

Strategy for improving skills in caring for people with dementia	Proportion of care staff who would like to pursue that strategy to improve skills in caring for people with dementia (%)
More one-day training courses	61
A longer course	46
Learning from more experienced staff	34
Short training sessions in the home	44
Other	10

NB: Respondents could choose more than one option

The enthusiasm and desire of care staff for learning and improving the quality of dementia care they provided is clear. 91% of care home staff said they would like to further their skills in dementia care, with the main preference for doing so being one-day courses (Table 4.4)

The main motivation for developing skills was to provide better care (Table 4.5):

4.2.1.3 Benefits of training

Our findings support previous research findings that dementia care training can reduce staff turnover and increase job satisfaction (National Institute for Health and Clinical Excellence / Social Care Institute for Excellence, 2007). There is evidence that short focused training courses (1–5 days) increases care teams' confidence and knowledge in working with older people (Lintern, Woods and Phair, 2000a; Mayall *et al.*, 2004; Moniz-Cook *et al.*, 1998). Studies have found that focused training interventions can reduce instances of disruptive behaviour and the use of unlicensed anti-psychotics (Fossey *et al.*, 2006) increase the opportunities provided by staff for residents to take part in decisions (Kihlgren *et al.*, 1993) as well as encouraging increased communication between staff and residents (Burgio, Allen-Burge and Roth, 2001). Importantly, Burgio found that training improved communication between staff and residents without increasing the time required for care tasks.

Table 4.5

What would encourage care staff to improve their skills?

Factors motivating/helping care staff to improve their skills	Proportion of care staff who reported that this would help or encourage them to improve skills (%)
Being able to provide even better care to residents with dementia	88
If the training was within normal working hours	37
If improving skills meant wages increased	47
If improving skills meant a move up the career ladder	47

NB: Respondents could choose more than one option

The care staff in our questionnaire had taken part in a range of learning opportunities:

- NVQ course 68%
- other external training 69%
- in-house training course 86%
- learning from more experienced staff 79%.

We asked which of these people had found most helpful. The five most common answers were (some people stated more than one thing):

- learning from more experienced staff 30%
- external training course 21%
- in-house training course 21%
- NVQ 19%
- general dementia courses 11%.

Staff reported that the courses/training opportunities were helpful in increasing their awareness and understanding of the needs of residents with dementia. They also provided more insight into the condition. Encouragingly, 83% of care staff felt the training opportunities covered the things they wanted to learn about. 13% felt they did not.

In-house expertise

The finding that staff find it most helpful to learn from more experienced staff highlights the importance of ensuring that senior staff are good role models and that they are working from best practice models. Otherwise, poor practice

simply proliferates. The literature reports on the helpfulness of specialist expertise to lead and implement interventions in the field of dementia care. Specific benefits have been found on staff management of problem behaviours (Moniz-Cook *et al.*, 1998, 2001; Opie *et al.*, 2002; Rovner *et al.*, 1996), levels of resident depression and cognitive impairment (Proctor *et al.*, 1999), general clinical practice (Hoek *et al.*, 2003; Rantz *et al.* 2001), and in reduced use of medication (Ballard *et al.*, 2002; Rovner *et al.*, 1996).

Activity co-ordinators, who are specifically employed by care homes to facilitate structured activities for residents, have been an option in the UK. Similarly the roles of Therapeutic Recreation Specialists in the US and Recreation Therapists in Australia have been developed and qualifications are available. There is a lack of research about the efficacy of this type of role. In the UK, this role has a limited status, with the remit being on organising diversionary activities.

As part of the Enriched Opportunities Programme it was decided to develop a senior staff role called a Locksmith who was internal to the team, whose *raison d'être* was to ensure residents and tenants reach their potential for well-being. The title 'Locksmith' was chosen to reflect their central responsibility in discovering and developing keys that would unlock the potential for well-being in individuals with dementia. Locksmiths also required the authority to take a lead in staff training and mentoring with regard to the Enriched Opportunities Programme. All Locksmiths were employed full-time as part of the senior team and as such had authority to lead staff and to challenge decisions.

4.2.1.4 Current training requirements

Despite the fact that the majority of care home residents have dementia, there are as yet no clear standards of the required level of dementia care training and we receive anecdotal reports of inconsistency in the standards used by CSCI inspectors. For example, some will say undertaking the Society's 'Yesterday, today tomorrow' is sufficient for a home that cares for people with dementia and others will say it is not. This is reflected by the 20% of care home managers reporting that 'Finding information about the type of dementia care training to provide' was one of the three biggest challenges in providing dementia care.

Alzheimer's Society would like to see the development of national standards for dementia care training for care home staff that ensure the workforce is equipped to meet the needs of those who make up two-thirds of residents, as well as giving carers and people with dementia looking for homes the confidence that the care team have the required knowledge and skills. The growing numbers of people with dementia and the expected increase in level of need among the care home population give this particular urgency.

