Alzheimer's Society
Leading the fight against dementia

My life until the end

Dying well with dementia

Document purpose	This report provides a broad overview of the key issues relating to end of life planning and end of life care as experienced by people with dementia. The report summarises existing evidence and presents new evidence from current carers, bereaved carers and people with dementia. It makes recommendations about planning for end of life and to improve co-ordinated care through to the end of life.
Title	My life until the end: Dying well with dementia
Publication date	October 2012
Target audience	This report is intended for a range of audiences including central and devolved government, policy makers, health commissioners, and health and care providers. Its recommendations are intended to raise awareness, inform policy and change practice.
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Author	Martina Kane, Senior Policy Officer, Alzheimer's Society
Contact	Alzheimer's Society's Public Policy team can be contacted on 020 7423 3500 or at ppa@alzheimers.org.uk
Web	**www.alzheimers.org.uk/endoflife**
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Executive summary

One in three people over the age of 65 will die with some form of dementia (Brayne et al, 2006). As the population ages and more people develop dementia, end of life issues will become increasingly important, not only in dementia care, but for society as a whole.

Yet there are reports of extensive problems with end of life care for people with dementia. Alzheimer's Society spoke to over 38 people, spanning those with dementia, carers and former carers, and heard of issues across all areas of the system. This report addresses seven key issues that dementia presents at the end of life:

- **Public awareness** – A lack of common discussion of matters around death and dying among the public means that the wishes of people with dementia, even on basic matters, are often unknown as they reach the end of their life.
- **Care planning and proxy decision making** – As the condition progresses it is more difficult for people with dementia to contribute to decisions about their end of life care, so planning in advance is essential. Even so, those who make decisions on behalf of the person with dementia face an ethically complex situation.
- **Dignity** – While dignified care is essential for all, too often people in later stages of dementia are treated without dignity, which can make their final days even more distressing for their families.
- **Pain** – Difficulty with communication can mean that the person is not able to articulate basic needs such as pain, discomfort, hunger and thirst in the final stages, which makes meeting these needs a particular challenge for clinicians.
- **Withholding and withdrawing treatment** – The uncertain course of dementia can also make it difficult for professionals to give a prognosis. Not knowing how long someone might live makes it more difficult to plan the palliative care that person should receive.
- **Emotional and spiritual concerns** – There is often little regard for the emotional or spiritual support that may be needed at end of life for people with dementia.
- **Place of care and death** – Differences in the quality of experience were reported when the person with dementia died in hospital, at home, in a care home and in a hospice.

The present health and care system is not meeting the challenge posed by dementia. Specialist palliative care services and tools (such as the Liverpool Care Pathway) are underused or used inappropriately with people with dementia. Each person with dementia is different, and it is essential that the wishes of each individual are understood and carried out so that people with dementia can die with dignity, free from pain and in the place of their choice. This report places the voices of people affected by dementia and end of life care at its heart.

Methodology

Semi-structured interviews were carried out with 38 participants. These consisted of 25 interviews with former carers, 10 interviews with current carers and three interviews with people with dementia.

The interviews took place either face to face or on the telephone and were recorded. All interviews with people with dementia took place face to face. Support was available for participants after the interview through Alzheimer's Society's National Dementia Helpline. Care was taken that recordings of the interviews and details of the participants were kept securely.

Participants were asked to discuss:

- details of the end of life planning that had been discussed with them, their assessment of its quality and what could have made it better
- their opinions on what made dying with dementia different from dying of other illnesses
- their assessment of the quality of end of life services (if they had direct experience of these), and what could have made them better
- what they would build into a system of end of life services if they were designing it themselves.

In addition, material on good practice was sought from colleagues who work with dementia and dying, within Alzheimer's Society and beyond, both through formal interviews and other correspondence. A literature review explored the policy background and whether the issues experienced by participants were encountered more widely.

Policy landscape

The unique environment in England provided by the Prime Minister's Challenge on dementia, the Wales Together for health – delivering end of life care delivery plan, and the potential for capacity legislation in Northern Ireland, bring the issues surrounding dementia at the end of life in the UK into sharp focus. In particular, the drive towards building communities that are 'dementia friendly' must include a cultural shift where advance care planning is the norm, and where communities and health services have the resources to support people with dementia right to the end of their lives. There are pockets of good practice across the UK, but the experiences of people in this report show there is still much to be done to make good practice the norm, and to ensure that circumstances do not arise that may lead to poor and undignified treatment.

This report makes recommendations for change that would improve care and help make the final days of more people with dementia as good as they can be.

'Death and dying should be a natural matter to discuss… Palliative care for me, starts, should start, the minute that you get a diagnosis… This business of dying is quite a natural process. People tend to regard dying as something unnatural, but it isn't.'

Peter Ashley, living with dementia*

***Peter Ashley asked to be identified wherever his words are used.**

Recommendations

This report makes recommendations in seven key areas, as outlined below.

Public awareness

There needs to be greater public awareness of the importance of talking about death and dying and planning end of life care in advance.

- Dementia should be used as a key example of why planning throughout life is important.
- There should be greater recognition of dementia as a terminal illness, and of the fact that end of life care in dementia would improve with increased formal and informal advance care planning.
- The 'dementia friendly communities' strand of the Prime Minister's Challenge on dementia should consider how communities could be better prepared to deal with the full course of dementia, right up to the final days of life.

Care planning and proxy decision making

There should be greater support for people with dementia to plan for their future care, both using legal provisions and more informally, including contributing to decisions about where they would like to be cared for and the treatments they would and would not want to receive.

- A bill creating mental capacity legislation in Northern Ireland, similar to that already enacted in England and Wales, should be brought forward and acted on.
- GPs and other health and social care professionals supporting people with dementia at an early stage of their illness should be supported to encourage people with dementia to plan their future care.
- There should be greater training for care home staff in initiating and conducting conversations about end of life care planning.

Dignity

All people with dementia should be able to come to the end of their lives with dignity, with staff training and other systems geared to support this, even when communication has diminished.

- There should be increased resources to make aspirations for receiving dementia training a reality for all staff in all locations. This training must include understanding problems with communication.
- Initiatives to promote dignity and to see each person as an individual, such as Alzheimer's Society's This is me leaflet, should become embedded in everyday practice in all settings where people with dementia are cared for.

Pain

All people with dementia should be free from pain at the end of their lives, with training and systems designed to detect and manage pain even when communication is diminished.

- More research should be undertaken to understand the detection of pain in people with advanced dementia.

- There should be more training for all staff on detecting and treating the symptoms of pain in people with dementia.

Withholding and withdrawing treatment

There should be significant, co-ordinated and holistic support for the person with dementia and their carers wherever the decision is taken to withhold or withdraw treatment.

- Regular monitoring and adequate access to palliative care services should always be available when treatments are withheld and withdrawn. This includes a comprehensive assessment of pain, specialist care that is available at any time of the day or night, and emotional support offered to family and carers.

- More research should be undertaken observing the final days of people with dementia, to provide medical professionals with a clearer understanding of this time.

- There should be pre- and post-registration training and continuing professional development for staff working and communicating with families at this emotionally difficult time.

Emotional and spiritual concerns

Greater attention should be paid to the emotional and spiritual needs of people with dementia in order to provide truly holistic care.

- Professionals working with people with dementia at the end of their lives should take care to understand the emotional and spiritual needs of each person, and take action to meet these needs.

- There should be emotional and spiritual support available for the carer during the final days of the person with dementia, as well as bereavement support that recognises the unique experience of caring for a person with dementia.

Place of death

People with dementia at the end of their lives should be able to access high-quality services to meet their needs at any time of the day or night regardless of the setting.

- The government should pay special heed to the needs of people with dementia while piloting the Palliative Care Funding Review, and should implement findings of the pilot to allow a system that will support people with dementia. While piloting, particular attention should be paid to the integration of services and the impact on people with dementia of the proposal that there should be free social care in the last year of life. The government should also implement the recommendation that people at the end of life, and their carers, should receive a holistic needs assessment and be supported by a care co-ordinator.

- Commissioners should commission services that enable people with dementia to be cared for where they want to be at the end of their lives. This includes commissioning for community and care home settings, and considering different models of care that meet the needs of people with dementia throughout the course of their illness.

- There should be more resources to support GPs in managing the end of life care of people with dementia.

Hospitals:
- There should be greater training and support for ward staff on signs that people with dementia are reaching the end of their lives. This would enable a shift to palliative care, incorporating support for families and carers.

- There should be improved communication with families and carers to explain and explore options for care in the final stages.

Care homes:
- There should be more training for care home staff on delivering end of life care for people with dementia. This includes: acting on plans for emergency care, advance care plans and advance decisions that have been put in place, and working with medical professionals to co-ordinate a good end of life experience.

Own home:
- Attention should be paid to the specific needs of people with dementia when commissioning specialist care to reach out to people at the end of life in their own homes. Commissioners should use the National Institute for Health and Clinical Excellence (NICE) quality standard (NICE, 2010a) to identify services that support people to stay at home. Good practice in this area should be widely shared.

Hospice and specialist palliative care:
- More should be done to extend dementia training in the hospice environment, recognising dementia as a specialist care need.

- Hospices and specialist palliative care services should review their policies and practices to enable joint working to meet the needs of people with dementia in their communities.

1 Background to dementia and end of life

‘I think, at the end, it wants to be so the person is least stressed or upset or in [as little] pain as possible, so they can be calm and go with dignity. When they get to the point of no return, as it were, I think they should be allowed to go peacefully. Not be mucked about with unnecessarily.’

Daughter of a person with dementia

1.1 Definition of terms

Throughout this report, the terms ‘end of life care’ and ‘palliative care’ are used.

End of life care is defined in the End of life care strategy (Department of Health, 2008) as care that ‘helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement’. It refers to the wider network of care provided by numerous agencies when someone is nearing the end of their life, such as the services that may be provided by a care home, the GP and community teams working together, along with palliative care.

Palliative care is defined as ‘the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families’ (NICE, 2004). It is not designed to prolong life, and is only received by someone where there is knowledge that they are close to death. It may involve specific medical care designed to relieve pain, along with tools that provide a framework for care, such as the Liverpool Care Pathway (Marie Curie Palliative Care Institute Liverpool, 2012).

