

Chapter 5: Living well with dementia

Living well with dementia at home

'I have also lost handling things like knives and forks.' (person with dementia)

'He used to be an engineer and he was very precise in everything he did, and now when he gets problems doing things he gets very frustrated. Very frustrated. He gets angry and he'll shout at me, "I never used to be like this."' (carer)

'I rely greatly on my wife and my carers...I'd be in terrible trouble without them.' (person with dementia)

'That was a wonderful feeling: to know that there were people, in the right area, who absolutely cared for you.' (person with dementia)

'I could cope with him in the day. I couldn't cope at night. Without sleep it was hopeless. I was on the verge. I said to the doctor, "If I don't kill him, I'll kill myself". That's how bad it was.' (carer)

'The memory nurse...she was very good wasn't she. She gave us lots of information we didn't know or wouldn't even have thought of. She was excellent.' (carer)

'I need to make those decisions while I have enough mental capacity to be able to do that and to understand the implications of it before I get too far down the line. So it has given me the time to think about that. That is important.' (person with dementia)

'I think the powers that be don't realise that when someone has dementia, the partner who is caring for them also has their own mental problems.' (carer)

'Most important of all to be given all the information they need: not about what's just happened but about what is likely to happen and where you can go for assistance.' (carer)

'Sometimes they think of you as if you are gaga: [speaking slowly] "can you do this, can you do that?"' (person with dementia)

'Everybody I have met has been absolutely amazed that I can still talk and still think, even though I have a diagnosis of dementia. They do not understand it. I think that is indicative of what the public is like.' (person with dementia)

'Because we were able to have home carers, organised by the social services, my husband was able to spend the last six years of his life in our own home, where he was very happy, instead of going into residential care, which would have made us all very sad. The carers came three times a day and we also had district nurses and a respite service who looked after him when I went shopping. I was able to look after him 24 hours a day. None of this would have been possible without the carers.'

'The carers do the best they can, but they have to be in and out in 20 minutes, which doesn't really leave any time to do things properly.' (carer)



Living well with dementia in care homes

'I cannot speak highly enough about this home. My mother is 93, and before, she lived in isolation 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.' (carer)

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

'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.' (carer)

'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.' (carer)

'I would say that of the last 30 residents I have assessed over the last two years, the majority were on anti-psychotic medication, and I would estimate that over 50% of dementia clients within care homes are on anti-psychotic medication.' (care home manager)

'Instead of trying to understand why my husband was getting upset and angry, they put him on sedative drugs and didn't take him off them for months. I only realised when I questioned his medication.' (carer)

'And I think my other concern is...that often, when 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. 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.' (carer)

'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.' (carer)

Community personal support

Objective 6: Improved community personal support services. Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, people who pay for their care privately, through personal budgets, or through local authority-arranged services.

How this can be delivered

- Implement *Putting People First* personalisation changes for people with dementia, utilising the Transforming Social Care Grant.
- Establish an evidence base for effective specialist services to support people with dementia at home.
- Commissioners to implement best practice models thereafter.



The case for change

1. Two-thirds of all people with dementia live in their own homes in the community. Some will be in the early stages of their illness, and others near the end of their lives. The right support, at the right time and in the right place, is especially important for people with dementia, to give them choice and control over the decisions that affect them. Some people will just want access to services that should be available to everyone locally, such as transport, leisure, housing and information. Some will need a little more help, for example, maintaining their homes and gardens, their physical health, and peer support networks. As people's conditions progress they will want access to good-quality personal care and intensive support. People will still want to choose how and by whom that care and support is provided, regardless of who is paying for it, and will expect to be treated with dignity and respect at all times. In line with the principles set out in the Government's *Think Family* report,³⁴ they will also expect their broader family circumstances, including the needs of any dependent children, to be taken into account and for support to be provided in a holistic way.
2. Apart from family members or friends, who provide the vast bulk of care and support, home care is probably the single most important service involved in supporting people with dementia in their own homes. The Commission for Social Care Inspection (CSCI) has found that good-quality, flexible home care services contribute significantly to maintaining people's independence, reducing social isolation, preventing admissions to care homes and hospitals, and supporting carers.³⁵ Studies carried out by CSCI and others point to the importance of continuity, reliability and flexibility of home care services, in ensuring that people with dementia and their carers have choice and control over the services they receive. These are important messages for commissioners of home care services, both for mainstream home care services and for specialist dementia services for people with more complex needs. For people who wish to purchase care and support themselves, with the help of a carer or advocate, commissioners need to ensure there is a range of appropriate services in their area.
3. Current practices of specifying tasks rather than outcomes, not having the time or consistency of worker to develop the relationship between the individual and care worker, and care workers being rushed and visiting for short (eg 15-minute) periods are particularly problematic for people with dementia. As successful commissioning is key to improving home care services for people with dementia and their carers, a toolkit has been produced by the Care Services Improvement Partnership (CSIP) and is available at www.dh.gov.uk/dementia. Emerging research-based evidence shows considerable benefits to both people with dementia and their carers from specialist dementia home care when compared with standard home care services. Improved

