

Living and dying with dementia in England:

Barriers to care

December 2014

Contents

Foreword	4
Introduction	5
Theme one: identification and planning	9
Theme two: inequality of access	11
Theme three: quality of care	16
Conclusion	20
References	21

Foreword

Dementia is a growing issue and concern for societies across the world. Our ageing population means that dementia will affect an increasing number of people over the coming decades. It represents one of the major health and social care challenges facing the UK.

While much of the focus of research and discussions is rightly on the challenge of finding cures for the different forms of dementia, we must be realistic and acknowledge that the eradication of dementia is, at present, a medium to longer term project rather than a short term goal. Therefore we must place equal emphasis on the care which is provided to people with dementia and the support which is available to their families and carers.

That is why Marie Curie and the Alzheimer's Society have come together to write this report. We believe it represents an important contribution to the ongoing debates about how we address the challenge of improving care and support available to people with dementia and their families. It is only by identifying the barriers which currently

prevent or limit access to the highest quality care and support that we can begin to improve the care and support which is available.

As major national charities working to improve end of life care and strengthen the focus on dementia, we are committed to providing leadership and to supporting all those organisations which provide support and care to people in the final stages of dementia, and their families, to improve the care that is available.

Over the coming months, we will bring together those who have experience of supporting people with dementia at the end of life and those who deliver care and support across the health, housing and social care sectors. We will explore how we start working towards removing the barriers which currently prevent people with dementia and their families from accessing the highest quality care and support. Our collective goal must be to ensure that everyone, regardless of their condition, where they live, or the services they use, gets the best possible care and support at the end of life.

Dr Jane Collins, Chief Executive, Marie Curie Cancer Care

Jeremy Hughes, Chief Executive, Alzheimer's Society

December 2014

Introduction

The [G8's dementia summit](#) held in London in December 2013 prompted a renewed focus on dementia and in particular the challenge faced in the UK and globally from the projected '[explosion](#)' in dementia cases over the coming decades. Much of the focus of the summit and the resulting media coverage was on the search for a 'cure' for dementia. However, given that dementia is a collection of different diseases, with different causes, the reality is that there can be no single cure for dementia. This means that we are looking for cures rather than a cure and that is a much longer term goal than may initially be imagined.

The focus and coverage of the G8 dementia summit reflects wider contemporary debates about dementia in the UK and elsewhere. These tend to focus almost exclusively on early stages of the condition, on diagnosis and on the search for a cure, with little reference to the final stages of the condition and the fact that dementia is a terminal condition.

Initiatives such as [The Prime Minister's Dementia Challenge](#) and [Dementia Friends](#) have helped to strengthen our focus on the need to enable people with dementia to live well for as long as they can and to make UK society more dementia friendly.

There has been much less focus on the inevitable conclusion of what is a progressive, terminal condition and we must improve the care of people in the later stages of dementia. As it stands, with notable exceptions such as [My life until the end: Dying well with dementia](#) by the Alzheimer's Society and the work of the [National Council for Palliative Care \(NCPC\)](#) and the Dying Matters coalition, the death and dying phase of dementia remains the forgotten aspect of what has been referred to as a '[silent epidemic](#)'.

This paper explores how we can ensure that there is a stronger focus on dementia as a terminal condition and in particular the barriers which prevent many people with dementia from accessing and receiving appropriate high quality care at the end of their lives. There are three key barriers:

- 1) identification and planning**
- 2) inequality of access**
- 3) the quality of care experienced by people with dementia**

This paper explores how we can improve the care and support for people who are living and dying with dementia, as well as their families and carers. And also how we can reach those health and social care professionals who care for and support them. It focuses on what needs to improve in England, but draws on developments and research from across the UK.

What is dementia?

Dementia does not have one single cause. It is caused by a range of underlying conditions including Alzheimer's, vascular dementia, dementia with Lewy bodies and fronto-temporal dementia¹. Throughout the remainder of this paper, dementia is used as a shorthand for this broad range of conditions.

Dementia is a progressive neurodegenerative disease. This means that the symptoms become more severe over time. Symptoms usually include memory loss, confusion, speech difficulties, mood and behavioural changes² and problems with self-care and other aspects of daily living. There are some treatments to alleviate the symptoms,³ but dementia is not curable and is a terminal illness.

The final stage of dementia is comparable with other terminal illnesses as the prognosis is often similar⁴. While we argue that it is important to focus on the latter stages of the condition, we recognise that planning and intervention in the earlier stages are also essential to ensure a good death for a person with dementia. Better planning and support in the early stages of dementia can improve informed decision making in the latter stages. This applies also to those with dementia who may die from another condition.

It is also important that we acknowledge that the reality for many people with dementia is that they will be living with different conditions, including cancer and those associated with frailty and older age.

Dementia: The numbers

Around [850,000 people live with dementia in the UK](#). Latest figures from the Alzheimer's Society show that in England, 714,000 people are living with dementia.

The vast majority (almost 95%) of those living with dementia are over the age of 65⁵. There are, however, 42,325 people under 65 who have dementia⁶. Dementia also has an interesting gender profile - two thirds of people with dementia are women⁷. The latest data suggests that for the first time dementia or Alzheimer's is now the biggest single cause of death amongst women in England and Wales, having surpassed different forms of cancer for the first time⁸. The Alzheimer's Society provides further [key data](#) regarding current and future trends.

Providing definitive figures for the number of people with dementia is problematic because diagnosis is difficult, particularly in the early stages. Similarly it is difficult to identify the number of people dying as a result of dementia. Many deaths are not directly attributed to dementia, but rather to the immediate cause of death, such as an infection or another coexisting condition⁹. In England and Wales in 2013, 31,850 women and 15,262 men had their death attributed to dementia or Alzheimer's.

Between 2003 and 2013 the percentage of deaths from dementia and Alzheimer's disease rose from 4.7% to 12.2% for women and from 2% to 6.2% for men¹⁰.