1.2 Background to dementia

The term dementia describes a set of symptoms that include loss of memory, mood changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer’s disease. Dementia is progressive, which means that people with dementia and their carers are coping with changing abilities over time. These changes in ability include a reduction in the person’s capacity to make decisions about major life events and circumstances as well as day-to-day decisions. Eventually they will need help with all their daily activities, spanning health and social care. Dementia is recognised as a terminal condition (Department of Health, 2009).

- 800,000 people in the UK have dementia (Alzheimer’s Society, 2012).

- One in three people over the age of 65 will end their lives with a form of dementia (Brayne et al, 2006). In 2010, there were over 400,000 registered deaths of people over the age of 65 from all causes in England and Wales (Office for National Statistics, 2011). Therefore, it would be expected that approximately 130,000 people died with dementia that year.

- In 2010, only 25,000 registered death certificates had a form of dementia listed as an underlying cause (Office for National Statistics, 2011). An additional 8,000 had 'senility' recorded. It is likely that many more people die with dementia every year, but this is not recorded on their death certificates.

- Dementia is the third most common underlying cause of death for women in England and Wales, behind heart disease and stroke. It is the seventh most common cause of death in men. Alzheimer's disease and other types of dementia account for 7% of all deaths in women and 3.1% of all deaths in men (Office for National Statistics, 2011).

- 63% of people who have dementia recorded as the underlying cause of death on their death certificate experience the end of their lives in a care home. A further 30% experience the end of their lives in hospital (see Appendix 2).

The Office for National Statistics data on the number of people with dementia recorded on their death certificate is likely to be an underestimate of the number of people who actually die with dementia. Historically, doctors have not routinely recorded dementia on death certificates if it was an underlying cause, rather than the primary cause. Many people with dementia never receive a formal diagnosis, which also contributes to a lack of recording. While there has been a dramatic improvement in this practice in the last 10 years, the figures are still not in line with the prevalence that we would expect. A substantial number of people have the outdated and unspecific term 'senility' on their death certificate, or do not have their dementia recorded at all.

1.2.1 Dying and dementia

There are three ways in which people with dementia die (Cox and Cook, 2002).

- People may die from the complications arising from end-stage dementia.

- People may be in the early stages of dementia and die from another illness (eg cancer).

- People may die with a mix of problems. Dementia may not be the main cause of death, but it interacts with other conditions and can complicate and worsen them.

Research has shown that people with dementia can often have trouble eating and contract pneumonia along with fevers and fits (Mitchell et al, 2009). Many people with dementia may also have long-standing medical conditions which will complicate their care, such as diabetes, arthritis, heart problems and trouble breathing.

All of the 800,000 people with dementia in the UK will face additional complications at the end of their lives, regardless of which disease causes their death. The dementia itself causes problems in areas that are key to planning for and ensuring a good death. These include:

- diminishing mental capacity

- difficulty with communication, which is particularly problematic when the person is communicating their hunger, thirst, discomfort, pain or other needs

- uncertainty in prognosis.

Professionals may also lack the skills to deal with the challenges presented when someone who has dementia is at the end of their life. This may manifest by the professional:

- being unwilling to discuss death and dying
- communicating insensitively
- overlooking other health conditions and managing only dementia, or vice versa
- not being able to detect or ease the symptoms or basic needs the person has, such as the need to eat or drink
- not being able to detect or meet the emotional, spiritual or other needs of the person
- not working with relatives to enable them to be involved at the end of the person's life
- having difficulty with decisions about the person's care (such as whether or not the person can remain at home or in the care home, or if they need to be transferred to hospital).

In addition, many of the systems for end of life care are designed around people with cancer, rather than people with dementia. People with dementia may not be referred for specialist end of life care (such as at a hospice), and specialists in end of life care are more used to dealing with conditions with a steep period of decline (such as cancer) rather than the more uncertain prognosis of dementia.

1.2.2 A good death

The End of life care strategy (Department of Health, 2008) suggests:

'Although every individual may have a different idea about what would, for them, constitute a "good death", for many this would involve:

- Being treated as an individual, with dignity and respect;
- Being without pain and other symptoms;
- Being in familiar surroundings; and
- Being in the company of close family and/or friends.'

Alzheimer's Society believes this is just as true for people with dementia as it is for people who have other health conditions.

1.3 Background to end of life care and dementia policy

Attention to end of life issues in dementia is beginning to grow. Many policy initiatives have been developed in the last five years, in both end of life care and dementia care. Research into the area is also growing, but there is still much to be done to implement good practice and eradicate unacceptable standards of treatment.

There are separate plans in England, Wales and Northern Ireland regarding end of life care, with numerous initiatives within each country's strategy. The Department of Health's End of life care strategy (Department of Health, 2008) in England provided the foundations for many of the initiatives in current end of life policy, including locality registers, the Dying Matters Coalition and the Palliative Care Funding Review. In Wales, the Welsh Palliative Care Implementation Board was established to implement the recommendations of the 2008 report led by Viv Sugar (Palliative Care Planning Group Wales, 2008). At the time of writing, Together for health – delivering on end of life care, a draft delivery plan, was out for consultation (Welsh Government 2012). In Northern Ireland, Living matters dying matters (Department of Health, Social Services and Public Safety Northern Ireland, 2010), a five-year strategy for service planning and delivery, was published. This lays out 25 recommendations across palliative care.

There are also national policies in place for dementia in England, Wales and Northern Ireland. These all include strands calling for adequate provision for dementia care, which would include the care people receive at the end of their lives. Dementia and end of life policy plans also overlap in other areas. For example, the NICE Quality standard on dementia (NICE, 2010a) includes a quality statement that addresses planning the palliative needs of people with dementia. End of life care has also been included in the care strand of the Prime Minister's Challenge on dementia. However, it is still not routine to consider end of life care and dementia together when creating end of life or dementia policy.

More detail is available in Appendix 1.

2 Evidence for this report

2.1 Methodology

Owing to the complicated and sensitive nature of the subject matter and the vulnerable nature of the participants, the study to inform this report was designed to explore and understand the issues with a small number of participants. It was not feasible to carry out a study to gain large-scale quantitative data, as we were only able to provide support to a small number of people. However, throughout this report, quantitative research has been included where it exists.

Due concern was given to the ethical dimension of this study. One of the cornerstones of ethical research is informed consent, which creates difficulties when working with people with diminishing capacity and vulnerable people at the end of their lives. It was therefore decided that participants should 'opt in' to the study, rather than being approached to take part. Advertisements were placed in the Alzheimer's Society magazine Living with dementia, and on the online forum Talking Point. Those who responded were sent information about the research and a consent form explaining the study. This meant there were a smaller number of people with dementia involved than carers, due to the nature of the people who use these resources (see section 2.2).

Semi-structured interviews were carried out with 38 participants. These consisted of 25 interviews with bereaved carers, 10 interviews with current carers and three interviews with people with dementia.

The interviews took place either face to face or on the telephone and were recorded. All interviews with people with dementia took place face to face. Support was available for participants after the interview through Alzheimer's Society's National Dementia Helpline. Care was taken that recordings of the interviews and details of the participants were kept securely.

Participants were asked to discuss:

- details of the end of life planning that had been discussed with them, their assessment of its quality and what could have made it better
- their opinions on what made dying with dementia different from dying of other illnesses
- their assessment of the quality of end of life services (if they had direct experience of these), and what could have made them better
- what they would build into a system of end of life services, if they were designing it themselves.

In addition, material on good practice was sought from colleagues who work with dementia and dying, within Alzheimer's Society and beyond.

Participants' material is used anonymously within the report. However, one participant living with dementia asked that he be identified in any use of his material, as he is passionate about speaking out about his condition. He is identified where his quotations are used.

2.2 Carers' experience as a proxy for the experience of people with dementia

It is obviously impossible to gain direct feedback from people who have experienced a complete end of life care service for themselves. These services are accessed by people at the end of their lives up until the point at which the person dies. In addition, people with dementia who are in the care of end of life services are usually at a stage where they are unable to communicate verbally. The people with dementia who participated in the study were at an early stage of their illness and did not have direct experience of end of life services, although they did have experience of dementia services and advance care planning.

However, many of the people who participated in the study were bereaved carers or relatives of someone with dementia, and therefore provided useful information on the end of life care that the person received. While this does not directly represent the feelings of the person with dementia, it adds valuable information in an area where there is currently very little. The model of using carers and relatives as a proxy experience of the person receiving end of life services is the model used by the VOICES survey (Addington-Hall et al, 2011), the proposed indicator for the NHS outcomes framework (Department of Health, 2011a).

3 Issues in end of life care for dementia

This section provides information on some of the key issues faced in end of life care when the person has dementia. It is based on the evidence provided in the interviews and draws on relevant research where available. It covers:

- public awareness
- care planning and proxy decision making
- dignity
- pain
- withholding and withdrawing treatment
- emotional and spiritual concerns
- place of care and environment.

3.1 Public awareness

In the interviews, participants reported that the person with dementia had not generally discussed their wishes around death and dying prior to diagnosis, and in many cases not even after diagnosis. This left the people who later had to make decisions on behalf of the person with dementia unaware of their wishes. Participants revealed that it was only prior personal experience of someone else's illness and death, or prior personal experience of dementia through a parent or another relative, that made some people with dementia specify what they would like for the future. There was support for a more open culture. One participant suggested that carers' support groups should talk more about end of life. Another talked about the culture in their family where death was not a taboo subject, and urged more to be like them.

In current UK culture, death and dying are not widely talked about. This is to the detriment of people with dementia. If death and dying were more widely discussed, and planning for end of life was routine practice among the general public, there would be clear plans in place for end of life care before dementia was diagnosed; no-one would reach the end of their lives and not have their wishes known. Currently the reverse is true. Talking about death and dying is often seen as morbid, and many people avoid it completely. The lack of public understanding of dementia, and the lack of willingness to discuss death and dying in society, combine to create a double stigma around dementia and death. This means that it is rarely thought about, and conversations that could achieve positive outcomes for personal choice at the end of life do not take place.