The development of a structured training programme for dementia care staff should be accompanied by the provision of a career structure for those who

would like to climb the career ladder. For some care staff, this would provide motivation to learn new skills and stay within the dementia care field. The provision of higher education options in dementia studies being offered by a number of UK universities is also an option for those who are leading care in this field. There is no point in training front-line care workers if those who are responsible for leading care remain ill-informed.

4.2.1.5 Optimising and maintaining the benefits of training over time

Training should not be a one-off event, but rather part of an ongoing programme of training and education to ensure the benefits of training are maintained. Regular staff supervision alongside positive reinforcement of good practice is necessary to sustain good practice learnt during training. Burgio, Stevens and Burgio (2002) found that skills learnt during a behavioural management training programme had an immediate impact on the communication skills of nursing assistants, but those who received a formal staff management programme designed to maintain training effects over time were significantly more likely to have retained their improved communication skills at six months than those who received the standard supervisory routine.

4.2.2 Good management is essential

Good management is essential in order to provide good quality dementia care within a care home. Managers must set the expectations and ethos of the home from recruitment and induction onwards, as well as support and motivate staff. Effective management is important in ensuring that staff are rewarded for good performance and skills learnt through training are implemented. A good management style that supports staff to be involved in decisions around their work is also important in improving outcomes for residents. Staff who perceived more involvement in decisions showed few negative staff/resident interactions (Jenkins and Allen, 1998). In the learning disabilities field, involvement in decisions has been found to be a powerful predictor of resident-oriented care (Raynes, Pratt and Roses, 1979).

Carers were very clear that effective management was vitally important in the home:

‘Good standards and person-centred care (both nursing, social-activity, quality of life etc and with relatives) has to come from home management and flow down!’

In particular, carers valued managers who were not just in the home in normal office hours but varied their hours to be there during evenings and weekend. They also congratulated the ‘hands on’ managers who were often found around the home interacting with staff and residents.

‘The new manager at my current home has definitely been a breath of fresh air. He is very much hands on. The previous manager was very much “I will tick all the boxes but that’s it.”’

4.2.3 Staffing levels

We have already highlighted that carers felt staffing levels negatively affected the quality of care available to residents with dementia. Inadequate staffing levels will also inevitably make care staffs’ jobs far more difficult. The NICE clinical guideline identifies that staff shortages and pressures affect care. It highlights that often managing risk is all staff have time for when staffing levels are low.

Care staff clearly feel that increasing staffing levels is important in supporting them to do a good job. When care staff were asked about what could help overcome the things they found most difficult in caring for people with dementia, ‘higher staffing levels / having the right staff available’ was the second most frequent response. ‘Employ more staff / specialist staff’ was the fifth most frequent response from care home managers when asked what one thing would improve dementia care.

4.2.4 Staff issues summary

Staffing policy must be geared towards quality. If we are going to provide the level of care to which people with dementia in care homes have a right, we must ensure the workforce are properly trained at all levels and that improved practice is supported and motivated. Staffing levels need to be adequate to enable them to do their jobs properly. This needs to be underpinned by wider recognition of the fantastic work that many care staff are doing to provide a quality of life to some of the most vulnerable people in society.

4.3 Support from external services

One quarter of care home managers listed accessing advice from external services as one of the top three challenges in providing good dementia care. This should be taken seriously as care homes are part of the local health community and the care of their residents with dementia is a partnership between the home and local health and social care services. Carers have complained of the lack of specialist input once the person they care for goes into residential care. There needs to be a recognition that the responsibility of the local old age psychiatry team for the specialist care and treatment of people with dementia remains once a person enters a care home.

‘Before my wife was assessed as requiring NHS Continuing Care and admitted to the care home and I was caring for her at home, her condition was reviewed by a consultant psychiatrist, we were visited by a psychiatric

nurse at regular intervals and she attended two day centres each week where she was observed by trained staff. Her GP was someone who had known her as a patient for many years. All this came to an end when she entered the care home. All the qualified medical attention she has now is a registered mental health nurse (the Unit manager) five days a week, general nurses on other days and the local GP.'

Everybody's Business, the Government's key policy document detailing how services for older people with mental health problems should be organised, makes it clear that care homes should receive good support from external services. The document states:

'Homes should develop good links with local specialist services such as community mental health teams for older people. They can offer advice and support, coaching and training. Residents should have access to and involvement of GPs and other mainstream services in the usual way.'

The service model described in the National Service Framework for Older People also stipulates that specialist mental health services for older people should provide advice and outreach to those providing residential care and nursing homes and sheltered housing.

The experiences reported by care home managers suggest that action is needed to ensure implementation of Everybody's Business. This is demonstrated by the considerable variety among responses to the questions:

- What support do you receive from the local older people's mental health service? and
- What support do you receive from other community health services in the care of people with dementia?