A recent cohort study in Northern Ireland concluded that:

'The cause of death documented for AD patients may be affected by the physician's knowledge of the patient or reflects the approach to management of patients with end-stage dementia.'¹¹

The likelihood is that, in England and across the UK, the number of deaths from dementia is currently being significantly under-reported and these official figures are not a reflection of the real picture. For example, a significant number will be recorded as being caused by 'senility'.

Dementia is therefore an important issue at the end of life for a growing number of people in the UK. According to the 2011 census, there were approximately 8.5 million people living in the UK over the age of 65: these individuals can be considered to be at a higher risk of developing dementia¹².

This figure is set to rise in the future because the UK has a rapidly ageing population. Between 2001 and 2011, the proportion of the UK population aged 65 and over increased from 15.89% to 16.34%¹³. By 2030, the proportion of the UK aged over 85 is expected to double. Xie, Brayne et al estimate that one in three people over the age of 65 years who die will have some form of dementia¹⁴.

As the proportion of the population aged 65 and over increases, so the number of people at risk of developing dementia increases. It is essential that we address the issue of end of life care for people with dementia now.

Dementia: A long and unpredictable condition

It is important to underline the unpredictable nature of dementia; however, people with dementia are likely to live longer than those with some other life-limiting conditions. The period from diagnosis to death varies, depending on what condition has caused the dementia symptoms, but all have a relatively long disease trajectory.

People with Alzheimer's have been known to live for up to 10 years after the initial diagnosis, although this depends on the age when the diagnosis is received¹⁵. People diagnosed with fronto-temporal dementia can expect to live between six and eight years, while people with dementia with Lewy bodies can live between six and 12 years¹⁶. Those diagnosed with vascular dementia can expect to live a shorter length of time after diagnosis – approximately five years¹⁷.

The length of time a person can expect to live with dementia also depends on the stage that the disease is at when they are diagnosed. Dementia's relatively long and unpredictable disease trajectory (see Figure 1) makes it difficult for doctors to provide an end of life prognosis – and perhaps makes doctors unwilling to do so. A study of nursing home deaths found that most people with dementia were given a prognosis of more than six months, but 71% of these people died within the six month period¹⁸.

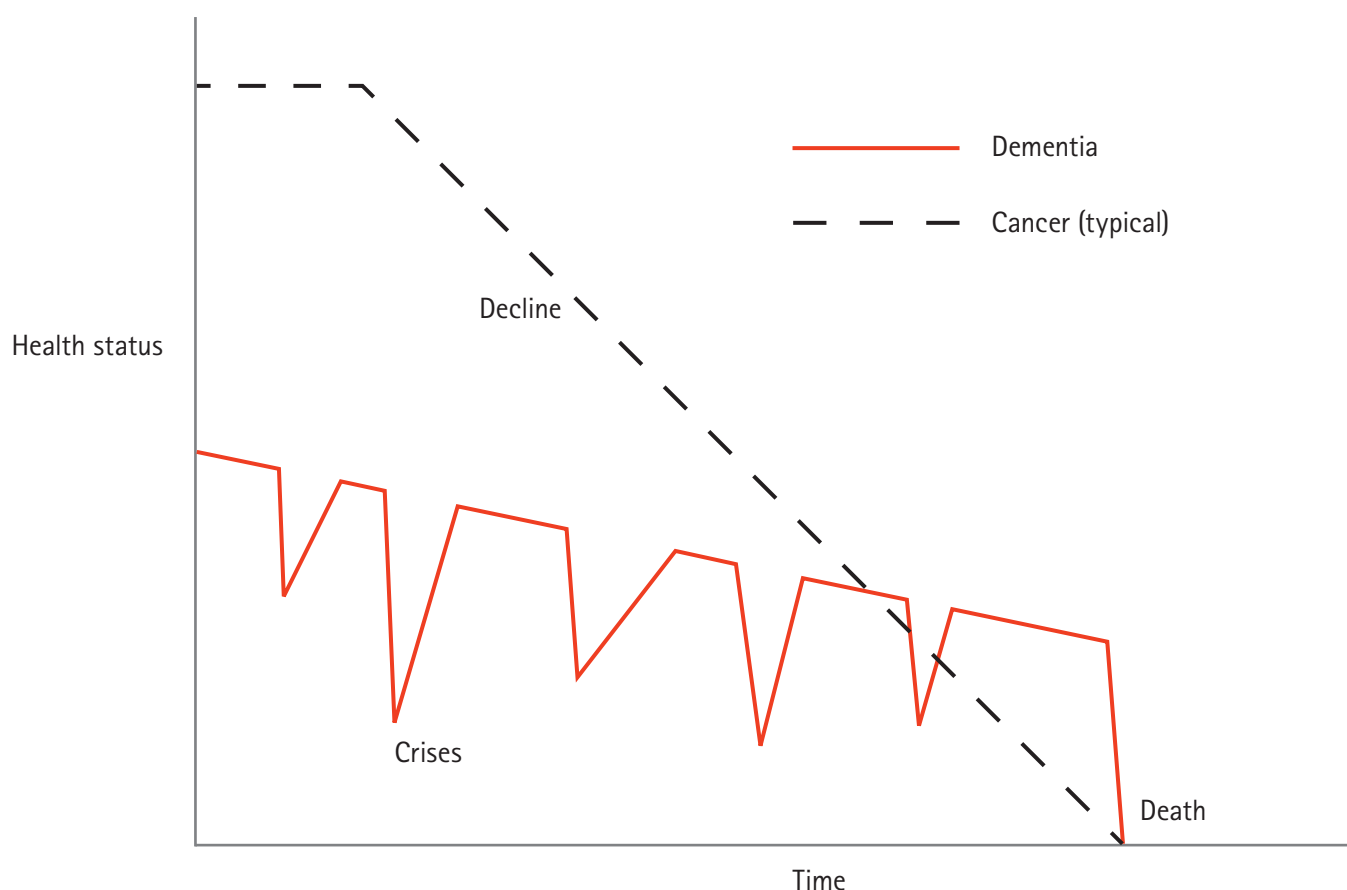


Figure 1 Terminal trajectory typical of cancer and dementia (adapted from Sachs, et al., 2004¹⁹)

The period for which a person with dementia might require care is long compared with a number of other terminal illnesses. People with dementia also often struggle with daily living and taking care of themselves at an earlier stage than those with some other conditions due to the nature of the symptoms. Many people with dementia will find themselves living in care homes. This raises an important question – how well are social care and palliative care services coordinated and aligned across the country so that an individual can routinely access palliative care, regardless of where they live?