> **‘I do try to talk about death with my own family too. I mean I say to my husband, “you should do this and you don’t do this”. But so many people don’t have those conversations. And it was talked about in a light-hearted way; it wasn’t always doom and gloom, even though it was about death. When we talked about it, it wasn’t everyone sitting there crying, it was just something else that we talked about, not a big deal you know. And my mother wasn’t particularly religious, so it wasn’t a religious conversation, and we would just sort of joke about it almost. I am so glad it was that way rather than us not knowing what she would have liked at the end. Because you have got so much to think about all the way through it.’**
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> **Daughter of a person with dementia**

There is also a broad lack of engagement with dementia as a terminal condition. While it is possible to live, and in some cases live well, for many years with dementia, it is a progressive disease and one of the leading causes of death for both men and women. This is coupled with a reluctance to diagnose at all. Approximately 57% of people with dementia never get a formal diagnosis (Alzheimer’s Society, 2012), which means that they may not be aware of the need to plan for the future. Due to the age group of people most commonly affected by dementia, it is also likely that a high proportion of the undiagnosed are older people who may have concurrent conditions.

These factors make it important for Alzheimer’s Society to engage with and promote conversations about death and dying widely, using dementia as an example of why it is important. In addition, it is essential that the recent drive towards dementia friendly communities, announced in the Prime Minister’s Challenge on dementia, has a place for planning for the end of life. A dementia friendly community must be a compassionate community, and one that is set up to address the full course of the disease, from planning for the future to the final days of life.

Demonstrating good practice

Dying Matters Coalition

Alzheimer’s Society is a member of the Dying Matters Coalition. Set up as part of the national End of life care strategy and headed by the National Council for Palliative Care, the Coalition aims to change public knowledge, attitudes and behaviours towards death, dying and bereavement.

They run an annual Dying Matters awareness week and have extensive materials aimed at many different audiences to encourage conversations about death and dying. These include a brief leaflet called Time to talk, about starting end of life care conversations with people affected by dementia. More information is available at **www.dyingmatters.org**

Recommendation: There needs to be greater public awareness of the importance of talking about death and dying and planning end of life care in advance.

Recommendation: Dementia should be used as a key example of why planning throughout life is important.

Recommendation: There should be greater recognition of dementia as a terminal illness, and of the fact that end of life care in dementia would improve with increased formal and informal advance care planning.

Recommendation: The 'dementia friendly communities' strand of the Prime Minister's Challenge on dementia should consider how communities could be better prepared to deal with the full course of dementia, right up to the final days of life.

3.2 Care planning and proxy decision making

> **'It was not a subject which was ever discussed as a family, so I still don't know what his wishes would be. We looked for a living will, but there was nothing. The hardest thing is knowing what to do to make the decision on his behalf. We still, the three siblings, cannot all agree. So we can't really put anything in place. The decisions will have to be made when the time comes.'**
>
> **Daughter of a person with dementia**

When interviewed, very few people with dementia or carers remembered the subject of end of life being discussed with the person with dementia by health professionals. A common experience was that care planning was not discussed at all. Many reported that it was only discussed because the conversation was initiated by the person with dementia or by the carer. Not having care plans in place or a clear idea of what the person with dementia would want can lead to extensive problems as capacity diminishes and decisions have to be made on their behalf.

However, it was clear that planning care, even if it is an unstructured conversation about the person's wishes and does not involve a formal tool or Lasting Power of Attorney, makes decision making easier at the end of life. Participants commented on this extensively, talking about problems they encountered when advance plans had not been made. One participant talked about the difficulties she experienced because she and her siblings did not agree on their father's care. The literature also reflects this, with those making decisions finding it easier if they know what the person would have wanted (Wendler and Rid, 2011). Understanding the person's wider wishes, such as their idea of a good death and spiritual, cultural, emotional and family factors that they would want taken into account, is particularly important when making decisions on their behalf.

As dementia progresses, the person is said to lose 'mental capacity'. This means that the person will be less able to process information and will therefore be increasingly less able to make decisions, including those about their care. This becomes a particular problem in end of life care, as once it is clear that the person does not have much time left, the imperative shifts from treating the condition to making the person comfortable. In cases where a person still has capacity, they would be involved in the decision to shift from treatment to palliative care, along with decisions such as where they would like to die and what treatments they wish to receive. However, where capacity to make these decisions is lost, this is no longer possible and decisions will have to be made on their behalf. This diminishing capacity makes dementia unlike other conditions.

3.2.1 The Mental Capacity Act

The Mental Capacity Act 2005 (MCA) provides a legal framework in England and Wales for decision making on behalf of someone who lacks capacity. This is based on five principles:

- Every adult has the right to make his or her own decisions and it must be assumed that they can unless it is proved otherwise.
- A person must be given all reasonable help to make and communicate their own decisions before it is assumed that they are unable to make their own decisions.
- Just because someone makes what might be seen as a poor or unwise decision, it should not be assumed that they are unable to make decisions.
- Any decision made for a person who is unable to so for themselves must be done in their best interests.
- Any decisions made for someone else should be as unrestrictive as possible on a person's rights and freedoms.

The MCA states that capacity is decision- and time-specific, so there is no blanket declaration that someone does or does not have capacity; instead each decision should be considered individually. The MCA also allows someone to appoint a Lasting Power of Attorney (LPA) over their health and welfare, specifying a particular person who is able to make decisions about their care, should they lose capacity to make that decision in the future. If the person loses capacity to make a particular decision, the attorney becomes the proxy decision-maker and must make the decision in the person's best interests that is also the least restrictive on the person's rights and freedoms.

However, uptake of health and welfare LPAs is low. In response to a freedom of information request, the Office of the Public Guardian provided Alzheimer's Society with the number and type of LPAs registered from 1 October 2007 (when it was first possible to register) until 30 June 2012, as outlined in the table opposite.

Table 1: Uptake of Lasting Powers of Attorney in England and Wales

	Number	Percentage of total LPAs
LPA – financial and property	414,811	80%
LPA – health and welfare	106,299	20%
Total registrations	521,110	100%

These figures are for all LPAs registered, not just those made by people with dementia. This level of uptake suggests that there is poor understanding of what health and welfare LPAs can offer. This is particularly concerning for people with dementia as it indicates that the available channels for a person's wishes to be legally represented are not being used.

The MCA covers England and Wales, but there is still no mental capacity legislation in Northern Ireland. While there is an imperative in common law to make decisions in the person's best interest, legislation on capacity would be beneficial. The General Medical Council (GMC) guidance states that the input of carers and legal proxies should be sought when making decisions about the care of someone who lacks capacity (GMC, 2010).

The MCA also provides a framework for someone to express wishes on which treatments they would not want. This includes refusing treatments such as cardiopulmonary resuscitation (CPR) or artificial nutrition and hydration. The MCA calls these advance treatment refusals an 'advance decision'. Advance decisions that meet the requirements of the MCA must be followed by medical professionals.

Advance care planning, which may include an advance decision to refuse treatment, is important. It allows a person with dementia to have input into their future care, particularly if they have strong views on a certain subject.

Again, unlike in England and Wales, there is no legal framework governing advance decisions in Northern Ireland. In Northern Ireland these are referred to as advance directives or living wills. It has been highlighted under the GMC guidance that it is likely that an advance directive to refuse medical treatment would be followed in Northern Ireland; legislation on this would be beneficial to make the law clearer.

Making a decision on someone else's behalf can be very difficult for the person who is in the position of proxy, whether they have legal backing behind them or they are contributing to a decision informally. Recent research by Alzheimer Scotland found that people nominated as proxies often lacked information and didn't feel supported to use the principles of the legislation under which they were acting (Alzheimer Scotland, 2012). Advance care planning is therefore important, not only for the person with dementia, but for those who may be making decisions on their behalf in the future. Having more information helps to make more informed, and therefore better, decisions. Planning also avoids leaving unresolved problems for others to grapple with, and can provide a clear direction, which is helpful if there are complex family relationships.

Demonstrating good practice

Planning for your future care: A guide
The National end of life care programme, University of Nottingham and Dying Matters Coalition have produced a guide for members of the public. It explains advance care planning and outlines the different options available to people when planning for their end of life care. The guide was not designed specifically for people with dementia, but is a useful tool for anyone thinking about the future.

For more information see **www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare**

The clinical value of advance planning for end of life care is also clear. A recent study (Baker et al, 2012) found that advance care plans drawn up in primary care could help reduce unplanned hospital admissions by 52%, as more was understood about the person's wishes, which means that when they expressed a wish not to be hospitalised it was possible for this to be followed.

It is therefore important to find out as much as possible about the person's wishes through formal and informal advance care planning.

Recommendation: There should be greater support for people with dementia to plan for their future care, both using legal provisions and more informally, including contributing to decisions about where they would like to be cared for and treatments they would and would not want to receive.

Recommendation: A bill creating mental capacity legislation in Northern Ireland, similar to that already enacted in England and Wales, should be brought forward and acted on.

3.2.2 Unwillingness of professionals to discuss care planning

As discussed above, participants reported that professionals were unwilling to engage with end of life issues at the diagnosis stage. Some participants reported that no future planning at all was discussed with them. Many reported that professionals only suggested that they get financial matters in order, and did not raise the issue of future care. Reports of where conversations did take place suggested that they were often badly handled, usually where the professional was not a specialist in either end of life or dementia care. Research in this area shows that staff training and confidence can make a difference to whether care planning takes place (Social Care Institute for Excellence, 2012).

There is a clear role for diagnostic services and primary care to encourage greater discussion of advance care planning with people with dementia early on. Being able to plan for the future is seen as a key benefit of detecting and diagnosing dementia early. However, currently only 43% of people with dementia have a diagnosis (Alzheimer's Society, 2012). There are policies in place to improve this, but it is also essential that professionals are adequately skilled in starting conversations on planning. A survey by Dying Matters found that 35% of GPs have never initiated an end of life care conversation with one of their patients (ComRes, 2012). It is essential that greater support is provided to GPs and other primary care professionals to develop their skills in engaging with end of life planning.

Demonstrating good practice

Difficult conversations – National Council for Palliative Care
Developed in consultation with people with dementia and carers, this booklet is a useful starting point for health professionals when having difficult conversations about death and dying. It goes through the benefits of talking about dying in advance, what the conversation should cover, when a good time for the conversation might be, who to speak with, and other advice for professionals and informal carers.