³⁴ Social Exclusion Task Force (2008). *Think Family: Improving the life chances of families at risk*. London: Cabinet Office.

³⁵ CSCI (2006). *Time to Care?* London: TSO.

outcomes include reduced stress and risk of crises for carers, and extended capacity for independent living for people with dementia.³⁶ Some examples of innovative practice are emerging from dedicated home care dementia teams. They ensure the provision of additional time prior to the commencement of the care package, to build a rapport, learn about the person with dementia, their family, their preferences and their life as a whole so that the service is truly person-centred.

4. A comprehensive community personal support service would provide:
 - home care that is reliable, with staff who have basic training in dementia care;
 - flexibility to respond to changing needs, not determined by rigid time slots that prevent staff from working alongside people rather than doing things for them;
 - access to personalised social activity, short breaks and day services;
 - access to peer support networks;
 - access to expert patient and carer programmes;
 - responsiveness to crisis services;
 - access to supported housing that is inclusive of people with dementia;
 - respite care/breaks that provide valued and enjoyable experiences for people with dementia as well as their family carers;
 - flexible and responsive respite care/breaks that can be provided in a variety of settings including the home of the person with dementia;
 - independent advocacy services; and
 - assistive technologies such as telecare.
5. Services need to be able to work for the diverse groups of people who may be affected by dementia. For example, people with learning disabilities who develop dementia will generally be of a younger age group and may have needs which services designed for people 30 or 40 years older find hard to meet.
6. In order to identify, collate and evaluate the data available on existing models of generic and specialist personal support, a collation and evaluation period will be necessary to enable good-quality advice and information to be made available for commissioners.

³⁶ Rothera I, Jones R, Harwood R et al (2007). 'An evaluation of a specialist multiagency home support service for older people with dementia using qualitative methods'. *International Journal of Geriatric Psychiatry*, 23:1, 65–72.

7. People with dementia are known to be an ‘at risk’ group in terms of abuse, particularly (although not exclusively) through financial exploitation, fraud and theft. Reliance on others for support to manage finances can expose people with dementia to the risk of abuse. Additionally, the complex dynamics of caring relationships mean that people do not always report abuse or mistreatment. This becomes even more problematic if the individual lacks the capacity to be able to complain. Feedback from the consultation process has highlighted concerns from carers and professionals about inadequate safeguards for people with dementia. Managers and staff in all settings need to be alert to the possibility of abuse of all kinds, and be familiar with the local arrangements for reporting allegations of abuse, safeguarding people with dementia and their carers, and protecting their human rights. Services should make sure that there is clear information available on how to complain about poor standards of care, or report concerns about possible abuse.

Carers – the most valuable resource for people with dementia

Objective 7: Implementing the Carers’ Strategy for people with dementia. Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers’ Strategy are available for carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

How this can be delivered

- Ensuring that the needs of carers for people with dementia are included as the strategy is implemented.
- Promoting the development of breaks that benefit people with dementia as well as their carers.