The progressive and degenerative nature of dementia, coupled with current and projected levels of dementia diagnosis, mean that it is essential that we explore how we can make all relevant health and social care services more dementia friendly and appropriate, particularly for those approaching the end of life.

What prevents people with dementia from accessing high quality end of life care?

There is a growing evidence base which suggests that people with dementia are not being appropriately identified for end of life care, and that they have less access to, and receive poorer quality, care than people with other terminal illnesses. These three barriers extend through a person's dementia journey, from before receiving a formal diagnosis through to accessing appropriate care in the last days of life. It is only by addressing the barriers people with dementia face in these three areas that we can ensure that there is a stronger focus on the needs and experiences of people living and dying with dementia, and their families and carers.

Theme one: identification and planning

Barriers: Lack of timely and appropriate diagnosis

Dementia is often difficult to diagnose in its early stages and people who have signs of the condition may be slow to seek help²⁰. In the earliest stages, symptoms such as confusion and memory loss may be dismissed by people with dementia, families and professionals as normal signs of ageing.

A formal diagnosis from a doctor or other health professional is generally required for people to access many services, and this restricts the support people receive if there is any delay in them receiving a diagnosis. There is no general diagnostic test for any type of dementia. Diagnosis currently involves looking at an individual's clinical history, cognitive testing and possibly neuro-imaging.

The two key issues here are:

- **reluctance or fear on the part of people with dementia to identify or acknowledge symptoms**
- **the ability of health and social care professionals to accurately identify and diagnose dementia, particularly in its earliest stages.**

Rates of diagnosis vary significantly across the UK and within the individual countries and nations. In England it is estimated that the average rate of dementia diagnosis is 48%, with an estimated 416,000 people in England living with dementia without a diagnosis. This compares to a diagnosis rate of 63.2% in Northern Ireland²¹.

Timely diagnosis has a major potential impact on subsequent access to support, treatment and appropriate care.

Barriers: Lack of recognition of dementia as a terminal condition

There appears to be a failure to identify dementia as a terminal illness in some quarters for example by health and social care professionals. This has implications for the type of care which is provided for people with dementia; indeed most people with dementia have, historically, not had access to specialist palliative care²². In 2004, the World Health Organisation (WHO) [found that less than 1% of people in hospices in Europe had a primary diagnosis of dementia](#). If dementia is more routinely identified as a terminal diagnosis, health and social care professionals will be able to provide more appropriate support and care to people with dementia.

Barriers: Failure to identify dementia as a cause of death

This issue of poor identification is also reflected in the rate at which dementia is recorded as the cause of death on death certificates²³. The ultimate cause of death is often attributed to an infection or other common illness and is stated as such when the death is formally registered²⁴.

This creates a culture in which dementia is not recognised as a cause of death in its own right, potentially reinforcing the earlier lack of recognition of dementia as a terminal condition. This means that dementia is often overlooked despite the fact that it may have played a key role in a person's decline and ultimate death.

For example, where a person with dementia loses the ability to swallow and therefore to eat and drink, their body, without the use of artificial feeding, will slowly begin to close down and they will ultimately die at the point at which their organs fail. In some instances, this death might

be simply recorded as being as a result of heart or multiple organ failure and not the progress of dementia which precipitated the ultimate decline.

The number of deaths with a mention of dementia recorded on the death certificate in England almost doubled between 2001 and 2010, rising from 6.6% to 12.0%²⁵. As Sleeman et al argue 'Improved death certification is essential to fully understand place of death in dementia'.²⁶

Barriers: Ineffective advance care planning

Once a person is identified as having a terminal illness, advance care planning is crucial. In theory it should be particularly important for people with dementia and other degenerative cognitive conditions, whose diagnosis means that they will increasingly lose capacity as their condition progresses. However, the reality is that for many people with dementia, advance care planning can be extremely problematic. A study from the US indicates that people with dementia were less likely to have advance care directives than people with other conditions²⁷. This is supported by evidence from the UK²⁸.

It is difficult to judge when advance care planning discussions should be initiated. Delayed diagnosis may mean that even in the earliest stages, people with dementia may not have retained the mental capacity required to make advance decisions. Even in the earliest stages of dementia, people can struggle to imagine their future self and, understandably, frame their views according to their current situation²⁹. Further, it is suggested that preferences change as the condition progresses³⁰.

Finally, many people with dementia in the early stages may be unwilling to accept that their condition will result in death and this can disrupt conversations over planning for this outcome³¹. This means that it is often left to family members to plan. The families of people with dementia are supported in their decision making by their 'knowledge of the person with dementia's previous views, clear diagnostic information, and family support'.³²

The wishes of a terminally ill person can also be expressed in the form of advance directives or Living Wills. In England and Wales, an advance directive is the only legally binding form of expressing views on care and is situation specific³³.

In the absence of an advance directive, families may express the wishes of the person with dementia. This is known as a proxy directive or a general values directive; however, these two forms of directive are not legally binding³⁴.

A person with dementia may also nominate a 'welfare attorney' or assign lasting power of attorney. This gives the attorney the power to make decisions based on the current situation. Attorneys should be specified well in advance of loss of competence³⁵. The alternative to advance care planning is the identification of someone trusted by the patient who can represent their wishes³⁶.