For more information see **www.ncpc.org.uk**

Recommendation: GPs and other health and social care professionals supporting people with dementia at an early stage of their illness should be supported to encourage people with dementia to plan their future care.

3.2.3 End of life planning in care homes

> **‘No-one discussed end of life until he was in the first care home and we had a meeting with the manager about various issues I had, and it was raised out of the blue at the end of the meeting. With five minutes to go in the meeting and it was raised as an “oh, by the way”. I was sat there thinking “Excuse me? What is this all about?” It was very, very badly handled, sort of thrown in as an afterthought and it took me by surprise. It was something which hadn’t really crossed my mind until they threw it in at the end of the meeting and I thought “my goodness, this is not the way to handle relatives”.’**
>
> **Daughter of a person with dementia**

The majority of interview participants reported that when the person they cared for moved into a care home, the person was asked about end of life wishes – in line with the national quality markers for care homes on recording end of life wishes (Department of Health, 2009). It was frequently reported that this was the first conversation that the person with dementia or the carer had been engaged in about their wishes, and there was great variability in how it was handled. One participant volunteered to participate in the research which informed this report because, at the suggestion of the care home, she had been allowed to take away a form and have a conversation with her mother regarding what she would like, which had been a very positive experience. However, far more commonly it was reported that the initial conversation at the care home was handled badly, with inadequate time being allowed, and staff lacking skills to handle it well.

It is common for people with dementia to enter care homes when their capacity has already diminished, so it may be too late for many to make complicated decisions about their care.

Demonstrating good practice

Decision making in advanced dementia: Planning ahead and getting it right. Alzheimer's Society, NHS Cornwall and the Isles of Scilly, and Cornwall Council
Following an audit of more than 200 admissions, and recognition of inappropriate hospital admissions as a problem for people with dementia, NHS Cornwall and the Isles of Scilly worked with Alzheimer's Society and Cornwall Council to create a pilot programme for care homes, which saw hospital admissions from the care homes involved fall by more than half.

Building on existing Society resources and expertise, and talking to recently bereaved families, they produced a new booklet for families and carers. Staff from care homes with some of the highest hospital admission rates were given bespoke training on how to use the booklet and address end of life issues. Families and carers are now invited to informal meetings to discuss their options with the care staff and others, including Alzheimer's Society where possible. They are given information and the new guidance. The aim is to encourage families and carers to think about what kind of care their friend or relative would like. These wishes are then recorded and signed off by the person's GP, before being used to shape the end of life care they will receive.

Since the pilot began, there have been no inappropriate hospital admissions for patients involved in the process, and carers have reported feeling far happier with their understanding of the issues involved and the decisions that have been made. Six community liaison nurses will now roll out the programme county-wide.

For more information see **www.cornwallandislesofscilly.nhs.uk**

While it is a positive indication that care homes are initiating conversations to formulate care plans, it seems that there is a need for greater training in how to handle the subject of end of life, particularly when dealing with someone who has dementia and may not be able to make decisions for themselves.

Recommendation: There should be greater training for care home staff in initiating and conducting conversations about end of life care planning.

3.3 Dignity

A key concern for many of the former carers who contacted us was the lack of dignity in the treatment of the person they cared for in their final days. There were frequent and distressing reports of very poor, undignified treatment, particularly in hospital.

> **'She was in hospital for five weeks, and she was very, very confused… She couldn't find the buzzer to call them because of her sight loss, but they kept moving the buzzer. I actually put a sign above her bed about her sight loss, but they took it down. She told me "The way they spoke to me, you would not talk to an animal like that". She kept telling me "I'm not lying, I'm telling you the truth"… Christmas day, and she still had a nebuliser, and they were very short staffed, and one of the catering staff came around with a tray of sherry, and just poured the sherry down my Mum's throat… It wasn't handled very well and my mother didn't deserve that.'**
>
> **Daughter of a person with dementia**

Research participants also reported particular problems with the basic needs of the person with dementia going unmet. Numerous participants reported that the person with dementia had not been helped to change, so they had to sit in their own faeces or urine for some time. One participant reported that her mother was left on a commode for several hours while the participant was absent. There were also reports of inappropriate food and drink being given. A participant commented that when she visited her father there was a cup of tea that had been put too far away for him to reach. There were comments that some staff were rude or uncaring, and that there was not due attention paid to the person's privacy, for example not making the necessary arrangements to make sure the person was covered while they were being helped to undress.

Dignity in treatment involves meeting the basic standards of care which a person should expect to receive. The VIPS programme suggests four major elements of care: valuing people (V), individualised care (I), personal perspectives (P) and social environment (S) (Brooker, 2007). However, it is clear not only from the participants' comments but also from the findings of the Ombudsman (Health Service Ombudsman, 2011), the Commission on Improving Dignity in Care (Commission on Dignity in Care for Older People, 2012) and the Royal College of Psychiatrists hospital audit (Royal College of Psychiatrists, 2011) that poor and degrading treatment is still a common experience. There is a lack of existing information to give an accurate national picture of the level of dignity people experience during the care they are offered at this stage in their lives. The Department of Health commissioned the VOICES survey, which asked bereaved relatives about the care that was received in the last three months of the life of the person they cared for (Department of Health, 2012).

Nearly 4% of relatives of people with dementia said that the person was never treated with dignity by hospital nurses, and a further 25% said that the person was only treated with dignity by hospital nurses some of the time. A higher proportion of relatives said that this was the case when the person had dementia on their death certificate than when dementia was not recorded, suggesting that people with dementia are treated with less dignity than people who die of other conditions.

Alzheimer's Society believes that the undignified treatment that many people with dementia receive is shocking and inexcusable. More should be done to prevent the significant harm and breaches of human rights which some people with dementia experience at the end of their lives. More should also be done to raise the basic standards of care that people with dementia receive.

Recommendation: All people with dementia should be able to come to the end of their lives with dignity, with staff training and other systems geared to support this, even when communication has diminished.

3.3.1 Communication

A key factor of the later stages of the dementia is a declining ability to communicate. The person with dementia may gradually lose the ability to communicate using language, and in the final stages can withdraw into themselves so it is very difficult to communicate through any means. As the person with dementia becomes more withdrawn, this hinders identification of basic needs such as hunger and thirst, and the person with dementia is unable to communicate these needs. When staff are busy, or don't understand the needs of the person they are caring for, problems with maintaining the dignity of the person with dementia can easily occur.

In hospitals, particular problems can arise if the dementia is undetected. People with dementia may be treated for the physical concern for which they were admitted, but not necessarily for the additional needs arising from their dementia. As a result, people with dementia end up staying in hospital longer than people without dementia who are being treated for the same condition. In addition, nursing staff are often struggling to do difficult and stressful work with inadequate training on dementia. The majority of nurses working on a general ward have little or no pre-registration training in dementia; 76% of nurse managers said that the fact that their nursing staff did not have this training was a key challenge in providing good dementia care. In addition, 89% of nursing staff identified working with people with dementia as very or quite challenging (Alzheimer's Society, 2009).

The National Clinical Director for Dementia has announced an aspiration for 100% of NHS staff to be dementia aware, 50% to be dementia trained, and 10% to be dementia experts (The Guardian, 2012). Alzheimer's Society supports this aspiration and believes that understanding difficulties in communication should be a key part of training.

Recommendation: There should be increased resources to make aspirations for receiving dementia training a reality for all staff in all locations. This training must include understanding problems with communication.

3.3.2 Relationship- and person-centred care

Demonstrating good practice

This is me
This is me is a simple and practical tool that someone going into hospital can give to staff to help them support the person with dementia. It provides a snapshot of the person, giving information about them as an individual, such as likes, dislikes, needs, preferences and interests. This helps staff to treat each person as an individual, thereby reducing distress for them and their carers and helping to prevent issues such as malnutrition and dehydration. To download a copy, visit the Alzheimer's Society website at **alzheimers.org.uk/thisisme**

This is me was first developed by the Northumberland Acute Care and Dementia Group and is supported by the Royal College of Nursing.

Greater recognition of the value of health professionals treating the person with dementia as an individual, often referred to as relationship-centred and person-centred care, would improve the level of dignity experienced by people with dementia. There are numerous programmes designed to enable people with dementia to be cared for with dignity in every setting. This includes dementia-specific training for non-specialists, and initiatives such as This is me.

There should be greater understanding of the role that family and carers can play in providing care at the end of life. This extends beyond decision making and sensitive communication, to professionals enabling family members to be involved where they wish to be. Family members should not be prevented from helping to feed and care for their relatives, and should be supported to do so when it is appropriate.

Alzheimer's Society supports initiatives that increase awareness of person-centred care and promote dignified treatment. They should become embedded in everyday practice in all settings where people with dementia are cared for. Increased dementia training for staff in these settings would also increase understanding of the condition and reduce undignified treatment.

Recommendation: Initiatives to promote dignity and to see each person as an individual, such as Alzheimer's Society's This is me leaflet, should become embedded in everyday practice in all settings where people with dementia are cared for.

3.4 Pain

Some of the respondents reported concerns that the person with dementia was experiencing pain during their final days, which was untreated. Owing to problems with communication, it can often be difficult for clinicians to assess pain in someone with dementia. This can be compounded in care homes or in someone's own home, where 24-hour care from people who are pain specialists is not available.

> **'My mother and I are clear in our minds that my father registered awareness of people and, most importantly, pain during those 11 days. We explained to every person involved with his care that his left shoulder was causing him a great deal of pain but it was not investigated. It was only in the last 24 hours of his life when my sister, who is a physiotherapist, arrived, that we realised that my father had a dislocated shoulder. We have been told that the diamorphine he received as part of a drug cocktail would not have relieved the muscular pain he was enduring. One can only imagine the agony he was in.'**
>
> **Daughter of a person with dementia**

In the past it may have been incorrectly assumed that people with dementia do not feel pain in the same way that people without dementia do. There is academic evidence to suggest that people with dementia in hospital receive fewer interventions to alleviate pain than people without dementia (Sampson et al, 2006). Pain from pre-existing conditions, (such as arthritis), or discomfort which cannot be communicated (such as constipation) can often go untreated (Scott et al, 2011). This is compounded by problems with communication, and by the pain itself causing the person with dementia to withdraw or to react to it with behaviour that is challenging for care staff. Staff may assume that this behaviour is a symptom of the dementia, rather than a reaction to pain.