The case for change

8. Most people want to remain living in their own homes for as long as possible. This message is consistently given by the public, by older people generally and by people with dementia specifically, be they young or old. Most family carers want to be able to provide support to help the person with dementia stay at home, but they sometimes need more assistance than is currently routinely available. Residential care may be the most appropriate and effective way of meeting someone's needs and providing a service of choice. But it should always be a choice. All too often people with dementia (particularly older people) find themselves on a conveyor belt that takes them into long-term residential care because it appears that there are no alternatives available. This is especially the case if the person is admitted to hospital after a crisis. This is partly because a lack of knowledge and understanding about dementia leads some professionals to the erroneous assumption that residential care is the only option. It is also due to home care staff and family carers not receiving training and advice in dementia, and so not having the skills and competences to provide appropriate care.
9. Equally there is a clear need for breaks and day services to support families in their caring role in the community. Such services need to be able to provide valued and enjoyable experiences for people with dementia and their family carers. They can play an important role in the prevention of institutionalisation and the maintenance of people with dementia in the community. The arrangements for such breaks need to be flexible and responsive to the needs of each individual with dementia and their carer. Breaks can be provided in a variety of settings, including the home of the person with dementia. They need to be available on emergency, urgent and planned bases. CSIP has produced a fact sheet on different models of breaks for people with dementia, with examples and contact details, available at www.dh.gov.uk/dementia.
10. The Department's Carers' Strategy was published in June 2008. Over 500,000 family members who care for people with dementia provide over £6 billion a year of unpaid care. A far-reaching consultation of carers contributed to the development of the Carers' Strategy. Its implementation will ensure a 10-year plan that builds on the support for carers and enables them to have a life outside caring. Joint working between those implementing the dementia and carers' strategies will be needed at a local, regional and national level to help the Carers' Strategy deliver for those that care for people with dementia.

Improved quality of care in general hospitals

Objective 8: Improved quality of care for people with dementia in general hospitals. Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there, and the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

How this can be delivered

- Identification of a senior clinician within the general hospital to take the lead for quality improvement in dementia in the hospital.
- Development of an explicit care pathway for the management and care of people with dementia in hospital, led by that senior clinician.
- The gathering and synthesis of existing data on the nature and impacts of specialist liaison older people's mental health teams to work in general hospitals.
- Thereafter, the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

The case for change

11. Up to 70% of acute hospital beds are currently occupied by older people³⁷ and up to a half of these may be people with cognitive impairment, including those with dementia and delirium.³⁸ The majority of these patients are not known to specialist mental health services, and are undiagnosed. General hospitals are particularly challenging environments for people with memory and communication problems, with cluttered ward layouts, poor signage and other hazards. People with dementia in general hospitals have worse outcomes in terms of length of stay, mortality and institutionalisation.³⁹ This impact is not widely appreciated by clinicians, managers and commissioners. The NAO has estimated the excess cost to be more than £6 million per year in an average general hospital.⁴⁰
12. There is a lack of leadership and ownership of dementia in most general hospitals. There are also marked deficits in the knowledge and skills of general hospital staff who care for people with dementia. Often, insufficient information is sought from relatives and carers. This means that person-centred care is not delivered and it can lead to under-recognition of delirium and dementia. Currently, families are often excluded

37 DH (2001). *National Service Framework for Older People*. London: TSO.

38 Royal College of Psychiatrists (2005). *Who Cares Wins: Improving the outcome for older people admitted to the general hospital*. London: RCPsych.

39 Ibid.

40 NAO (2007). *Improving services and support for people with dementia*. London: TSO.

from discharge planning, so false assumptions may be made about whether it is possible for people with dementia to be cared for at home. The NAO found that some general hospital services worked hard not to make the diagnosis of dementia, for fear it would delay discharge.⁴¹

13. Poor care can lead to malnutrition and dehydration for people with dementia, an outcome highlighted in the Age Concern England report *Hungry to be Heard*.⁴² Many examples were cited during the consultation on the National Dementia Strategy of people with dementia being left without assistance to eat or drink. As part of the Dignity in Care campaign, the Department of Health has produced a Nutrition Action Plan to which the key national organisations have signed up and which addresses issues of raising awareness, guidance, screening, training, and inspection and regulation. The action plan and supporting materials are available at www.dignityincare.org.uk.
14. There is often a lack of co-ordination between hospitals and care providers at the point of discharge, with delay in access to care packages such as home care and intermediate care that might enable successful discharge. There is a clear need therefore to improve the quality of care provided for people with dementia in general hospitals. The proposed improvements in core and continuing professional training set out in the next chapter should improve quality of care. Three ways suggested as having the potential to deliver further improvements are:
 - the identification of a senior clinician within the general hospital to take the lead for quality improvement in dementia care in the hospital;
 - the development of an explicit care pathway for the management and care of people with dementia in hospital, led by that senior clinician; and
 - commissioning specialist liaison older people's mental health teams to work in general hospitals.
15. The care pathway for the better management of people with dementia, including pathways out of hospital, should be developed in consultation with local social services and user and carer organisations. It could specify the arrangements for local leadership and accountability for dementia in general hospitals. Core competencies for all general hospital staff in contact with people with dementia (including Patient Advice and Liaison Services (PALS) and Local Involvement Networks (LINKs)) could be included, and training provided around these competencies.