In the absence of advance instructions, decision making ultimately sits with healthcare professionals, who must ensure that

'the treatment has to be necessary either to save life or to prevent a serious deterioration in health and must be in the patient's best interests'.³⁷

In such instances, families can express their wishes regarding treatment, but ultimately any decision is the responsibility of the healthcare professionals involved. This can create conflicts between health professionals and families; although in reality the wishes of family and care givers will usually be discussed in a calm atmosphere with the relevant health professionals and a consensus reached on the best way to proceed³⁸.

Theme two: inequality of access

Barriers: Access to palliative care

As has been discussed, for people with dementia to receive timely palliative care and holistic support, identification and recognition that they have dementia is a crucial first step. For some people, once dementia has been diagnosed, the next step might ideally be a referral to a palliative care service.

However, a recent hospital-based study in an acute medical ward in the UK suggested that people with dementia were less likely to be referred to palliative care and less likely to receive palliative medication than people who did not have dementia – just '17% of patients with dementia that subsequently died were referred to the palliative care team during their admission'.³⁹

This echoes the findings of a recent study in Scotland which found that just 20% of those with frailty or dementia had been formally identified as requiring palliative care, compared to 75% of those with cancer⁴⁰.

This data chimes with the widely held perception that palliative care services have historically failed to reach a significant number of people with dementia. The reasons for this may be explained by an acknowledgement that the roots of the modern hospice and palliative care movements developed in response to the needs of people with cancer. Additionally, dementia is a condition which is primarily addressed through social care, and many people with dementia live in care houses.

The National Institute for Health and Clinical Excellence has produced guidelines on dementia care including palliative and end of life care for people with dementia⁴¹. The guidance is clear:

'Dementia care should incorporate a palliative care approach from the time of diagnosis until death. The aim should be to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing, while also supporting carers during their bereavement, which may both anticipate and follow death.'

Health and social care professionals working with people with dementia and their carers should adopt a palliative care approach. They should consider physical, psychological, social and spiritual needs to maximise the quality of life of the person with dementia and their family.

Palliative care professionals, other health and social care professionals, and commissioners should ensure that people with dementia who are dying have the same access to palliative care services as those without dementia'.⁴²

Importantly, palliative care is identified as a valid and important treatment approach for individuals with dementia from the point of diagnosis. The authors of the Behavioural and Pain BEPAID study advocate the early introduction of palliative care for people with dementia⁴³.

Elsewhere in the UK, Standards of Care for Dementia in Scotland was published in 2011 and includes extensive reference to end of life care and palliative care and a specific commitment that people with dementia will:

'Have access to the full range of palliative care services and good quality compassionate care towards the end of life'.ⁱ

The [European Association for Palliative Care's White paper](#) offers a model (see figure 2) which plots the changing care goals and priorities throughout the course of the dementia.

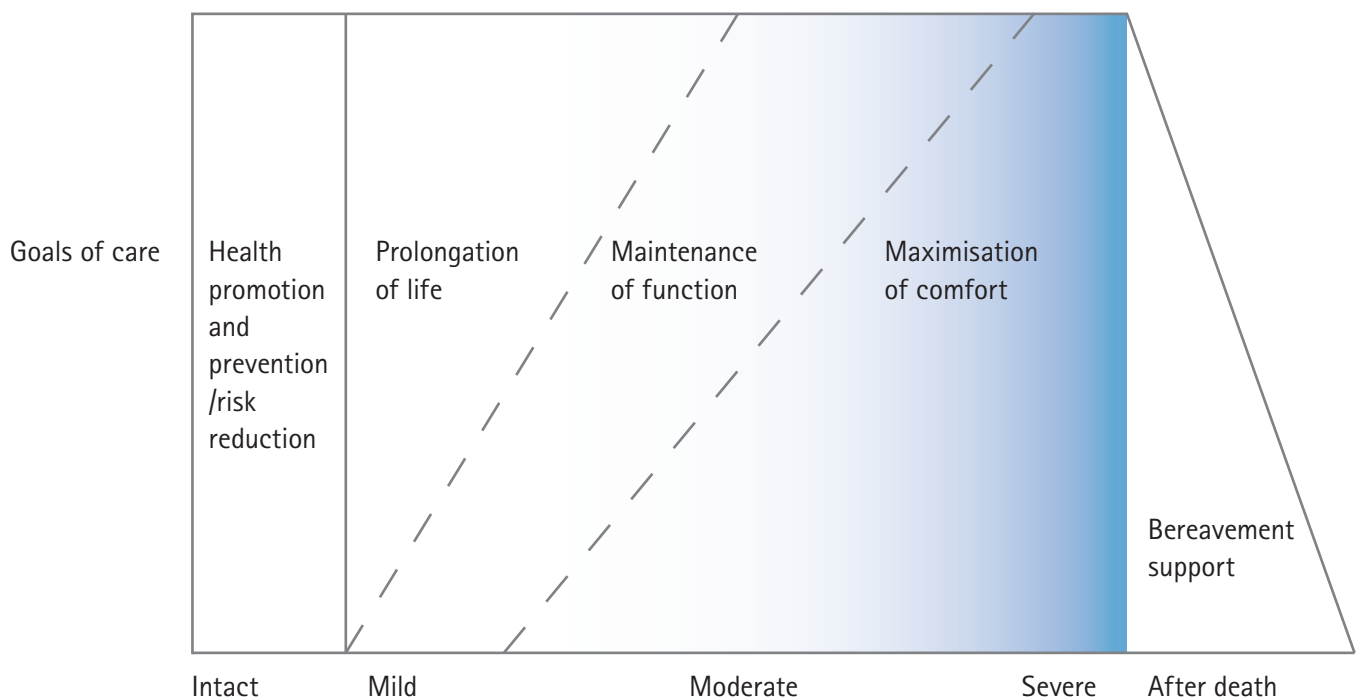
It is therefore vital that we enhance the role of palliative care for people with dementia, not just in the last few days of life, but much earlier in the development of the condition because of its emphasis on symptom management.