There have been academic studies to explore the detection of pain in people with dementia (Husebo et al, 2009; Hølen et al, 2007). Recent evidence also suggests that better pain management reduces the prescription of antipsychotic medication in people with moderate dementia (Husebo et al, 2011). Several pain scales have been developed for use with people with dementia who have diminishing capacity and communication, and there is ongoing academic work to explore if consensus can be reached on which tools should be used, for example the cross-European COST project.[2]

Making assessment of pain routine practice, and encouraging medical professionals to use all communication from the person with dementia (including facial expressions and other non-verbal communication) in order to assess whether the person with dementia is in pain, are the first steps to ensuring that people with dementia do not end their lives in pain. This includes using all information that is known about the person with dementia, including how they have reacted to pain in the past, and by assessing their behaviour and facial expressions. Routine use of pain assessment tools can be helpful in prompting this to be done and ensuring that it is done in a consistent manner. However, additional work needs to be done to ensure that clinical and care staff think about the possibility of pain and take action to manage pain.

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[2] www.cost-td1005.net

Demonstrating good practice

Lambeth and Southwark training on Doloplus-2 pain scale
More than 50 staff in nursing homes the London boroughs of Lambeth and Southwark received training to detect pain in people with advanced dementia using the Doloplus-2 pain scale. Evaluation showed that staff confidence in the pain scale rose to 98% after the training. One participant commented 'Before, if they are in a bad mood, we thought "They are in a bad mood". Now we think "Maybe they are in pain".'

Recommendation: All people with dementia should be free from pain at the end of their lives, with training and systems designed to detect and manage pain even when communication is diminished.

Recommendation: More research should be undertaken to understand the detection of pain in people with advanced dementia.

Recommendation: There should be more training for all staff on detecting and treating the symptoms of pain in people with dementia.

3.5 Withholding and withdrawing treatment

Two participants specifically volunteered to participate in the research to inform this report because of their experience of having treatment, including nutrition and hydration, withdrawn from the person who they cared for. They both reported that it was predicted that the person with dementia had very little time left, and it was suggested that food and water be withheld or withdrawn, which they agreed with. In both cases, this prediction was incorrect, and in both cases the person with dementia lived for longer than 10 days, in one case without adequate pain relief. Both participants talked about the enormous emotional strain that this put on them and their family.

> **'I just wanted someone to talk to who could tell me what to expect – when it was likely to happen or how long it may take. Probably nobody told me what was going to happen because they just don't know.'**
>
> **Wife of a person with dementia**

Withholding or withdrawing treatment is one of the most ethically complex and emotionally challenging aspects of end of life care. It is made particularly challenging in dementia as the person is likely to lack the ability to communicate their basic needs when this is being considered. It is also likely that the person's capacity to make decisions may have been diminishing for a long time.

Dementia presents particular difficulties to clinicians with regard to predicting the course of the illness and providing an estimate of the length of time the person has left to live. People live on average eight years after they receive a diagnosis, but this varies widely, with some people dying very quickly and others living for many more years (Van der Steen et al, 2002).

This can cause particular problems as many palliative care services are designed for short interventions. Someone with dementia could spend many months, and even years, at a stage where they need end of life care that does not fit a model which has been designed to address the needs of people dying from cancer, who might die within weeks. This is also true of models designed to be used in the final days, such as the Liverpool Care Pathway (Marie Curie Palliative Care Institute Liverpool, 2012).

The GMC guidance states that artificial nutrition and hydration are medical treatments, and that decisions about whether they should be used should be made in the same way as for other treatments, such as cardiopulmonary resuscitation (CPR). This includes whether the treatment is in the patient's overall best interest (GMC, 2010). The Guideline on dementia from NICE and the Social Care Institute for Excellence states that artificial feeding and hydration should not commence if disinclination to eat or inability to swallow are considered to be part of the progression of the disease, and will not change in future (NICE-SCIE, 2007). Alzheimer's Society believes that when someone with dementia is close to dying, the main issue of concern should be quality of life and quality of death, not length of life. Losing the ability to swallow can be part of the dying process in some cases and artificial nutrition and hydration in these cases may not be appropriate. However, it is important that there is honest and open discussion between medical professionals and the family, friends and carers of the person with dementia when a decision is being made to withhold or withdraw treatment. It is essential that the quality of life and comfort of the person with dementia are paramount. There should be specialist palliative care, including pain relief and other palliative treatments, available to the person at all times. It can also be helpful to provide comfort care, including human touch and moistening of the lips if nutrition and hydration are withdrawn. It is also essential that there is appropriate emotional support for families at this difficult time.

The problem of withholding and withdrawing treatment is magnified by dementia specialists not necessarily having the expertise that specialist palliative care services have. This includes an understanding of holistic treatment at the end of life. It also seems that the difficulty determining the length of time the person has left, as in the two cases mentioned above, can make the experience particularly harrowing for the families. More research observing the final days of people with end-stage dementia would be welcome, in order to provide a clearer understanding for medical staff and allow them to lay out expectations for the families.

Recommendation: There should be significant, co-ordinated and holistic support for the person with dementia and their carers wherever the decisions is take to withhold or withdraw treatment.

Recommendation: Regular monitoring and adequate access to palliative care services should always be available when treatments are withheld and withdrawn. This includes a comprehensive assessment of pain, specialist care that is available at any time of the day or night, and emotional support for family and carers.

Recommendation: More research should be undertaken observing the final days of people with dementia, to provide medical professionals with a clearer understanding of this time.

Recommendation: There should be pre- and post-registration training and continuing professional development for staff working and communicating with families at this emotionally difficult time.

3.6 Emotional and spiritual concerns

> **'He didn't know me when I went to see him. I would do and say all the little things that he would expect me to say and there was no response. I took up food that he particularly liked, for example he was very fond of crab sandwiches, so I would take in crab sandwiches and I would put it in his mouth and he would spit it out. That went on for three months until he died. The whole thing was dreadful really. I mean he was well looked after in the nursing home; they were very kind to me and my sons, but he just deteriorated so quickly. It was just a very harrowing, terrible time. Nobody told me that it could be like that… Him not knowing I was there, it just reduced me to tears. I used to spend most of my time weeping, but I thought "that is doing no good to him, me weeping like this". Then I realised one day he doesn't even know I'm crying, because if he did know he would have wanted to put his arms around me and want to know what is the matter.'**
>
> **Wife of a person with dementia**

Several participants in the study discussed the particular emotional difficulties that caring for someone with dementia at the end of their life presented them with. There were natural expressions of sadness and loss at the death, particularly as this was usually a close family member. Participants also commented that they found the loss of capacity itself emotionally distressing, as they saw character changes in the person they loved, or found the person withdrawing. This was particularly difficult if the person had previously been a source of emotional support in the relationship.

In addition, any incidents of poor or undignified care became even more distressing for the carer. One carer discussed how the poor care that her mother had received and the poor communication about her condition meant that following her death she was unwilling to return to the ward, even though she would have liked to see her mother's body. While all services should aspire to be of an excellent standard, this is particularly important for services dealing with people at the end of their lives, as this is when the person and their relatives are most vulnerable.

Bereavement is one of the most emotionally challenging times, and any difficulties with services, such as poor communication or difficulties with decision making, become even more emotionally charged. This can be compounded by other losses that the carers and family may feel as a person's personality has changed or their capacity has diminished. Having cared for the person for many years, family members may not be prepared to make difficult end of life decisions (Caron et al, 2005), and effective and sensitive communication from professionals to carers is needed at this time more than at any other.

Research has suggested that the emotional and spiritual needs of people with dementia are disproportionately neglected (Sampson et al, 2006). While cognition declines and the person with dementia may become withdrawn, it is still possible for them to be distressed or upset. Depression can be difficult to recognise in advanced dementia. Making sure the person is comfortable and minimising distress is an important part of care. It is also important to consider whether the person would like spiritual support. One of the people with dementia who contributed to this study talked strongly about her Christian faith as a key part of her considerations in end of life planning. Other participants discussed the importance of a calm environment at the end of life. The importance of family being present was also raised. A holistic approach to care demands that there is an awareness of each person's wishes and needs as an individual. It is important that these needs are understood and met where appropriate.

Demonstrating good practice

St Christopher's Hospice Namaste project

The St Christopher's Hospice Namaste research project, with six local nursing homes, is the first of its kind in the UK. It explores ways in which quality of life for people with end-stage dementia can be significantly improved. Namaste – a Indian term which means 'to honour the spirit within' – is a programme pioneered in the USA and designed to create a peaceful end to life by reducing anxiety and agitation through calming yet meaningful activity, comfort and pleasure. It uses simple techniques that can be delivered in nursing care homes both by staff and family members.

When people with advanced dementia enter the programme, a 'family conference' is held to discuss disease progression and peaceful end of life care, as well as how the programme can help their relative. The technique involves creating a Namaste room where the five senses are gently stimulated through things like soft music or birdsong, colour from paintings or voile curtains, pleasurable aromas, interesting tastes, and touch through hand or head massages. Residents spend all day (in between meals and care routines) in comfortable chairs in the Namaste room, where they are helped to interact with their surroundings. Staff build a 'biography' of the sensory things that are most meaningful for each resident.

For more information see **www.stchristophers.org.uk/namaste**

Emotional support during the final days of the person's life and bereavement support for carers are not widely available outside the hospice sector, but would be beneficial to many family members and carers of people with dementia.

Recommendation: Greater attention should be paid to the emotional and spiritual needs of people with dementia in order to provide truly holistic care.

Recommendation: Professionals working with people with dementia at the end of their lives should take care to understand the emotional and spiritual needs of each person, and take action to meet these needs.

Recommendation: There should be emotional and spiritual support available for the carers and family members during the final days of the person with dementia, as well as bereavement support that recognises the unique experience of caring for a person with dementia.