One-third of care home managers reported no support, or very little limited support from the local older people's mental health service. Others clearly had excellent links and support:

'We have an excellent relationship with our community mental health team and our CPN holds six weekly liaison visits to discuss, on an individual basis, our residents with a mental health diagnosis. This ensures that any changes in well-being or problems can be addressed either by the CPN or through the GP or referred to the consultant psychiatrist.'

'These visits were instigated by our CPN as a regular means of monitoring our residents and supporting the home and the staff team, which he has also done by providing training sessions for care staff. Our relationship is such that, if needed, I feel able to contact the CPN at any time in between these visits for help or advice as required.'

Responses to the question of what support was received were coded and the five most frequently given responses were:

- 1 Advice / specialist advice
- 2 Training
- 3 Poor / very little / limited support
- 4 Nothing
- 5 Support from psychiatrist / CPN (community psychiatric nurse)

Our findings are similar to previous research. Purandare *et al.* (2004) found care home managers perceived support from psychiatric services as poor. 80% of managers wanted more help with staff training.

A review of the implementation of the National Service Framework found all specialist mental health teams would see care home residents on a case-by-case basis, but only 51% provided training to care home staff. Several respondents to the survey decried the lack of capacity to undertake such work. The survey also found 8.9% of services provided a screening programme for care home residents (Tucker *et al.*, 2007).

There are important benefits of a good relationship between care homes and local health services. Opportunities for training from specialist teams should improve the quality of dementia care provided, as will being able to ask for advice on specific issues. Good links and support from the range of health services helps to ensure early identification of problems, which can be potentially cost saving particularly if admission to hospital is avoided. A report in the *Journal of Dementia Care* of a pilot Behaviour Sciences Nursing Service to support people with dementia in care homes and the staff who work with them found the service helped to avoid admissions to the assessment unit, a considerable cost saving (Scott and Hutchinson, 2007).

Ballard *et al.* (2007) found a psychiatric liaison service significantly reduced the use of potentially harmful neuroleptic drugs, reduced GP contacts and led to a three-fold lower number of days in psychiatric inpatient facilities. The discontinuation of neuroleptics in 40% of people taking them did not lead to an exacerbation of behavioural or psychiatric symptoms. Furthermore, neuroleptic drugs are known to increase the risk of falls and strokes and therefore it is likely that a reduction in their use through psychiatric service support could save the costs of dealing with these side effects.

Support for care homes from other professions is important. Zermansky *et al.* (2006) found pharmacists going into homes to do medication reviews reduced falls. Only 24% of care home residents had had a medication review, compared to 44% of people in their own homes. This is despite the average resident having been visited six times by a GP, which Zermansky points out were six missed opportunities for medication review.

Coordination with hospitals is another challenging area for care homes. We received a number of reports of poor communication regarding discharge arrangements and also people being unexpectedly discharged from hospital to care homes in the early hours of the morning. This should not happen unless all parties agree it is in the best interests of the person with dementia. Being moved to a care home in the middle of the night is extremely distressing and disorientating for the individual. Limited discharge information is another problem experienced by care homes. This highlights that in some areas there is a real need for coordination and communication between services for people with dementia if person-centred care is to be provided. We hope that the merging of the health and social care inspectorates will support the improvement of joint working in areas such as dementia where seamless services are so vital.

4.4 Summary and conclusions

These challenges highlighted by care home managers must be addressed if the quality of dementia care in care homes is to improve. It is also important that care homes are provided with adequate support by specialist health and social care teams, to enable well-coordinated, person-centred care.

4.4.1 Recommendations

- There must be an increased awareness of the level of skill involved in providing good dementia care and the good practice that exists in many homes. Care staff who are providing good care to some of the most vulnerable people in society should be valued accordingly.
- Training in dementia care must be mandatory for care home staff. A training programme should:
 - Be supported by a commitment from government to provide adequate funding, through simple to access sources.
 - Be recognised and supported by the regulation and inspection system.
 - Be supported by a career structure and linked to pay.
 - Be supported by a programme of support and effective management to ensure implementation.
 - Recognise the diversity within the care home workforce.
 - Help staff understand what a difference good care can make.
- Development of a training programme should involve all stakeholders to ensure that it is widely accepted.

- There must be consistent provision of liaison services with specialist teams. This and the overall coordination of care between care homes and other health and social care services should be monitored by inspection and regulation bodies.

Further information and guidance

The Alzheimer's Society Quality Care Programme – produces a range of publications promoting excellence in dementia care and runs an extensive training programme to complement the publications.

More information is available from:

www.alzheimers.org.uk/Working_with_people_with_dementia

Alzheimer's Society, 2002 'Choosing Residential Accommodation: a guide for gay and lesbian partners, relatives and friends'.

Available online: www.alzheimers.org.uk/Gay_Carers/residentialcare.htm

Age Concern, 2006, The Whole of Me: a resource pack – A resource pack on meeting the needs of older lesbians, gay men and bisexuals living in care homes and extra care housing.