We need to ensure that examples of excellent links between local palliative care services and care

homes and hospital services are replicated across the country and extended over a much longer time period. We also need to ensure that people with dementia in the last days of life, whether they are in their own home, their care home or in hospital can access palliative care specialists who then support colleagues to assess and manage pain.

It is important to consider what prevents many people with dementia accessing palliative care. The links between oncology departments and palliative care teams are well established. However it is not clear that the links between dementia specialists and palliative care teams are similarly well developed across all parts of the country. There may be additional barriers in the divide between health and social care. As previously noted, decision making about the move from active treatment to palliative care is complex⁴⁴. For people with dementia there is usually no single point equivalent to the conversation which someone with cancer may have with an oncologist about the transition from active treatment to palliative care. The degenerative nature of

Figure 2: Importance of palliative care in dementia and dementia severity



ⁱ <http://www.scotland.gov.uk/resource/doc/350188/0117212.pdf>

dementia should make the transition to palliative care easier; however, the data suggests that this is not the case. We have to find a way to better identify people with dementia at the point at which they need support from and will benefit most from palliative care teams.

Importantly it has been suggested that access to palliative care should be based on the patient's need, not their life expectancy, as it can offer huge benefits even for those who may have a less imminent expectation of death⁴⁵.

Barriers: Access to hospice care

The picture regarding access to palliative care for people with dementia that we have presented so far is highlighted further by the fact that in the UK it is still unusual for people with dementia to die in a hospice⁴⁶. In 2005, less than 2% of hospice in-patients had a primary diagnosis of dementia⁴⁷. Sleeman et al found that in England just 0.3% of people whose cause of death included a reference to dementia died in a hospice⁴⁸. This reflects the wider picture of hospice use which is still predominantly used by people with cancer.

It is important that we explore why hospice use is so low for people with a dementia diagnosis. Is it because hospices are unsuitable places for people with dementia, or are there other reasons which explain the low take up of both hospice and palliative care?

Do people with cancer represent the majority of those using hospices simply because oncologists are in the habit of referring those for whom there is no further active treatment to hospices and palliative care teams? Do we need to establish the same sort of relationships between other condition-specific specialists and hospices and palliative care teams? In some cases, care homes may be performing the same role as hospices.

Given the different nature of dementia and divergent needs of those with the condition, it is perhaps not surprising that there are relatively few dementia specialists working in palliative care settings⁴⁹. As we have already noted, the modern hospice movement and the palliative care

specialism grew out of caring for people with cancer. People with dementia have very different needs to those with cancer and caring for them requires very different skills.

In addition to issues relating to referrals, there are also questions about the spaces and layouts of hospices and whether these need to be different to meet the needs of people with dementia.

It is important to note that for some people with dementia, the move to a hospice (or any other care setting) can cause unnecessary confusion and distress at a stage in the condition when the person may be less able to cope with change. This may also partially explain why people in the latter stages of dementia rarely use hospice services⁵⁰. We also need to explore what more can be done to build connections between hospices and social care.

To address the current under-use of both hospice and specialist palliative care, one key message that we need to send out is that hospices are open and available for people with dementia and that staff and volunteers have the training and skills needed to deliver services to people with dementia. This will require commissioners to prioritise end of life care focused on dementia and resource it fully.

We must also learn from those hospices which are already providing high quality care for people with dementia.

Barriers: Access to funding

Access to funding for those approaching the end of life is complex. There are different rules and funding arrangements in place for social care in England.

As their condition deteriorates, people with dementia will have increasing health and social care requirements; they will need greater help with personal care as well as specific healthcare and hospital-based services related to their dementia.

While it is clear that people with later stage dementia will have considerable health needs, this is not reflected in their access to Continuing Health Care (NHS). CHC is the system whereby the NHS picks up the costs of caring for someone

whose primary needs are for healthcare in a non-hospital setting. It is suggested that disproportionately low numbers of people with dementia are receiving CHC⁵¹. As the All Party Parliamentary Group (APPG) on Parkinson's [Failing to Care](#) report found, we need better data collection to enable us to determine patterns and inequities of access to CHC for people with conditions like dementia⁵².

The APPG on Parkinson's analysis also highlights fundamental problems with assessment of applications for CHC funding in England. First, while there is a nationally recognised decision support tool (DST) and a national framework which sets out an assessment process in England, there is no compulsion to use it. Consequently, there are myriad different, local assessment approaches. This ensures that the system effectively has an in-built inequality.

Second, the guidance and the tools are often interpreted in a way that does not reflect the reality of different conditions, including cognitive degenerative conditions such as dementia, Parkinson's or motor neurone disease (MND). The focus of the assessment is the wording of the tool, rather than the needs of the individual:

'It is not used as a support but being interpreted legalistically. The focus of the assessor is on the semantics of each word rather than the essence of the patient's condition. It is often used literally and not interpreted intelligently'.⁵³

This can lead to perverse decisions:

'Parkinson's UK had been given an example of where someone with Parkinson's in receipt of NHS continuing care had undergone a reassessment. Since the previous assessment, the individual's mobility had deteriorated to the extent that they were now permanently bed bound. The use of the DST then gave the individual a lower score in the mobility category because they were at a reduced risk of falling. This subsequently rendered the individual

ineligible for NHS continuing care'.⁵⁴

Third, there is inconsistency in the way that assessments are carried out. For example, assessments do not always take into account the level of medication a person is receiving and may not consider the person in an unmedicated state.