3.7 Place of death

There is a drive within end of life policy to support people to be able to die in the place that they would choose (Department of Health, 2008). Often this is their own home, or the care home in which they live. Within the general population, 63% of people say that they would like to die in their own home (Gomes et al, 2011). Only 20.8% of people do so (Office for National Statistics, 2011). Throughout the interviews for this report, participants identified and explained the key challenges presented by different settings. Research has not yet been undertaken to explore whether or not there is a difference between where people with dementia would wish to die compared with the general population. However, there is a large body of evidence that suggests that moving someone with dementia to an unfamiliar environment, such as hospital, in the later course of the illness, can be difficult and distressing for the person (Alzheimer's Society, 2009).

The Office for National Statistics provided Alzheimer's Society with data on the place of death of people who had dementia recorded as an underlying cause of death on their death certificate in 2010 in England and Wales (see Appendix 2). However, many people with dementia do not have a diagnosis and may not have dementia recorded on their death certificates. This data should therefore be treated with caution, but it remains the best data available.

Table 2: Figures for deaths where dementia was the underlying cause recorded in different settings

Location	Number of deaths recorded in this setting where dementia is underlying cause	Percentage of total
Care home (local authority and non-local authority)	15,756	63%
Hospital	7,522	30%
Hospices (NHS and non-NHS)	44	>1%
Other communal establishment	288	1%
Own home	1,439	6%
Elsewhere	57	>1%

As the figures show, many people with dementia recorded on their death certificate die in a care or nursing home. Many also die in hospital. It is possible that the true figure for deaths in hospital is even higher as many elderly people with less advanced forms of dementia may be admitted to hospital for a different condition and have that condition recorded on their death certificate. This means that any additional complications caused by the dementia are not reflected in the statistics. In some cases it is appropriate for someone to be admitted to hospital, but many people with dementia only die in hospital because there is inadequate support which would allow them to die in the place they usually live.

The figures also show a comparatively low number of people who die in their own home. There are particular challenges to someone with dementia remaining in their own home, particularly around providing adequate support to allow this to happen. The number who died in hospices is very low, reflecting the fact that most hospices do not accept dementia alone as a reason for admission to a hospice.

Some of the issues presented in each of these locations are outlined in the following pages.

3.7.1 A co-ordinated care environment

Many of the problems identified by the participants stem from a lack of co-ordination in care. Carers frequently reported having to state details of care plans to each of the different professionals involved in care and, as discussed earlier, there were reports of undesired admissions to hospital.

> **‘When he went into the nursing home I knew quite quickly that I needed to raise the issue of whether he would ever have a tube inserted for feeding. The nursing home was full of people with tubes going out into their stomach, tubes going out of the other end, and actually no brain function, and that was horrific I thought. So knowing his views, with his daughters, we decided we needed something on record at the home. So we had a chat with the GP, and documents were placed on file, and actually the GP thought it was a sensible thing to do, but we were cautioned that if he ever did go into hospital we would probably have to have the debate again, which I think is a shame really, because if you have been through it once, it is distressing.’**
>
> **Wife of a person with dementia**

By contrast, some of the best experiences had occurred when care had been well co-ordinated, no matter the location. Much seems to have been done in recent years to encourage co-ordinated care for end of life. The end of life care stream of the DH’s Quality, Innovation, Productivity and Prevention (QIPP) programme has incentivised commissioners to look at end of life care as an area where cost savings can be made while improving outcomes for patients (Department of Health, 2011b). The fact that funding for end of life care stems from the NHS, rather than from social care, also makes it easier to demonstrate the savings back into the same budgets.

> **‘I had said she shouldn’t go back to hospital. She couldn’t see. She knew the voices of the carers in the home who were looking after her. When she had been in hospital another time she had fallen and it was just so traumatic for her, she just used to get so distressed, so I just said I wanted her to go peacefully in the place that she knew and people knew her. They agreed with that.’**
>
> **Daughter of a person with dementia**

Demonstrating good practice

Priorities for dementia care within the end of life care strategy's quality markers and measures for commissioners
Developed by the National Council for Palliative Care's (NCPC) Dementia working group, Priorities for dementia care within the end of life care strategy's quality markers and measures for commissioners (NCPC et al, 2010) takes the seven headings for quality markers for end of life care aimed at commissioners, and maps these against areas of priority from a dementia perspective. It clearly brings together the end of life and dementia strategies, providing a single reference point for commissioners. It also includes sources of further information or support to help bring together many relevant documents.

To access it, visit
www.ncpc.org.uk/publication/priorities-dementia-care-within-end-life-care-strategy%E2%80%99s-quality-markers-and-measures-co

Despite some steps forward, there could be significantly more development in this area. If implemented, the Palliative Care Funding Review (Hughes-Hallett et al, 2011) will create a tariff for palliative care needs: an amount of money that could be accessed by commissioners for patients' palliative needs in addition to the funding to meet the needs for their condition. This should provide adequate resources to allow the palliative care needs of people with dementia to be met, regardless of the setting of their care. The Palliative Care Funding Review also suggests that social care should be free in the last year of life. Alzheimer's Society has long campaigned for a fairer deal on social care funding for people with dementia, and believes that the distinction between health and social care is often unhelpful in providing co-ordinated care.

It is clear that general practice has a role in co-ordinating care in community environments. GPs have a duty of care over their patients and are the main point of medical care for residents in care homes and those living in their own homes. More resources and training should be available to equip GPs to support people with dementia in their end of life care, particularly in care home settings. This could include guides for GPs on the services available to people with dementia in their area, particularly alternatives to hospital, along with additional training on the management of later-stage dementia and how dementia may complicate the later stages of other conditions.

The Palliative Care Funding Review suggests that people at the end of their lives and their carers should receive a holistic needs assessment and be supported by a care co-ordinator. An implementation of this proposal would greatly benefit people with dementia, creating a single contact for their care and enabling more people to be supported to get the appropriate care for their needs, in the setting which is most suited to them.

Recommendation: The government should pay special heed to the needs of people with dementia while piloting the Palliative Care Funding Review, and should implement findings of the pilot to allow a system that will support people with dementia. While piloting, particular attention should be paid to the integration of services and the impact on people with dementia of the proposal that there should be free social care in the last year of life. The government should also implement the recommendation that people at the end of life, and their carers, should receive a holistic needs assessment and be supported by a care co-ordinator.

Recommendation: Commissioners should commission services that enable people with dementia to be cared for where they want to be at the end of their lives. This includes commissioning for community and care home settings, and considering different models of care that meet the needs of people with dementia throughout the course of their illness.

Recommendation: There should be more resources to support GPs in managing the end of life care of people with dementia.

3.7.2 Hospital

For the people who participated in the research for this report, the usual place of death for the person with dementia was hospital. A common narrative was that the person with dementia was hospitalised for a different condition – usually a fall or an infection – and then remained in hospital until the end of their life. Occasionally the person with dementia was admitted to hospital against their express wishes, as stated by the carers. Frequently, participants also reported poor or undignified treatment for the person with dementia while they were in hospital. However, some reported that once it was acknowledged that the person was at the end of their life and their care was transferred to the palliative care team, there was a marked difference.

> **‘The hospital staff were rubbish at communicating with my mum – she didn’t know why [dad] was still there, the home didn’t know why he was still there. For them, I think they were completely oblivious. My dad was really frail, really thin, not likely to get moving again. As a nurse, I know how this ends – he is going to get pneumonia and this is basically the end of his life. But there was no sense of any urgency from them about his quality of life and how being on an acute ward was affecting that. All I wanted them to do was get him out of there, just get him back to the nursing home.’**
>
> **Daughter of a person with dementia**

Unfortunately, these experiences are mirrored in what is known of the national picture. Care of patients in hospital is still largely crisis driven, which means that end of life care can often be poor (National Confidential Enquiry into Patient Outcome and Death, 2012). The VOICES survey found that relatives of people who had dementia recorded on their death certificate were less likely to rate the care they received from hospital nurses as excellent, and more likely to rate it as fair or poor than relatives of people who did not have dementia mentioned on their death certificate (Department of Health, 2012). Similar ratings were given for hospital doctors.

Each hospital death in the UK is estimated to cost £3,000 a year (Hughes-Hallett et al, 2011). The estimated cost of a day of community care at the end of life is £145, compared with an estimated cost of £425 for a specialist palliative care bed day in hospital. The indication is that changing the setting of care for a patient at the end of life has the potential to reduce the daily cost by £280 (Marie Curie Cancer Care, 2012). Research has shown that people with dementia are staying in hospital for longer than other people of similar age who go in for the same procedures. This suggests that care of people with dementia on a hospital ward is more costly than the average cost for people who are admitted to hospital for a similar medical condition. It has also been found that the longer people with dementia are in hospital, the more likely they are to be discharged into a care home, even if they had been living in their own home before going into hospital (Alzheimer's Society, 2009).

There needs to be a concerted effort to ensure that hospital admissions for people with dementia in the later stages of life happen only when appropriate. There also needs to be a drive to recognise when people with dementia in hospital are at the end of their lives, and to treat them appropriately. Difficulties with prognosis, capacity and communication mean that this can be more difficult, and end of life care tools, such as the Liverpool Care Pathway, are underused or sometimes misused for people with dementia. The first National audit of dementia in hospitals in England and Wales (Royal College of Psychiatrists, 2011) shows that only 35% (36/104) of hospitals said that their dementia care pathway (either in place or in development) interfaced with their end of life or palliative care pathways. The authors conclude that 'it is important that the care pathway for dementia is developed to be fully integrated and compatible with care pathways in the hospital in order to ensure that care and treatment needs are addressed holistically.'

Recommendation: There should be greater training for ward staff on signs that people with dementia are reaching the end of their lives. This would enable a shift towards palliative care, incorporating support for families and carers.

Recommendation: There should be improved communication with families and carers to explain and explore options for care in the final stages.

3.7.3 Care home or nursing home

A slightly smaller number of participants reported that the person they cared for died in a care home or nursing home, compared with the number who reported that the person died in hospital. Participants' experiences were mixed.