⁴¹ Ibid.

⁴² Age Concern England (2006). *Hungry to be Heard*. London: Age Concern.

Specialist liaison older people's mental health teams in general hospitals

16. Specialist liaison older people's mental health teams are already advocated by the NICE/SCIE guideline on dementia services.⁴³ They can provide rapid high-quality specialist assessment and input into care planning for those with possible mental health needs admitted to general hospitals, including input into ongoing care and discharge planning. They will generally consist of a multidisciplinary team of three to four members of staff (part-time consultant, staff grade doctor, nurse and psychologist/therapist) with administrative support and a base in the general hospital. They can cover the whole range of mental health problems in older adults, not just dementia. These teams can then work closely with the designated general hospital lead to build skills and improve care through the hospital. They need to have good links with the social work assessment teams based in or linked to the hospital. They are already provided in some but by no means all hospitals. Mental health care in accident and emergency departments is often focused on self-harm and acute psychosis in adults of working age. There is also a clear need for services to be commissioned to work on the wards with skills in the diagnosis and management of dementia.
17. There is currently considerable diversity in the models adopted and the nature and scope of the work completed by such liaison services in general hospitals. Reviewing the available evidence, including emerging information from research, indicates that the data need to be brought together formally in order to build the case for the commissioning of such services. There would therefore be the need for an initial period of collation and synthesis of the data available on the services that currently exist in order to inform future commissioning decisions.

Intermediate care for people with dementia

Objective 9: Improved intermediate care for people with dementia. Intermediate care which is accessible to people with dementia and which meets their needs.

How this can be delivered

- The needs of people with dementia to be explicitly included and addressed in the revision of the Department of Health's 2001 guidance on intermediate care.

⁴³ NICE/SCIE (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. London: TSO.

The case for change

18. Pathways out of hospital and to avoid hospitalisation, such as intermediate care, often exclude people with dementia, meaning that they cannot access rehabilitation services that could enable them to return home or prevent their admission to hospital. Specialist intermediate dementia or mental health care services that enable discharge from the general hospital setting are rare. Both factors appear to stem from a misunderstanding of the Department of Health guidance in this area. Staff working in intermediate care are often reluctant to offer people with dementia the opportunity to benefit from the service because they feel they are likely to need longer than the usual six weeks, and are therefore perceived to not meet the criteria. This is an erroneous interpretation of the Department's guidance. Also problematic is the false assumption that people with dementia cannot benefit from rehabilitation. Local criteria for services have therefore often specifically excluded people with dementia. Pressures to reduce lengths of stay in acute care, combined with risk-averse discharge planning, can mean that people with dementia are rushed into long-term residential care prematurely.
19. Community hospitals provide a valuable resource in a non-acute setting to enable recuperation and rehabilitation. Some of these services are specifically labelled as intermediate care. However, the same difficulties occur in community hospitals as in acute hospitals concerning staff knowledge and competences about dementia. This is particularly important as people with dementia often fall victim to the practice of moving people quickly out of acute hospitals to relieve pressure on beds. Commissioners will want to assure themselves that community hospitals are able to deliver good-quality rehabilitation and intermediate care services for people with dementia. CSIP has produced a Good Practice guide to reviews of community hospitals and intermediate care resources, available at www.dh.gov.uk/dementia.
20. There is good clinical evidence that people with mild or moderate dementia with physical rehabilitation needs do well if given the opportunity. People with severe dementia may need more specialist services geared to meeting their mental health needs as well as those providing general physical rehabilitation. Staff working in intermediate care, like any other staff group, need to have core training in dementia and access to advice and support from specialist mental health personnel to help them ensure that people with dementia are able to benefit from rehabilitation and reablement opportunities.