Fourth, there is the question of who carries out the assessment. Is the individual charged with undertaking the assessment the most appropriate person to do so? Are they known to the person with dementia and do they understand the different manifestations of their condition? There are clear issues relating to training and understanding of specific conditions and involvement of appropriate healthcare professionals.

It is important that the tools and guidance which are used to assess CHC eligibility reflect the realities of different conditions, including cognitive degenerative conditions such as dementia. The whole CHC system arguably needs a radical overhaul to make it dementia-friendly.

A report by the Wales Audit Office in 2013 noted concerns expressed by Alzheimer's Society and Age Concern that:

'Because of differences in the DST (Decision Support Tool) used in Wales and England, it may be more difficult for some people in Wales, most notably those with dementia, to meet CHC eligibility criteria'.⁵⁵

Similarly, in Scotland, the Continuing Health Care System has just undergone an independent review.

Barriers: Discrimination

The Alzheimer's Society has previously argued that individuals with dementia face discrimination in the care they are given because there is a lack of targeted services and care standards vary⁵⁶.

The Alzheimer's Society argues that those with dementia may experience "poor rates of diagnosis and a lack of appropriate services" because it occurs at a later stage in life and is assumed to just be a symptom of getting old⁵⁷.

It has also been suggested that those with dementia have poorer access to mental health services compared with younger people with mental health conditions⁵⁸. Older people with dementia may, therefore, not be getting optimum care simply because of their age. Dementia affects people's ability to defend themselves against discrimination⁵⁹, so issues of age discrimination may be more pronounced.

Younger people with dementia may also experience disadvantage in terms of access to services. Most people with dementia are aged over 65. This means services are targeted at older individuals and there could be a risk of younger people with dementia being excluded.

In the UK there are approximately 42,325 people living with early-onset dementia aged between 45 and 65⁶⁰. Specialist services for younger people with dementia are rare, and dementia services targeted at older people may not accept them – which means it can be difficult for younger people to access support⁶¹. Dementia services targeted at young people are needed so that these people get the support they require and are not excluded from services and discriminated against.

Connolly et al have suggested that people with dementia who are from ethnic minority groups might face a 'double disadvantage'.⁶² Marie Curie commissioned research by Kings College London into the [Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK](#) and has published an [accompanying policy paper](#) which explores these issues further. This work underlines the predicted growth in demand for end of life care from BAME communities over the next two decades.

Theme three: quality of care

Barriers: Inconsistency in care standards in hospitals

Almost two in five (39.6%) of people with dementia die in hospital⁶³. The National Care of the Dying Audit for Hospitals, England underlines the considerable variation in care on offer for people with different diagnosis in hospitals across England⁶⁴.

In 2008, it was estimated that people with dementia over 65 years of age account for 25% of hospital beds at any one time. When admitted to hospital because of another condition, they spend longer in hospital than those with the same condition who don't have dementia⁶⁵. Hospitals can be incredibly difficult places for people with dementia. In 2013, a Royal Society of Psychiatrists hospital audit highlighted low performance against essential standards for many hospitals in the care of people with dementia⁶⁶.

A key problem appears to be the inadequate identification of dementia when people with dementia are admitted to hospital. A Care Quality Commission (CQC) review of hospital episode data found that in 29% of cases a person's dementia was not recorded, despite having been recorded during previous admissions⁶⁷.

As the CQC note:

'An NHS Confederation briefing on dementia showed that hospitals often code the primary reason for admission to hospital, not the dementia. Not identifying, and then not coding and recording, the dementia leads to hospitals underestimating the numbers of people with dementia occupying beds.'⁶⁸

Barriers: Inappropriate hospital admissions

People with dementia in care homes are more likely to experience inappropriate admissions to hospital:

'[In] more than half (78 out of 151) of PCT areas, people in care homes with dementia were admitted to hospital with 'avoidable conditions' significantly more than people without dementia.'⁶⁹

Lack of training and awareness of end of life care among health and social care professionals, staff shortages and the non-availability of GPs (particularly out of hours) can all result in people with dementia being admitted to hospital at the first 'sign of decline'. Inappropriate admissions can cause unnecessary disruption for a person with dementia in the final days and weeks of life and they may end up not dying in their preferred place or in the most appropriate place for them.

Studies have shown that unplanned admission to acute hospitals also negatively impacts on survival times for people with dementia, which were half those without dementia⁷⁰.

This underlines the need for good care planning and excellent primary care and community support to help avoid unnecessary hospital admissions for people with dementia. In many instances this may include a role for external medical expertise, such as community nurses, going into the home to support care and nursing professionals at key stages.

It is important that we learn from those many care homes which are providing high quality care, working well with other professionals locally and are able to deal with what are often the complex needs of people with dementia at the end of life.

Over the last decade, the trend of increasing numbers of people with dementia dying in hospital has been reversed, with a growing proportion dying in care homes (55.3%) in England⁷¹. This compares with just 4.8% who died at home and 0.3% in hospices⁷², so it appears clear that the future demand is likely to be for greater capacity and expertise among health and social care professionals working in nursing and care homes.

As with many other conditions, most people with dementia would like to die at home or in their usual place of residence, for example a care home and their families would also prefer this⁷³. However, a significant proportion of people with dementia are likely to die in hospital⁷⁴. Spending periods of time in hospital can be extremely distressing for people with dementia. Research has shown that those admitted to hospital with dementia are more likely to die during an admission and in the six months after their hospital admission⁷⁵.

Barriers: Lack of continuity of care

Continuity of care is extremely important as changes in health or social care staff can create unnecessary distress⁷⁶. It is clear that familiarity benefits both the person with the dementia (and their family) and those providing care, in helping people to stay in their own homes for longer⁷⁷.

Similarly, unnecessary transfers from an individual's usual place of residence can have

a disconcerting impact, causing confusion and exacerbating uncertainty.

[Cracks in the Pathway](#), the Care Quality Commission's thematic review of dementia services, highlighted issues relating to poor information exchanges between different providers as people with dementia moved between services. In 27% of care homes and 22% it found:

'aspects of variable or poor care regarding the arrangements for how they shared information when people moved between services'.