> **'Mum was incredibly peaceful all the way through, absolutely no distress. I sat in the room with her at 7 o'clock one morning, and the day shift were just coming on. We could smell toast, we could hear people coming down for breakfast, so that – at some level – would have been very familiar. I could do things too, so because of Mum's Christian faith I would sometimes put some hymns on in the background, and then we had some times where I was just sitting and chatting and bobbing around… I could do things like brush her hair and stroke her face and tell her that I was popping out and that I loved her. There were photos of her dad that she could see, and there were fresh flowers around. It was actually better than going into a hospice because the staff had grown very fond of Mum and they did take the best care of her and she didn't have the disruption of having to go out of somewhere that she was familiar with, so she was surrounded by familiar sights and sounds and smells. We hadn't planned it that way, but if the doctor and the care home and I had planned it we couldn't have planned it more perfectly. Very lucky really.'**
>
> **Daughter of a person with dementia**

It was positive to hear that some of the reports of the very best care were in a care home setting. Some participants reported well co-ordinated care, with medical staff working well with the care home to allow the person to remain in a familiar environment.

Where participants reported poor experiences, this generally stemmed from staff's lack of experience in end of life specialities. It was sometimes difficult to get appropriately trained medical staff when they were needed, for instance to administer appropriate pain medication. There were no direct reports of hospice or specialist palliative care outreach services being available in a care home setting, so frequently care home staff had to work with GPs who were not necessarily skilled in end of life care.

In addition, several participants reported that the person was unnecessarily hospitalised right at the end of their life, owing to care home staff becoming panicked at the person's deteriorating condition. Several reported that they had negotiated with the care home and put in place clear instructions that, before the care home rang a paramedic, they should ring the carer and make the decision in consultation with them.

> **‘My wife knew what was happening to her and she said to me early on in the stage of development of dementia, “I just want to die!” Imagine my fury when she was dying with pneumonia in a nursing home; having failed to respond to two courses of oral antibiotic she was rushed to hospital by some locum doctor on a bank holiday weekend. Our local hospital were determined to inject her with massive doses of intravenous antibiotics although my daughter and I begged that they just let her pass away as comfortably as possible. They did not even have the guts to ask my wife, she knew what they were doing to her; she kept saying “you stupid people, you stupid people”. It was so very sad.’**
>
> **Husband of a person with dementia**

The experiences of the participants reflect other recent research into the subject. The national picture of end of life care in care homes for people with dementia is relatively good. The VOICES survey found that relatives of people with dementia recorded on their death certificate were more likely to rate the care in the care home in the last three months of life as good or excellent, and less likely to rate it as fair or poor, than the relatives of people who did not have dementia recorded (Department of Health, 2012).

Care in the final stages of dementia in a care home is where a large amount of the costs associated with dementia is found. Prices for a year of dementia nursing in nursing homes and residential homes in 2010 have been estimated at £73,900 (Treloar et al, 2009). The Elderly Care Market Survey of 2009 gives the total number of people in the UK with dementia living in residential and nursing care homes as 142,000, and the cost of their care in total was £4.7 billion (Laing and Buisson, 2010–11). The scale of these costs creates a national imperative to get the care delivered in these settings right, including end of life care.

The academic research also reflects difficulties in implementing advance plans. One report found that care home staff require education and support on discussing and implementing plans for care at the end of life in dementia (Livingston et al, 2012). This would enable the staff to implement advance care plans, including decisions not to hospitalise the person with dementia at a crisis point, knowing that they will be supported. It recommended that education should encompass communicating the complicated, unpredictable path of dementia near the time of death explicitly but sensitively, including recognising that people often do not hear difficult messages.

Recommendation: There should be more training for care home staff on dealing with end of life for people with dementia. This includes: acting on plans for emergency care, advance care plans and advance decisions which have been put in place, and working with medical professionals to co-ordinate a good end of life experience.

3.7.4 Own home

In the cases discussed in interviews for this report, a substantial minority of people with dementia did end their lives in their own home. Three of the people interviewed supported the person they cared for to die at home. Again, there were mixed experiences of this. One carer reported that, although the care was good and she would not have had it any other way, the number of visits from numerous people which the care at home necessitated could be intrusive.

> **‘It is intrusive, and I was always pleased when the people were gone, but I appreciated the additional help, and at end of life you certainly need it. But I was always pleased when I closed the door and I was sat with him and I could think, “Oh good, it is just us again”. But you can’t help that because they have to be there, and what they did was brilliant and meant that he was lovely and fresh and clean – and at home. I suppose you would put up with lots of things to keep someone at home.’**
>
> **Wife of a person with dementia**

There has been increased policy attention towards people being able to die at home, and there is good practice developing in this area. While this reflects an understanding that many people would choose their own home as their preferred place of death, it should be ensured that there is adequate care available in the person’s home, and that they are not moved to a care home or into hospital by default. Alzheimer’s Society has encountered various incidents where people with dementia who are receiving funded care, either through the NHS or through social services, have been forced to move to a care home when this is not their choice, because those providing their care are not able to provide services to meet their needs.

Care for someone with dementia at home at the end of their life can be expensive, but evidence is developing to show that home-based end of life care can lead to cost savings compared with the alternatives (Marie Curie Cancer Care, 2012). The costs of providing care in someone’s own home can vary, but overall research suggests that costs of dying at home with dementia are lower than in care homes and residential homes (Laing and Buisson, 2009). The average spend on care at home in England in the last year of life in 2010/11 was £25,675 (National End of Life Care Intelligence Network, 2012). In the London Borough of Haringey, the cost of end of life care for people with dementia living at home averaged around £40,000 for the last year (Sampson et al, 2012).

In particular, care costs for people with dementia in care homes and residential homes in their last year of life were higher than for those living at home. For example, in Haringey in 2012, costs for people with dementia who died while living at home were an average of £20,000 in their last six months, whereas the costs for those dying in care homes or residential homes were an average of £37,000 for their last six months (Sampson et al, 2012).

Part of the reason for the lower cost is likely to be that if people with dementia are supported to remain at home, less time is spent in hospital (Addicot and Dewar, 2008) and greater use is made of informal care (Hughes-Hallett et al, 2011) and community care. For example, if people with dementia admitted to hospital in their last year are supported to leave hospital one week sooner, the saving to the NHS could be as much as £80 million (Alzheimer's Society, 2009). Other research found that as much as 20% of the total average costs of care for people with dementia dying at home were for hospitalisations (Sampson et al, 2012).

People with dementia may have very high needs for a long period of time before they die, and keeping them at home requires large amounts of support and care. However, where someone with dementia dies should be led by their needs, what is known of their wishes, and the needs of the people caring for them. Supporting people with dementia to die at home is also a potentially cost-effective option.

Recommendation: Attention should be paid to the specific needs of people with dementia when commissioning specialist care to reach out to people at the end of life in their own homes. Commissioners should use the NICE quality standard to identify services that support people to stay at home. Good practice in this area should be widely shared.

3.7.5 Hospice

One participant reported that the person they cared for died in a hospice. This is unusual, as typically very few people with dementia die in hospices. The Office for National Statistics figures showed that only 44 people with dementia as an underlying cause on their death certificate died in a hospice in 2010 (ONS, 2012). In the case offered for this report, a formal referral was not made. The participant explored the hospice option for themselves, having previously been told by the hospital that the person with dementia would not be eligible for hospice care. However, the hospice was willing to take the person due to their concurrent heart condition.

The carer remarked on the notable difference between the hospital setting where the person had been previously, which was noisy and unsettling for the person with dementia, and the calm and individual treatment that was received in the hospice.

'The only reason she got in there was because she was dying of her heart complaint. Her dementia was sort of on top of all that… She was in a room by herself in the hospice. They haven't got this thing about cleanliness in the same way, so the floors are carpeted for a start. This kept the noise levels down too – the noise levels in the hospital were ridiculous. In the hospice they had buzzers which were related to a device that the nurse had in her pocket which vibrated. In the hospital the buzzers just buzzed. The nurses in the hospice all wore soft shoes. The nurses as well… They have a team system there, so she was allocated two nurses in particular. They had a little record player, so they could put soft classical music on. They put plants in the room and little things like that. Just much more caring. If I wanted to stay there was a room next door or there was a bed in her room. The night staff were wonderful. I was just sitting with her the last 24 hours. I couldn't ask for anything better.'

Husband of a person with dementia

In general, hospices do not tend to take people specifically for dementia, as they are often set up to care for people with cancer or other conditions. This is also likely to be a result of the strict prioritisation that must occur for hospice beds, due to the high costs associated with them. Alzheimer's Society still hears of cases where hospice care is withdrawn from people with terminal illnesses as they develop dementia. As continuity of care is essential, particularly for people with dementia at the end of life, this practice is unacceptable. It is probable that dementia will become a growing area for hospice care as the population ages and more people are likely to have dementia alongside another life-limiting condition, particularly where hospices are providing services in the community.

Recommendation: More should be done to extend dementia training in the hospice environment, recognising dementia as a specialist care need.

Recommendation: Hospices and specialist palliative care services should review their policies and practices to enable joint working to meet the needs of people with dementia in their communities.

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5 Useful resources

Below is a selection of resources. This is not an exhaustive list, but many of the resources listed pull together useful information which may help to improve end of life care for people with dementia.

Summary and statistical resources

National End of Life Care Programme. Care towards the end of life for people with dementia: an online resource guide. [online] Available at: www.endoflifecareforadults.nhs.uk/publications/care-towards-the-end-of-life-for-people-with-dementia [Accessed 5 September 2012].

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Commissioning

National Institute for Health and Clinical Excellence. End of life care for people with dementia: Commissioning guide implementing NICE guidance. [online] Available at: www.nice.org.uk/usingguidance/commissioningguides/eolcforpeoplewithdementia/eolcforpeoplewithdementia.jsp?domedia=1&mid=8E6BF1B4-19B9-E0B5-D4D218861172B805 [Accessed 5 September 2012].

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Care planning and decision making

National End of Life Care Programme. Thinking and planning ahead: Learning from each other a volunteer training programme about advance care planning. [online] Available at: www.endoflifecareforadults.nhs.uk/education-and-training/acp-for-volunteers [Accessed 5 September 2012].

General Medical Council. Treatment and care towards the end of life: Good practice in decision making. [online] Available at: www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp [Accessed 5 September 2012].