Available from: www.ageconcern.org.uk/AgeConcern/openingdoors.asp

Skills for Care, Knowledge Set for Dementia – provides a sets of key learning outcomes for dementia care.

Available from: www.topssengland.net/view.asp?id=701

British Geriatrics Society, 2006, Hospital discharge of older people with cognitive impairment to care homes.

Available from: www.bgs.org.uk/Publications/Compendium/compend_4-13.htm

5 Summary and key recommendations

The findings of this report paint a picture of very inconsistent care, whereby a fortunate group of care home residents with dementia experience good care that supports them to live enjoyable, fulfilling lives. For others, the failures of the system result in treatment that is in no way acceptable. Enabling the standard of dementia care in all homes to be consistently raised to that of the best must be an imperative for providers, health and social care teams and policy makers. Quality care makes a difference to people's lives.

There are a number of overarching issues to acknowledge in respect to dementia care in care homes:

Firstly, recognition and response to the fact that the primary task of the care home sector is providing good quality care for people living with dementia. At least two thirds of care homes residents have dementia and it is likely this will increase as people with less severe needs are supported to stay at home. There must be adequate training and expertise to enable all care home staff to adequately meet the person-centred needs of people with dementia. The care home system must improve to meet the current needs of its residents as well as the future population, by adequate training, specialist support and an appropriate regulatory system.

Secondly, the expectations of the quality of life that can be experienced by people with dementia in care homes needs to be much higher. Residents with dementia have the right to contented, interesting lives and the culture of the home should encourage good relationships and personal wellbeing. However, although we know much about how to maintain quality of life as dementia progresses, too often the bar is set too low. Higher expectations across all stakeholders are a necessary driver for change and must be a key component of the inspection process.

People value care homes that create a good atmosphere and positive relationships amongst staff, residents and relatives. Residential care becomes a person's home and therefore the outcomes sought will be different from acute care, for example. Policy goals must reflect this by prioritising social needs alongside safety. Long-term care is about living ones life.

Recommendations

- 1 Training in dementia care must be mandatory for care home staff. Care home staff must have the skills to maximise quality of life for residents with dementia, who form the vast majority of the care home population.

- Commission for Social Care Inspection (CSCI) guidance states that dementia registered beds should be for those whose needs cannot be met by general care services and that many people with dementia will be in non-dementia registered beds. The general care home workforce must therefore be trained in dementia care.
 - Development of a training programme should involve all stakeholders to ensure that it is widely accepted. Strengthened involvement of older people's mental health teams is essential. The development of the National Dementia Strategy should provide an opportunity to involve all key stakeholders in developing workforce development plans.
 - The dementia care training programme should:
 - Be supported by a commitment from government to provide adequate funding, through simple to access sources.
 - Be recognised and supported by the regulation and inspection system.
 - Be supported by a career structure and linked to pay.
 - Be supported by a programme of support and effective management to ensure implementation.
 - Recognise the diversity within the care home workforce as well as the care home population.
 - Cover recognition of emerging dementia, in order to address current rates of underrecognition and the resulting problems.
 - Target front-line workers, shift leaders, home managers and those responsible for clinical and operational standards.
- 2** The merging of CSCI and the Healthcare Commission in England to form Ofcare should provide an opportunity to develop a regulation and inspection system for England that promotes excellent dementia care in care homes. Overall, inspection and regulation systems should:
- Acknowledge that dementia care is the primary role of the sector.
 - Focus on outcomes of most importance to people using the services. For people with dementia in care homes, this means that meeting residents' social needs must be a high priority. The inspection and regulation system should ensure that residents have a range of opportunities for activity and occupation across the wide range of cognitive and physical abilities in dementia care.
 - Ensure that residents have access to outside space and that those with severe dementia are supported to access gardens if it is appropriate for them.

- An inspection system that focuses on outcomes of importance to residents will not be overburdensome for good homes as maintaining standards in these areas will be something that is part of their everyday work. The need to support quality care must be the priority for inspection systems.
- 3** Local authorities have an important role to play in improving the quality of care home provision in their local area.
- Local authorities and care homes must negotiate a fair price for caring for people with dementia, that reflects the additional costs of caring for people with mental health problems.
 - We strongly support CSCI's calls for more commissioning for quality and the use of incentive payments for quality care. It is unacceptable for local authorities to continue commissioning poor quality homes and failing to reward those who are working to promote quality of life for their residents.
 - Local authorities should publish annual reports on the quality of their residential care, which address what they perceive as the good points and the problems and what they intend to do to remedy.
- 4** There must be full implementation of existing national policy on links between specialist older people's mental health services and care homes, which are currently far too patchy.
- There is evidence that liaison services can potentially improve care and save costs, resources must be available to enable policy advocating these links to be implemented.
- 5** Systems for sharing good practice amongst care homes should be supported on a national basis.
- Examples of networks to enable sharing of good practice exist and Alzheimer's Society would like to see a drive to encourage wider provision. Systems could include websites with practical advice, regional/local networks of homes and work-shadowing schemes.
- 6** The development of specialist assessment procedures that are systematic and standardised in approach should lead to more coherent care for people with dementia.
- Development of such procedures should improve the consistency of systems of assessment and documentation used by different professionals, including care homes. Working with the same documentation and procedures should improve coordination of care.
 - Standardised specialist assessment procedures for people with dementia that add to a proposed common assessment framework, should seek to improve liaison between primary and secondary care and care homes, reduce the variability in the quality of assessment and ensure ongoing monitoring.