Work is also needed to ensure that nursing and care home staff, social care providers and local GPs are confident about working with people with dementia and are able to take the steps required to prevent unnecessary admissions, which lead to breakdowns in continuity and place the individual at greater risk of decline.

Barriers: Poor pain management

Dementia may not in itself cause pain, but as most people with dementia are over 65 they may be suffering from conditions such as arthritis or cardiac disease which do⁷⁸. Researchers have shown that as dementia progresses, people become less able to identify pain:

'Compared with the control group, people with dementia were less able to identify painful situations and used fewer categories to define their concept of pain'.⁷⁹

They conclude that clinicians should bear this in mind when assessing people with dementia for pain⁸⁰.

Health professionals tend to have to rely on close observation of changes in people's behaviour to identify the level of pain that they are experiencing and manage pain correctly⁸¹. As the disease progresses, reporting of pain by the person generally decreases and becomes less accurate⁸².

Studies have underlined the degree to which people with dementia in hospital are perceived to be in pain in the last few days of life:

'50% of patients were noted by clinicians to be in pain in the last 48 h (hours) of life. Mean pain score throughout admission for these that died was 2.69 on the PAINADⁱⁱ, in comparison to 1.49 for those who were discharged. Of those that died, 45% of carers were a little dissatisfied/ dissatisfied with the overall quality of care provided on the ward'.⁸³

Managing pain is more complicated for people with dementia and this means that people with dementia are more likely to experience inadequate pain management than people with some other terminal conditions⁸⁴.

It is also important that we consider whether the conceptions of pain which are used in palliative and end of life care are largely rooted in conditions such as cancer and whether we need to explore whether it is more appropriate to talk of pain and discomfort for people with dementia.

We need to build on existing expertise and resources such as the National Council for Palliative Care's [How would I know? What can I do?](#) guidance. We need to do this as part of wider work to increase awareness and understanding among health and social care professionals of pain and discomfort for people with dementia, particularly in the last few days of life, but also throughout the progression of their dementia.

Barriers: Inappropriate interventions

The use of aggressive treatment for people with dementia is common and can include tube feeding and antibiotic treatment for infections⁸⁵. Evidence suggests, however, that this treatment is inappropriate and does not improve survival⁸⁶. A study into family satisfaction with nursing home care suggested that aggressive treatments such as feeding tubes decreased satisfaction with care⁸⁷.

It would appear that such interventions are not what most families want or what their loved ones need. Families desired a focus on improving people's comfort and an increase in advance care planning, both of which could be provided under a palliative care approach⁸⁸. Palliative care is likely to be a more appropriate intervention for people at this stage.

Barriers: Failure to adapt practice to reflect the different nature of dementia

Many of the common practices and approaches which underpin good end of life care have been developed in response to conditions such as cancer and COPD. In most instances, individuals with such conditions retain an acute awareness of what is happening around them until a relatively late stage of their condition. They retain cognitive ability in respect of decision making, awareness of pain and of the responses of those around them. As we have seen, for those with advanced dementia this is rarely the case.

What is required is a fundamentally different approach to care for those people with dementia. For example, health and social care professionals are trained to routinely tell family and carers that the last of the senses to go prior to death is hearing and that the person can hear what they say to them. Such advice is often accompanied by a caution to avoid saying anything which might cause distress to the person.

ⁱⁱ Pain Assessment in Dementia Scale (PAINAD)

While a person with dementia will similarly retain the ability to hear family members, this does not mean that they have recovered the ability to comprehend what is being said to them, a faculty which may have been lost some months or years before. It is therefore important that health and social care professionals adapt their approaches and relevant practice to reflect the very different reality of dementia.

Barriers: Lack of support for carers

The characteristics of dementia include behavioural and personality changes, which can cause difficulties for those caring for people with dementia⁸⁹.

Those with moderate or advanced dementia can be physically aggressive, experience hallucinations, be agitated or anxious and have sleeping disorders⁹⁰. These symptoms can cause emotional and physical stress for the terminally ill person and carers⁹¹. People with dementia and their carers need specific support that may not be required by those with other terminal conditions. We need to improve the support available for those caring for people with dementia.

Families of those with dementia may also require a different type of bereavement support to those dying of some other conditions. While most people grieve after a person has actually died from a terminal illness, the families of those with dementia may experience different stages of loss as the condition progresses, for example when the person with dementia no longer recognises them⁹². Bereavement support needs to reflect this important difference.

Conclusion

An ageing population and the resulting projected growth in dementia will pose a particular set of challenges to the health and social care system in England over the coming decades. In order to meet these challenges we need to start removing the barriers which currently prevent people with dementia from accessing high quality end of life care.

The bottom line is that we will not be able to meet the needs of the growing number of people with dementia by continuing to provide care and support in the way that we do today. We need to recognise that dementia is a terminal condition and that people with dementia have very different needs and experiences to people with other terminal conditions.

Many of our responses to terminal illness and ultimately to death and dying have been shaped in response to cancer. The modern hospice movement, palliative care and even the criteria by which Continuing Healthcare (CHC) funding applications are considered to have been shaped in response to the needs and experiences of people with different forms of cancer.

Our challenge over the next decade is to build on the progress which has been made in many areas of the country in transforming core services so that they are able to respond to the needs of people with conditions such as dementia. This will require action across many different aspects of health and social care and the involvement of a number of organisations.

To this end, Marie Curie and the Alzheimer's Society are committed to working with a range of partner organisations to raise awareness and understanding of key aspects of dementia and end of life care and to address the barriers identified throughout this report.

We will do this over the coming months by bringing together people with direct experiences of caring for someone with dementia at the end of life and those who plan, design and provide care and support. This will include representatives of NHS organisations, both national and local commissioners, a range of Royal Colleges, charities, social care providers and those with expertise in hospice and palliative care.