For people with dementia and carers

Alzheimer's Society. Advance decision. [online] Available at: www.alzheimers.org.uk/factsheet/463 [Accessed 5 September 2012].

Dying Matters. Putting your house in order: Five things you can plan for end of life. [online] Available at: www.dyingmatters.org/sites/default/files/user/images/Resources/Promo%20materials/Leaflet_9_Web.pdf [Accessed 5 September 2012].

For GPs
Dying Matters. Time to talk: Starting end of life care conversations with people affected by dementia [online] Available at: www.dyingmatters.org/page/dying-matters-launches-dementia-leaflet [Accessed 5 September 2012].

For care home staff
National End of Life Care Programme. Capacity, care planning and advance care planning in life limiting illness: A guide for health and social care staff. [online] Available at: www.endoflifecareforadults.nhs.uk/publications/pubacpguide [Accessed 5 September 2012].

Emotional concerns

Alzheimer's Society. Grief and bereavement. [online] Available at: www.alzheimers.org.uk/factsheet/507 [Accessed 5 September 2012].

Alzheimer's Society. Talking Point forum. [online] Available at: http://forum.alzheimers.org.uk/forum.php [Accessed 5 September 2012].

Care in different settings

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Appendix 1: Policy framework in the UK nations

England

End of life policy

The 2008 Department of Health End of life care strategy (Department of Health, 2008) paved the way for some important steps towards improving end of life care:

- The National end of life care programme, the NHS delivery arm of the End of life care strategy, was established.
- There have been numerous end of life research initiatives, including the VOICES survey (Department of Health, 2011c), which captures after death the experiences of end of life care as reported by the carer. This has been piloted in two locations and will be rolled out nationally and form a clear benchmark for whether or not end of life care is delivering the outcomes that people want to receive. It has been suggested that this will also be an indicator in the NHS outcomes framework (Department of Health, 2011a).
- Electronic palliative care registration systems (end of life registers) have been established in numerous areas.
- The Palliative Care Funding Review (Hughes-Hallett et al, 2011) was published in 2011 and examined the structure of payment for services within end of life care. It recommended that a tariff should be developed, which would then be allocated to anyone on end of life registers, specifically to pay for palliative care needs. It also recommended that social care should be free for people on end of life registers, a recommendation which was echoed in the Commission into the Funding of Care and Support, chaired by Andrew Dilnot (Commission on Funding Care and Support, 2011).
- The Dying Matters Coalition, of which Alzheimer's Society is a member, was set up through the National Council for Palliative Care with funding from the Department of Health.

Additionally, end of life is increasingly seen as an area where improvements in care in community settings can reduce the need for costly hospital admissions. One of the 12 national Quality Innovation Productivity and Prevention (QIPP) workstreams focuses on care at end of life.[3] The NICE quality standard for end of life care was published in November 2011 (NICE 2011).

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[3] www.dh.gov.uk/en/Healthcare/Qualityandproductivity/QIPPworkstreams/DH_115469

Dementia policy relating to end of life

The 2009 Department of Health Dementia Strategy for England has an explicit objective for 'people with dementia and their carers to be involved in planning end of life care' (Department of Health, 2009). However, this is not one of the four areas in the strategy prioritised by the coalition government when they came to power in 2011.

The NICE quality standard for dementia was published in 2010 (NICE, 2010a). One of the 10 strands that this examines states that in the later stages primary care teams should assess people with dementia and plan their palliative care needs. At present, this will only apply to England. The NICE commissioning guide (NICE, 2010b) is designed to support commissioners in structuring services for people with dementia at end of life.

The Prime Minister's Challenge on dementia did not initially include end of life care as a specific focus of the Health and Care champion group, but the group are now working in this area.

Wales

End of life policy

The 2008 Sugar report on palliative care planning (Palliative Care Planning Group Wales, 2008) made recommendations to the Welsh Assembly Government. These were accepted and the Welsh Palliative Care Implementation Board was established to implement the recommendations. Their most recent report on progress (Palliative Care Cymru Implementation Board, 2011) suggested that they had achieved the objectives of the report, but had identified further areas that need attention, although these did not specifically include dementia. Ringfenced funding for palliative care was maintained in 2011–12.

At the time of writing, Together for health: Delivering on end of life care (Welsh Government 2012) was in a period of consultation. This suggested four outcomes expected by 2016 which would support dying well:

- Supporting living and dying well – People in Wales have a healthy, realistic approach to dying. They are encouraged to adopt healthy lifestyles, yet are informed and supported to make arrangements in advance for the end of life.

- Detecting and identifying patients early – People with palliative care needs are identified early to enable the best care to be planned in advance.

- Delivering fast, effective, person-centred care – People receive fast, effective person-centred care in order to maintain quality of life for as long as possible. Patients and their families have their needs identified and met so they feel well supported and informed, able to manage their illness.

- Reducing distress in the terminal phase for the patient and their family – Patients entering the terminal phase of their illness and their families feel well cared for and are pain- and symptom-free. Symptoms and problems that are likely to arise are addressed appropriately and promptly.

Dementia policy relating to end of life

The Dementia vision for Wales (Welsh Assembly Government, 2011) does not specifically mention end of life care, but includes measures that may improve care of dementia in the final days, including increased detection, integrated service provision and increased training.

Northern Ireland

End of life policy

In March 2010, Living matters dying matters (Department of Health, Social Services and Public Safety, 2010), a five-year strategy for service planning and delivery was published. This lays out 25 recommendations across palliative care, none of which are dementia-specific.

However, the Department of Health, Social Services and Public Safety are also developing service frameworks for each condition. Each of these includes standards for supportive and palliative care. Dementia has not been prioritised specifically as one of these standards, although ‘mental health’ has, and the draft includes provisions for the care of people with dementia.

Dementia policy relating to end of life

Improving dementia services in Northern Ireland: A regional strategy (Department of Health, Social Services and Public Safety, 2011) makes reference to the Northern Irish strategies on end of life care. It suggests that end of life care is an important part of dementia care and suggests that trusts develop palliative and end of life services for people with dementia within the framework of the palliative and end of life care strategy.

Appendix 2: Office for National Statistics information on place of death

Place of occurrence of death selected causes 2010 England and Wales

Total deaths

ICD-10 code	Underlying cause (ICD chapter) and age	Male	Female
F01 – F019*	Vascular dementia	300	375
F03	Unspecified dementia	4,925	12,749
G00 – G00.9	Alzheimer's disease	2,122	4,635
There were no deaths attributed to the underlying causes F00–F009 or F03–F039			
Total for all dementias		7,347	17,759
Total for all dementias, both m/f			**25,106**

*Please note there were no deaths attributed to F00 or F02.

Home

ICD-10 code	Underlying cause (ICD chapter) and age	Male	Female
F01 – F019*	Vascular dementia	22	20
F03	Unspecified dementia	200	678
G00 – G00.9	Alzheimer's disease	148	371
There were no deaths attributed to the underlying causes F00–F009 or F03–F039			
Total for all dementias		370	1,069
Total for all dementias, both m/f			**1,439**

*Please note there were no deaths attributed to F00 or F02.

Care homes

ICD-10 code	Underlying cause (ICD chapter) and age	Local authority Male	Local authority Female	Non-local authority Male	Non-local authority Female
F01 – F019*	Vascular dementia	7	12	108	181
F03	Unspecified dementia	155	649	2,415	7,666
G00 – G00.9	Alzheimer's disease	73	240	1,186	3,064
There were no deaths attributed to the underlying causes F00–F009 or F03–F039					
Total for all dementias		235	901	3,709	10,911
Total for all dementias, both m/f			1,136		14,620
Total for local and non-local					**15,756**

*Please note there were no deaths attributed to F00 or F02.

Hospices

ICD-10 code	Underlying cause (ICD chapter) and age	NHS Male	NHS Female	Non-NHS Male	Non-NHS Female
F01 – F019*	Vascular dementia	0	0	0	0
F03	Unspecified dementia	0	1	7	18
G00 – G00.9	Alzheimer's disease	0	1	9	8
There were no deaths attributed to the underlying causes F00–F009 or F03–F039					
Total for all dementias		0	2	16	26
Total for all dementias, both m/f			2		42
Total for NHS and non-NHS					**44**

*Please note there were no deaths attributed to F00 or F02.

Hospitals (acute or community, not psychiatric)

ICD-10 code	Underlying cause (ICD chapter) and age	NHS		Non-NHS	
		Male	Female	Male	Female
F01 – F019*	Vascular dementia	158	157	0	2
F03	Unspecified dementia	2,092	3,570	3	5
G00 – G00.9	Alzheimer's disease	655	874	1	5
There were no deaths attributed to the underlying causes F00–F009 or F03–F039					
Total for all dementias		2,905	4,601	4	12
Total for all dementias, both m/f			7,506		16
Total for local and non-local					**7,522**

*Please note there were no deaths attributed to F00 or F02.

Other communal establishment

ICD-10 code	Underlying cause (ICD chapter) and age	Male	Female
F01 – F019*	Vascular dementia	4	3
F03	Unspecified dementia	45	134
G00 – G00.9	Alzheimer's disease	40	62
There were no deaths attributed to the underlying causes F00–F009 or F03–F039			
Total for all dementias		89	199
Total for all dementias, both m/f			**288**

*Please note there were no deaths attributed to F00 or F02.

Elsewhere

ICD-10 code	Underlying cause (ICD chapter) and age	Male	Female
F01 – F019*	Vascular dementia	1	0
F03	Unspecified dementia	8	28
G00 – G00.9	Alzheimer's disease	10	10
There were no deaths attributed to the underlying causes F00–F009 or F03–F039			
Total for all dementias		19	38
Total for all dementias, both m/f			**57**

*Please note there were no deaths attributed to F00 or F02.

Alzheimer's Society | Leading the fight against dementia

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit **alzheimers.org.uk** or call the **Alzheimer's Society National Dementia Helpline** on **0300 222 11 22** (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

Alzheimer's Society
Devon House
58 St Katharine's Way
London E1W 1LB

T **020 7423 3500**
F **020 7423 3501**
E **info@alzheimers.org.uk**
alzheimers.org.uk

Code 911