Alzheimer's Society has an important part to play in improving the quality of care in care homes. The Society works continuously to improve the quality of care in care homes through working with providers and with governmental bodies, such as CSCI. We have a representative on the London CSCI dementia forum and are due to be providing specialist training for the CSCI experts by experience programme in partnership with Help the Aged.

Alzheimer's Society is the leading dementia care training provider for many care homes, including five of the biggest providers in the UK. We provide a popular dementia care learning programme and broad range of seminars which range from introductory to specialist subjects. We also run train the trainers courses to broaden our reach and impact on the quality of dementia care.

Our publications are also used by care providers to inform care provision, planning and review. Providers have found our 'Quality dementia care in care homes' publication very useful in evaluating their care and developing improvement plans. Our starting guide to working in dementia care, 'Each day is different' provides an easily accessible guide and provides practical tips to help boost carers confidence. Our publications on the environment, nutrition ('Food for thought') and activities provide further resources. Our new publications will address leadership and challenge traditional attitudes and approaches to care.

Alzheimer's Society is also exploring working with care homes to develop dementia specialist carers to provide leadership, role modelling and support for their colleagues working with people with dementia on a daily basis.

Appendix A

Facts and figures

A.1 Care home population

- 700,000 people in the UK have dementia. Over a third of people with dementia (244,000) live in care homes (Alzheimer's Society, 2007).
- Two-thirds of care home residents in the UK have dementia (Alzheimer's Society, 2007). This varies according to the type of home, with the highest prevalence in EMI homes (Table A.1):

Table A.1 **Consensus estimates of the prevalence of late onset dementia among residents of care homes: different types of home**

Type of home	Prevalence of residents with dementia (%)
Care home only	50.1
Care home with nursing	66.2
EMI home	79.9

- The prevalence of dementia among residents of care homes rises with age (Table A.2):

Table A.2 **Consensus estimates of the prevalence of late onset dementia among residents of care homes, by age**

Age in years	Female (%)	Male (%)	Total (%)
65-69	59.9	56.1	55.1
70-74	59.9	55.4	55.4
75-79	62.9	55.7	57.9
80-84	66.1	56.9	61.6
85-89	65.9	62.7	62.9
90-94	66.9	64.3	63.9
95+	67.6	62.9	66.4

- 45% of care home residents have moderately severe to very severe cognitive impairment (Darton, Forder, Bebbington *et al.*, 2006).¹
- Dementia is the strongest determinant of entry into residential care in over 65s (Alzheimer's Society, 2007).
- 36% of people with dementia live in care homes (Table A.3).
- 40% of people with dementia in care homes are not in dementia-registered beds (Table A.3).

Table A.3 **Estimated number of people with dementia in care homes and dementia registered beds**¹

	Total number of people with dementia	Number of people with dementia in care homes	Number of dementia registered beds in care homes (nursing and residential) ³	Proportion of people with dementia in care homes in dementia registered beds (%)
England	562,182	205,196	124,040	60
Wales	36,137	13,190	5,476	42
Northern Ireland	15,455	5,641	3,838	68
Total	613,774	224,027	133,354	60

While these figures provide strong evidence for the importance of addressing the quality of dementia care in care homes, there is a need to update the evidence base. The Dementia UK report authors found only three studies that met their inclusion criteria for the systematic review of prevalence of dementia in care homes. One of these studies used recorded diagnoses of dementia, which is likely to underestimate true prevalence because of poor recognition of dementia by staff. This is borne out by the much lower prevalence found in this

1 These figures differ from the Dementia UK figures as different methods of data collection were used.

2 Estimated numbers of people with dementia and proportion in care homes from Dementia UK, number of dementia registered beds from NAO report (England), the Care and Social Services Inspectorate Wales and Regulation and Quality Improvement Authority (Northern Ireland)

3 CSCI guidance states that many people with dementia will be in the general care home sector and dementia registered beds are for individuals whose needs cannot be met by general care homes.

study than the two which directly evaluated residents. In addition, no studies consider prevalence in NHS continuing care facilities.