21. To address these concerns, the Department is reviewing and updating its 2001 guidance to reflect the new policy landscape and to correct misconceptions. It will make explicit the need to enable people with dementia to access intermediate care, whether through support to mainstream services for people with physical rehabilitation needs or by developing specialist intermediate care for people with more advanced or complex mental health needs. It will take account of the acute care pathways developed through the Next Stage Review and the prevention and early intervention agenda of *Putting People First*. The new guidance is scheduled to be available in the spring of 2009.

Housing and telecare for people with dementia

Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers. The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.

How this can be delivered

- Monitoring the development of models of housing, including extra care housing, to meet the needs of people with dementia and their carers.
- Staff working within housing and housing-related services to develop skills needed to provide the best quality care and support for people with dementia in the roles and settings where they work.
- A watching brief over the emerging evidence base on assistive technology and telecare to support the needs of people with dementia and their carers to enable implementation once effectiveness is proven.

The case for change

22. There has been little research conducted into the role of supported housing in dementia care. Nevertheless, those studies which have been conducted demonstrate that, on the whole, people with dementia can benefit from the support offered in sheltered and extra care housing. They are not always offered this opportunity. A study in 1995⁴⁴ found that sheltered housing can offer a positive environment to people with dementia, provided that appropriate opportunities for social interaction are available. The role of housing staff was identified as critical in the integration of tenants with dementia.

⁴⁴ Kitwood T, Buckland S and Petre T (1995). *Brighter Futures: a report on research into provision for persons with dementia in residential homes, nursing homes and sheltered housing*. Oxford: Anchor Housing Association.

23. More recently the importance of flexible care packages in meeting the needs of people with dementia in extra care housing has been demonstrated.⁴⁵ Many areas are now offering this sort of flexible, responsive care package through floating support services. Many residents with dementia in sheltered or extra care housing have complex health and care needs. The Housing Corporation/Housing 21 study found that these needs could be met where health, social care and housing worked together to provide a whole system strategy, although the researchers acknowledged that this remains a key challenge in supported housing.
24. The evidence base on design principles is sparse, but there is consensus on key principles and a number of good practice checklists are available. There is a more substantial evidence base to show the opportunities offered by assistive technology and telecare to enable people with dementia to remain independent for longer, and in particular to help the management of risk. But the data on newer approaches are still sparse and inconclusive. An evaluation of one scheme demonstrated cost effectiveness and reports of improved quality of life.⁴⁶ Large-scale DH field trials of such technology are currently under way.
25. This is an evolving field, but one that is of potentially high and central importance in enabling people with dementia to live well with their condition. There is much that is being done currently that is positive in terms of housing options and assistive technologies that are part of mainstream care for people with dementia, and that contribute to their independence and safety. However, with respect to more recent innovations, this is not an area where the strategy is able at this time to make specific recommendations. Instead, central, regional and local teams should keep in touch with initiatives in the areas of housing and telecare and make appropriate commissioning decisions as data become available, for example from the Department's large-scale field trials of telecare and assistive technology.

⁴⁵ Vallely S, Evans S, Fear T and Means R (2006). *Opening doors to independence: a longitudinal study exploring the contribution of extra care housing to the care and support of older people*. London: Housing Corporation and Housing 21.

⁴⁶ Woolham J (2005). *The effectiveness of assistive technology in supporting the independence of people with dementia: the Safe at Home project*. London: Hawker Publications.

Improving care for people with dementia in care homes

Objective 11: Living well with dementia in care homes. Improved quality of care for people with dementia in care homes through the development of explicit leadership for dementia care within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes.

How this can be delivered

- Identification of a senior staff member within the care home to take the lead for quality improvement in the care of dementia in the care home.
- Development of a local strategy for the management and care of people with dementia in the care home, led by that senior staff member.
- Only appropriate use of anti-psychotic medication for people with dementia.
- The commissioning of specialist in-reach services from older people's community mental health teams to work in care homes.
- The specification and commissioning of other in-reach services such as primary care, pharmacy, dentistry, etc.
- Readily available guidance for care home staff on best practice in dementia care.

The case for change

26. One-third of people with dementia live in care homes and at least two-thirds of all people living in care homes have a form of dementia. This state of affairs has not been planned for, either through commissioning services or through workforce planning. The need for workforce development is profound, and training in this area is covered in the next chapter. This section focuses on: making dementia an explicitly owned priority within care homes; enabling a minimum standard level of input into care homes from specialist mental health services for older people; and using the inspection regimes to drive up care quality. Following the NICE/SCIE clinical guideline on dementia, SCIE work is now focusing on supporting the independent sector in its work on dementia care. More specifically, as part of the implementation of this Strategy, the Department will be discussing with SCIE and others how to promote best practice in dementia care in care homes.