Updated studies would also enable examination of how recent policy focussing on supporting people in their own homes have affected the proportion of people with dementia in care homes. If those with less complex needs are to be supported in the community those with the most complex needs, particularly dementia, will dominate long-term care. Improved data collection would present a clearer picture of today's care home population and therefore how the skills and standards required of homes must adapt to changing needs.

In April 2006 Laing and Buisson reported that there were 421,000 people in care homes compared to 511,000 people in 1996. The change reflects the fact that people with less complex needs are now being supported in the community.

PSSRU figures also demonstrate the increasing levels of cognitive impairment in care home residents. In 2005 45% of care home residents had moderately severe to very severe cognitive impairment. This proportion has increased by 10% since 1995.

Table A.4 Proportion of care home residents with different levels of cognitive impairment in 1995 and 2005

MDS Cognitive Performance Scale	1995	2005
Intact	20.2	14.8
Borderline intact	12.7	8.3
Mild impairment	11.2	10.9
Moderate impairment	21.1	21.1
Moderately severe impairment	8.4	13.2
Severe impairment	24.4	27.2
Very severe impairment	2.1	4.6

(Darton R, Forder J, Bebbington A *et al.*, 2006)

A.2 Costs of dementia care

The financial cost of dementia in UK amounted to £17.03 billion per year (Alzheimer's Society, 2007).

- The estimated annual cost of a person with dementia in different settings are (Alzheimer's Society, 2007):

– People with dementia in residential care	£31,263
– People in the community with severe dementia	£37,473
– People in the community with moderate dementia	£25,877
– People in the community with mild dementia	£16,689
- For people in residential care 92% of the cost (£28,646) is for accommodation. Informal care costs account for 3% (£938), social services 1% (£378) and NHS costs 4% (£1,334).
- Laing and Buisson 2007 survey of fees found that the average price of care (for all older people not just those with dementia) was £627 for private nursing care for elderly people and £445 for private residential (personal) care.
- In 2004 the Joseph Rowntree Foundation calculated a 'fair price for care' at £574 per week for nursing homes (£686 in London and outer environs), £445 for residential care and £474 (£582 in London and outer environs) for residential care for people with dementia (Laing, 2004).

A.3 Paying for care homes

- The costs of care homes are split between families (30%) and public funding (70%) (Quoted in National Audit Office, 2007; estimated by the English Community Care Association).

A.4 Care home size

- The average sized home for over 65 year olds has 34 places (this compares to an average size of 9 places in homes for younger people with learning disabilities). The largest homes, on average, are those registered to take older people with dementia.
- There is no correlation between size of home and achievement against National Minimum Standards, however studies of homes for people with learning disabilities show that small group homes do generally offer much better individualisation and self-determination (Commission for Social Care Inspection, 2006).

A.5 Workforce

- Only 25% of the social care workforce possess a qualification (Department of Health, 2006).
- Turnover rates in the local authority social care workforce have averaged around 12% between 2001 and 2005 (Department of Health, 2006).
- A 2001 report found turnover was over 30% in nine months in some care facilities (Margallo-Lana, Reichelt, Hayes *et al.*, 2001).
- In some tabloid newspapers negative coverage outnumbers positive by 38:1 (Eborall and Garmeson, 2001).

Appendix B

Policy context

Residential care has not been a focus of Government policy in recent years, which has concentrated on supporting people in their own homes. However, the provision of dementia care, regardless of setting, must be addressed as a whole system. There is a danger that public policy is neglecting the impact on the care home population of supporting people with less complex conditions at home. Care homes' management and workforce, physical environment and support available from specialist services will need to develop to meet the different needs of this population.

B.1 Regulation and inspection

The regulation and inspection system for care homes aims to improve care and stamp out bad practice. Homes are inspected against standards set by government. The inspection bodies take a view of the whole of a care service during inspections and consider the needs of the particular residents in that home when assessing performance. Therefore it is not possible to give a binding interpretation of what is meant by each standard. For example, in terms of training it is a requirement in England that 50% of staff have achieved NVQ level 2, but beyond this the home also has to demonstrate that 'there is a staff training and development programme which meets National Training Organisation (NTO) workforce training targets and ensures staff fulfill the aims of the home and meet the changing needs of service users.' There is no requirement for the NVQ to address dementia care.

Arrangements in each country are as follows:

England

The Commission for Social Care Inspection (CSCI) is responsible for the regulation and inspection of care homes in England. They inspect against the National Minimum Standards (NMS) (Department of Health, 2003), which were issued by the Department of Health (DH) as part of the implementation of the Care Standards Act 2000.

Short Observation Framework for Inspectors (SOFI)

CSCI aim for the inspections to be based on the outcomes achieved for the care home residents. Inspectors have found it difficult to assess the quality of a home from the perspective of a person with dementia. In response to this CSCI have worked with the Bradford Dementia Group to develop the Short Observation Framework for Inspectors (SOFI). Using this tool helps

inspectors understand the residents' experience, particularly in terms of their observable well-being, level of engagement and style of staff interaction. It involves observing a maximum of five residents for two hours and recording observations every five minutes. The data gathered should be triangulated and should be used to trigger further investigations, into staff training or medication usage for example. Alzheimer's Society also provides a training programme for CSCI inspectors to support them in assessing the quality of dementia care. CSCI is due to merge with the Healthcare Commission in 2009 to form Ofcare and this will be an opportunity to revise the inspection and regulation system.

Wales

The Care and Social Services Inspectorate for Wales regulates and inspects care homes in Wales. They inspect against National Minimum Standards for Care Homes for Older People issued by the Welsh Assembly Government under section 23 of the Care Standards Act 2000 (CSA). The regulatory requirements are set out under the CSA and in the Care Homes (Wales) Regulations 2002 ('the Regulations') as amended by the Care Home (Wales) (Amendment No 2) Regulations 2003 and The Care Homes (Amendment) (Wales) Regulations 2003.

Northern Ireland

The Regulation and Quality Improvement Authority (RQIA) is the regulation and inspection service in Northern Ireland. It carries out these duties in accordance with regulations in The Health and Personal Social Services (Quality, Improvement and Regulation)(Northern Ireland) Order 2003. The care standards for residential and nursing homes are currently in draft form only and have been since 2005.

B.2 Dementia care policy

Dementia policy was relatively neglected until 2005. However, there are a number of documents that have relevance to dementia care in care homes.

England

Standards of care for England were set out in the National Service Framework (NSF) for older people, which has been criticised for the lack of detail and targets around dementia care. The standards apply to people in all settings, including care homes. The service model around dementia care specifies that local councils commissioning social care must require providers, including care homes, to ensure staff can recognise signs of dementia, refer when appropriate and provide appropriate care. In particular it highlights that older people in care homes should be able to participate in a range of stimulating activities, which

should meet their needs and preferences. The NSF also states that the NHS and local councils should work with care home providers in their area, to develop services to meet the needs of the local population. The requirement to provide specialist care home places for older people with dementia is emphasised. The service model outlined in the NSF includes specialist services providing outreach services to care homes.

There were no targets around these particular aspects of the NSF and a number of reports and reviews of implementation of the NSF have found that progress on services for older people with mental health problems has been poor (Tucker, Baldwin, Hughes *et al.*, 2007; Healthcare Commission, CSCI and Audit Commission, 2006).

The Department of Health have set out how they intend to address the particular problems in services for older people with mental health problems in the policy document 'Securing Better Mental Health for Older Adults' (2005). This document recognised the need for a whole-systems approach and warned that 'We must ensure that service developments in one sector do not have unintended consequences for the individual using services in another sector. Such complexity requires a whole-systems response, both from Government and from local health and social care communities.'

Following concerns that services for older people with mental health problems were falling behind others, the Department of Health published Everybody's Business (2005). This sets out the key components of an older people's mental health service for England. The following issues relevant to dementia care in care homes were highlighted:

- People with dementia will be cared for by mainstream staff with specialist staff for those whose needs can't be met by mainstream staff.
- Good links between residential care and local specialist services.
- Staff working with people with dementia require strong communication skills.
- Residential care is a key area for workforce development and commissioning and it is emotionally demanding work.
- The aim of residential care should be to enable older people with mental health problems to be as socially included and independent as possible.
- Comprehensive assessment is a prerequisite to ensuring the appropriateness of a placement to meet a person's needs, and the most efficient use of resources.

The NICE/SCIE dementia clinical guideline published in November 2007 contained many helpful recommendations, particularly around the dementia care environment and staff training. The guideline applies to England and Wales. Although implementation of the recommendations is not mandatory,

health and social services bodies are expected to follow them and will be inspected against the guidelines.

National Dementia Strategy

The Department of Health is to produce the first National Dementia Strategy for England over 2007/2008. It will cover improving understanding of dementia, promoting timely diagnosis and improving the quality of care. Alzheimer's Society will be closely involved in its development and it is hoped that the Strategy will result in fuller implementation of the sensible recommendations contained in the NICE guideline (2007) and Everybody's Business (2005).

Wales

The Welsh Assembly government have developed a NSF for older people in Wales, based on the English version but adapted to reflect the needs of older people in Wales. It highlights that the provision of care home places should include a range of facilities, be adequately staffed with appropriate skills and supported by specialists when required.

Wales have also developed a strategy for Older People and are about to appoint a Commissioner for Older People in Wales.

Northern Ireland

The NICE/SCIE dementia clinical guideline, along with NICE guidance on Alzheimer's drugs, is under consideration by the Minister for Health Michael McGimpsey, for application to Northern Ireland.