27. There is no doubt that residential care may be the most appropriate and effective way of meeting the needs of someone with dementia and a service of choice. There are care homes that provide excellent care for people with dementia. Such homes generally pay close attention to leadership and staff management, staff training and development, and person-centred care planning. They also provide a physical environment that enables people with dementia to move around the home safely. They provide purposeful activities that relate to individual preferences rather than general entertainment; actively involve relatives and friends in the care of residents; and develop strong links with and involvement in local communities. There is a growing interest in Life Story work which provides an effective vehicle for care home staff to communicate and develop relationships with residents, based on their unique life experiences. Equally the provision of therapeutic activities within care homes, such as art therapy, music therapy or dramatherapy, may have a useful role in enabling a good-quality social environment and the possibility for self-expression where the individuality of the residents is respected.
28. However, evidence from the Alzheimer's Society Home from Home report⁴⁷ on the current reality indicated that:
- 54% of carers reported that their relative did not have enough to do in a care home;
 - the typical person in a care home spent just two minutes interacting with staff or other residents over a six-hour period of observation (excluding time spent on care tasks);
 - the availability of activities and opportunities for occupation is a major determinant of quality of life affecting mortality, depression, physical function and behavioural symptoms, but that these activities are seldom available; and
 - staff enjoy providing opportunities of activity and occupation and would like to be able to do more of this within their work, but do not feel they have the time.
29. The report found that maintaining good relationships between relatives and the home, and supporting the ongoing relationship between relatives and the person with dementia, have important benefits for both parties, including carers' degree of stress, residents' quality of life and engagement in activity. A study by CSCI of care homes has shown the quality of staff communication with people with dementia has a major impact on their quality of life. Leadership, ethos of the care home, staff training and support and development are the crucial factors in supporting good practice.⁴⁸ Commissioners can develop service specifications with providers which include

⁴⁷ Alzheimer's Society (2008). *Home from home*. London: Alzheimer's Society.

⁴⁸ CSCI (2008). *See me, not just the dementia: Understanding people's experiences of living in a care home*. London: CSCI.

these key factors, and identify how performance will be assessed in contract monitoring and evaluation.

30. The mental health needs of people living in care homes are extensive and generally not well met. Up to 75% of residents in non-specialist care homes for older people have dementia,⁴⁹ and the prevalence rises to between 90 and 95% in homes for the elderly mentally infirm.⁵⁰ In addition, an estimated 50% of all care home residents have depressive disorders that would warrant intervention.⁵¹ Behavioural disturbance in dementia in these settings is both very common and a cause of stress to residents and staff. It is striking that there is very little in the way of active non-pharmacological management of these problems in these settings, despite accumulating evidence of the effectiveness of old age psychiatric intervention.⁵² Current input from mental health services is generally on an ad-hoc basis or reactive with referrals at times of crisis.
31. One issue that is of particular concern is the use of anti-psychotic medication in care homes for the management of behavioural and psychological symptoms in those residents with dementia. Those who have criticised current practice include the Parliamentary Accounts Committee,⁵³ the Alzheimer's Society⁵⁴ and the All-Party Parliamentary Group on Dementia.⁵⁵ It appears that there are particular risks that are serious and negative in the use of anti-psychotic medications for people with dementia. These include increased mortality and stroke. There is accumulating evidence that in care homes they are initiated too freely, they are not reviewed appropriately following initiation, and they are not withdrawn as quickly as they could be. However it is also the case that behavioural problems in people with dementia can be dangerous and disruptive, and in some cases medication is the least worst option. Improving the quality of care in care homes requires this issue to be addressed effectively.
32. In response to the widespread concern at the inappropriate use of anti-psychotic drugs for people with dementia, the then Minister for Care Services announced a review of the issue in June 2008. This is being led by Professor Sube Banerjee, the joint lead of the National Dementia Strategy. This review is expected to complete its work and issue a full public report in the spring of 2009.