B.3 Mental Capacity legislation

The Mental Capacity Act 2005 introduced in England and Wales should bring a significant improvement to the rights of vulnerable people in care homes. It requires that care staff must assume a person is capable of making decisions, unless it is established that they cannot. Staff must provide support to help people make their own decisions and if a decision has to be made on their behalf, it must be the one that is least restrictive of their basic rights and in their best interests. The Act also introduces new criminal offences of ill-treatment or willful neglect of a person who lacks capacity to make relevant decisions. Willful neglect generally means that a person failed to carry out an act they knew they had a duty to do.

Mental Capacity Act 2005 is not applicable to Northern Ireland and no comparable legislation is (yet) in place. The approach to decision-making on behalf of adults aged 16 and over who lack capacity to make decisions on their own behalf in Northern Ireland is currently governed by common law.

B.4 Human Rights Act

The Human Rights Act gives individuals the right to be treated with fairness, dignity and respect and residents of local authority owned care homes have their rights protected by this Act. However, residents in privately owned care homes do not have this protection, even if the local authority funds the individual's care. A recent case argued that a home was carrying out a public function by caring for people referred by a council, and was therefore bound by the Human Rights Act, but the House of Lords ruled against this. Charities and civil rights groups are campaigning for the Government to close this loophole and end the two-tier system.

B.5 Workforce

The need to develop the status and skills base of the social care workforce is now well-recognised and has been addressed in Government policy. As part of this, regulation of the social care workforce was introduced in 2003. Registrants will need to satisfy a number of criteria covering qualification and training. Each country in the UK has its own regulatory body. They are the Care Council for Wales; the General Social Care Council (for England); the Northern Ireland Social Care Council and the Scottish Social Services Council.

England

The White Paper, *Our health our care our say*, stated that it is unacceptable that the most vulnerable in society are cared for by the least well-trained. The paper did not include any milestones or targets for workforce development (beyond creation of new practitioners with special interests), but highlighted that the distribution of funding for training and developing health and social care staff should reflect the priorities of the white paper - one of which is building up skills in social care.

Dementia knowledge set

Skills for care is the social care workforce strategy body for England, which develops national occupational standards for adult social care workers and supports employers. It has produced a useful knowledge set for dementia to help employers understand the learning outcomes they should be aiming for for their staff. The aim of the knowledge set is 'to improve consistency in the underpinning knowledge learnt by the adult social care workforce in England.' They are for use by service providers when developing in house training or making decisions when buying training packages.

The recent national review of the social care workforce in England, entitled *Options for Excellence* (Department of Health, 2006), picked out a number of priorities including better support and career progression opportunities, as

well as effective supervision and leadership. It includes a number of actions, for example developing a strategy to support workforce development in the third sector and in the longer term developing career pathways across the public, private and third sector employers. The Options for Excellence also recommended involving service users in staff training.

Wales

The WAG published 'The Social Care Workforce in Wales - Definitions and Challenges' (September 2001) which sets out key information about the workforce in Wales and the changing patterns and trends in that workforce. It also identifies key areas for action. The report looked at staff retention and indicated that systematic induction, probation, training and appraisal systems could reduce turnover.

Every unitary authority in Wales has a Social Care Workforce Development Partnership (SCWDP) whose aim is to increase the proportion of competent and qualified staff in social care.

B.6 Funding of training

The majority of care homes are within the private sector. The Options for Excellence review recommended that employers should spend the equivalent of at least 3% of their workforce costs on developing their workforce. It also agreed with the Department of Health that, 'The commissioning of social care services should include contribution to costs of establishing and maintaining an appropriately competent workforce' ('Building capacity and partnership in care' www.dh.gov.uk). Employees are expected to contribute 15% of the total cost of their training - but this should be in time (i.e. time spent compiling evidence for the NVQ) rather than money.

There is no single source of funding for training. Sources in England include:

- The Training Strategy Implementation (TSI) funding provided by the Department of Health for disbursement to social care employers through employer led partnerships to support the achievement of the national minimum standards in care.
- National Training Strategy (NTS) grant provided by the Department of Health via local authority social services departments to support the training of social care staff across the statutory, private and voluntary sectors. Different authorities offer different forms of support to independent providers.

In Wales, each Social Care Workforce Development Partnership (SCWDP) supports the training of independent and voluntary sector care providers that have contracts with the council to provide care. It provides free training courses and also training resources.

Sources of funding for workforce training in residential and nursing care homes in Northern Ireland are somewhat complex.

Statutory and voluntary residential care homes. Broadly speaking, baseline funding for training in this sector (excluding nursing care homes) is allocated through the Personal Social Service Training Strategy, administered by the Department of Health, Social Services and Public Safety (DHSSPS). Additional funding (not normally to exceed more than 50% of the organisation's own investment) to meet strategic social care need, may be secured through the annual bidding process. As there is a limited budget the department's contribution diminishes in line with heightened demand.

Statutory and voluntary nursing homes can access funding for training from DHSSPS through trusts.

Private residential and nursing homes largely access training through institutions within the further and higher education system or by self and employer contribution.

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