49 Macdonald AJ, Carpenter GI, Box O et al (2002). 'Dementia and use of psychotropic medication in non-'Elderly Mentally Infirm' nursing homes in South East England'. *Age and Ageing*, 31, 58–64.

50 Margallo-Lana M, Swann A, O'Brien J et al (2001). 'Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments'. *International Journal of Geriatric Psychiatry*, 16:1, 39–44.

51 Ames D (1991). 'Epidemiological studies of depression among the elderly in residential and nursing homes'. *International Journal of Geriatric Psychiatry*, 6:6, 347–54

52 Proctor R, Burns A, Powell HS et al (1999). 'Behavioural management in nursing and residential homes: a randomised controlled trial'. *Lancet*, 354(9172): 26–9

53 NAO (2007). *Improving services and support for people with dementia*. London: TSO.

54 Alzheimer's Society (2008). *Home from home*. London: Alzheimer's Society.

55 All-Party Parliamentary Group on Dementia (2008). *Always a last resort*. London: Alzheimer's Society.

33. In the course of developing the Strategy, one means suggested to address these problems has been a system of regular specialist mental health assessment following admission, and regular specialist review for this vulnerable population. This would enhance the quality of care by providing a regular forum for discussion between nursing staff, GPs and mental health teams to identify and manage the mental health problems of care home residents. Any intervention would need to be in partnership with the GPs responsible for care within care homes. In this system the quality of mental health care for residents in care homes could be improved by:
- detailed specialist assessment of mental health needs following admission;
 - regular six-monthly mental health reviews of residents in conjunction with the GP and nursing home staff;
 - providing access to specialist advice for problems arising between reviews to prevent problems by means of a regular pattern of visiting;
 - the formulation and deployment of non-pharmacological management strategies for behavioural disorder in dementia, so avoiding the initiation of anti-psychotic medication;
 - specialist input into decision making concerning the initiation, review and cessation of anti-psychotic medication for people with dementia;
 - rapid specialist review of all those with dementia initiated on anti-psychotic medication;
 - rapid specialist response to problems as they occur within homes; and
 - assessment of the residential care provided and the potential for improvement to create a more therapeutic environment.
34. All the above would act to minimise the use of such medication. Commissioners could achieve this by commissioning an extension of the existing role of the old age community mental health teams building on existing capacity, rather than by setting up a separate service. Joint commissioning of in-reach services from other professionals, such as community pharmacists, community dentists, arts therapists and geriatricians, could also improve support to care homes and enhance their environment.
35. Given demographic projections for a major increase in the number of people living with dementia in the years ahead, commissioners will need to give careful strategic consideration to local care home capacity. Some people with dementia (especially those with severe and complex needs without family carers) will continue to require residential care provision. Although it may be possible to reduce the proportion of people with dementia who live in care homes, population growth means it is likely that there will be a need for at least the current care home capacity in absolute terms.

Therefore, taking the longer view with the implementation of this Strategy, we may see a smaller proportion of people with dementia going into long-term care, but the same or a larger number of people continuing to need such care.

End of life care for people with dementia

Objective 12: Improved end of life care for people with dementia. People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.

How this can be delivered

- Initiating demonstration projects, piloting and evaluation of models of service provision prior to implementation, given the current lack of definitive data in this area.
- Developing better end of life care for people across care settings which reflects their preferences and makes full use of the planning tools in the Mental Capacity Act.
- Developing local end of life care pathways for dementia consistent with the Gold Standard framework as identified by the End of Life Care Strategy.
- Ensuring that palliative care networks, developed as part of the End of Life Care Strategy, support the spread of best practice on end of life care in dementia.
- Developing better pain relief and nursing support for people with dementia at the end of life.

The case for change

36. From the consultation process the Department heard that there needed to be stronger emphasis on developing end of life care in dementia and linking service development to the Department's End of Life Strategy. In dementia, end of life planning needs to take place early, while someone has sufficient mental capacity and where decisions and preferences can be recorded consistent with the principles set out in the Mental Capacity Act. This could include the use of lasting powers of attorney, advance decisions and advance statements.
37. The End of Life Care Strategy, published in July 2008, made clear the need for the development of end of life pathways which draw on the good practice shown in the Liverpool pathway and the Gold Standard framework. Local work on end of life care needs to focus on the large numbers of people who will die with dementia. In addition, in workforce development for end of life care, commissioners and providers need to consider how to ensure that effective end of life care for people with dementia can be

made real, including the effective use of specialist liaison with palliative care providers and skilled training in pain detection, pain relief and end of life nursing care.

38. For a given disorder, people with dementia have 4–6 times the mortality than the cognitively intact.⁵⁶ There is strong evidence to suggest that people with dementia receive poorer end of life care than those who are cognitively intact in terms of provision of palliative care.⁵⁷ For example, few people with dementia have access to hospice care.
39. The subject of pain illustrates the discriminatory care provided for people with dementia. In the last year of care giving, 63% of family carers reported that the patient had been in pain either ‘often’ or ‘all the time’.⁵⁸ Yet people with dementia receive less analgesia than other older people for a given illness.^{59, 60} Dementia may impair the ability of an individual to make themselves understood, and at least some of the agitated and aggressive behaviours seen in late-stage dementia may be an expression of pain.^{61, 62} People with dementia admitted to hospital for hip fracture with the same surgical intervention received less than half the pain relief of those who were cognitively intact.⁶³ The majority of those with dementia were in severe pain post-operatively and this pain was not actively managed.⁶⁴ However, communication problems in dementia may lead staff to ‘surmise that pain not expressed is pain not experienced’, and that pain expressed as aggression or confusion may lead to labelling and management as ‘difficult’.⁶⁵

56 Morrison RS, Siu AL (2000). ‘Survival in end-stage dementia following acute illness’. *Journal of the American Medical Association*, 284, 47–52.

57 Sampson EL, Gould V, Blanchard MR (2006). ‘Differences in care received by patients with and without dementia who died during acute hospital admission: A retrospective case note study’. *Age and Ageing*, 35, 187–89.

58 Schulz R, Mendelsohn AB, Haley WE et al (2003). ‘End-of-life care and the effects of bereavement on family caregivers of persons with dementia’. *New England Journal of Medicine*, 349(20): 1936–42.

59 Scherder EJ, Bouma A (1997). ‘Is decreased use of analgesics in Alzheimer’s disease due to a change in the affective component of pain?’ *Alzheimer Disease and Associated Disorders*, 11, 171–74.

60 Horgas AL, Tsai P (1998). ‘Analgesic drug prescription and use in cognitively impaired nursing home residents’. *Nursing Research*, 47, 235–42.

61 Geda YE, Rummans TA (1999). ‘Pain: Cause of agitation in elderly individuals with dementia’. *American Journal of Psychiatry*, 156(10): 1662–63.

62 Buffum MD, Miaskowski C, Sands L, Brod M (2001). ‘A pilot study of the relationship between discomfort and agitation in patients with dementia’. *Geriatric Nursing*, 22(2): 80–85.

63 Morrison RS, Siu AL (2000). ‘Survival in end-stage dementia following acute illness’. *Journal of the American Medical Association*, 284, 47–52.

64 Morrison RS, Siu AL (2000). ‘A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture’. *Journal of Pain and Symptom Management*, 19, 240–48.

65 Riesenber D (2000). ‘Hospital care of patients with dementia’. *Journal of the American Medical Association*, 284, 87–89.

40. So there are major problems in end of life care for people with dementia. One report⁶⁶ has summarised the situation as follows: “...people with dementia often die with inadequate pain control, with feeding tubes in place, and without the benefits of hospice care.” The particular issues of capacity and the impacts of dementia mean that dementia-specific approaches need to be developed if the needs of people with dementia and their families are to be addressed. This is acknowledged in the Department’s End of Life Care Strategy. The National Council for Palliative Care has been evaluating end of life care for people with dementia, and has published a series of useful publications on current best practice.^{67, 68}



66 Sachs GA, Shega JW, Cox-Hayley D (2004). ‘Barriers to excellent end-of-life care for patients with dementia’. *Journal of General Internal Medicine*, 19, 1057–1063.

67 National Council for Palliative Care (2006). *Exploring Palliative Care for People with Dementia: A Discussion Document*. London: Alzheimer’s Society/NCPC.

68 National Council for Palliative Care. *Creative Partnerships: Improving Quality of Life at the End of Life for People with Dementia* (January 2008) and *Progress with Dementia – Moving Forward: Addressing Palliative Care for People with Dementia*. (August 2007). London: NCPC.