Our task over the course of 2015 will be to identify the practical steps which will enable us to remove each of the barriers identified by this report. We will report back on progress and the practical steps which have been taken in December 2015.

Over the coming decades, a growing number of people will experience the different forms of dementia.

The challenge for society will be to ensure that these people are supported to live their lives as they want for as long as they can. And that, when they approach the last weeks and months of their lives, they are able to access the most appropriate care, advice and support.

To make this a reality we need to start redressing the balance now, and we must all play our part.

References

- ¹ Alzheimer's Society. What is dementia? Factsheet. 2012
- ² *ibid*
- ³ *ibid*
- ⁴ Sampson EL. Palliative care for people with dementia. *British Medical Bulletin*. 2010;96:159-174.
- ⁵ Alzheimer's Society. <http://tiny.cc/dementiainfo>
- ⁶ *ibid*
- ⁷ Dementia 2013 infographic <http://tiny.cc/dementia7>
- ⁸ Statistical bulletin: Deaths Registered in England and Wales (Series DR), 2013 <http://tiny.cc/dementia8>
- ⁹ Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*. 2004;19(10):1057-1063.
- ¹⁰ Statistical bulletin: Deaths Registered in England and Wales (Series DR), 2013 <http://tiny.cc/dementia10>
- ¹¹ Todd, S. Barr, S. and Passmore, A.P. Cause of death in Alzheimer's disease: a cohort study, *QJM: AN International Journal of Medicine*, 2013. <http://tiny.cc/dementia11>
- ¹² Office for National Statistics, 2011 Census: Digitised Boundary Data (England and Wales) UK Data Service Census Support. <http://edina.ac.uk/ukborders>
- ¹³ *ibid*
- ¹⁴ Xie & Brayne, Survival times in people with dementia, <http://tiny.cc/dementia14>
- ¹⁵ Alzheimer's Society. The progression of Alzheimer's disease and other dementias. <http://tiny.cc/dementia16>
- ¹⁶ *ibid*
- ¹⁷ *ibid*
- ¹⁸ Bayer A. Death with dementia – the need for better care. *Age and Ageing*. 2006;35:101-102.
- ¹⁹ Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*. 2004;19(10):1057-1063.
- ²⁰ Alzheimer's Society. Diagnosing Dementia. <http://tiny.cc/dementia24>
- ²¹ Alzheimer's Society (2013) <http://tiny.cc/dementia25>
- ²² Palliative care in dementia: issues and evidence, Julian C. Hughes, David Jolley, Alice Jordan and Elizabeth L. Sampson <http://tiny.cc/dementia26>
- ²³ Todd, S. Barr, S. and Passmore, A.P. Cause of death in Alzheimer's disease: a cohort study, *QJM: AN International Journal of Medicine*, 2013. <http://tiny.cc/dementia27>
- ²⁴ Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*. 2004;19(10):1057-1063.
- ²⁵ Katherine E Sleeman, Yuen K Ho, Julia Verne, Wei Gao, Irene J Higginson and on behalf of the GUIDE Care project Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001-2010 <http://tiny.cc/dementia29>

References

- ²⁶ *ibid*
- ²⁷ Engel SE, Kiely DK, Mitchell SL. Satisfaction with end-of-life care for nursing home residents with advanced dementia. *Journal of the American Geriatric Society*. 2006;54(10):1567-1572.
- ²⁸ Liz Sampson & Alastair Burns, Planning a personalised future with dementia: 'the misleading simplicity of advance directives' *Journal of Palliative Medicine*, May 2013 vol. 27 no. 5387-388 <http://tiny.cc/dementia32>
- ²⁹ *ibid*
- ³⁰ *ibid*
- ³¹ Goodman C, Amador S, Elmore N, Machen I. Preferences and priorities for ongoing and end-of-life care: A qualitative study of older people with dementia resident in care homes. *International Journal of Nursing Studies*. 2013 (in press).
- ³² Gill Livingstone, Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK, *BMJ* 2010; 341 doi <http://dx.doi.org/10.1136/bmj.c4184> (Published 19 August 2010) *BMJ* 2010;341:c4184 legal aspects of dementia
- ³³ Jacoby R. Ethical and. *Psychiatry*. 2007; 6(12):508-510
- ³⁴ Jacoby R. Ethical and. *Psychiatry*. 2007; 6(12):508-510
- ³⁵ Nuffield Council on Bioethics. Dementia: ethical issues. 2009
- ³⁶ Goodman C, Amador S, Elmore N, Machen I. Preferences and priorities for ongoing and end-of-life care: A qualitative study of older people with dementia resident in care homes. *International Journal of Nursing Studies*. 2013 (in press).
- ³⁷ Jacoby R. Ethical and legal aspects of dementia. *Psychiatry*. 2007;6(12):508-510
- ³⁸ *ibid*
- ³⁹ Sampson EL, Gould V, Lee D, Blanchard MR. Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing*. 2006;35(2):187-189.
- ⁴⁰ Lilin Zheng, Anne M. Finucane, David Oxenham, Peter McLoughlin, Hazel McCutcheon, Scott A. Murray <http://tiny.cc/dementia44>
- ⁴¹ NICE. Dementia: Supporting people with dementia and their carers in health and social care. National Institute for Health and Clinical Excellence. 2012.
- ⁴² *ibid*
- ⁴³ K Lord, N White, S Scott and E L Sampson, The Behaviour And Pain (Bepaid) Study: Dementia Patients Who Die In The Acute Hospital, 2013 <http://tiny.cc/dementia47>
- ⁴⁴ Broom A, Kirby E, Good P, Wootton J, Adams J, The art of letting go: referral to palliative care and its discontents. *Soc Sci Med*. 2013 Feb;78:9-16. doi: 10.1016/j.socscimed.2012.11.008. Epub 2012 Nov 15. <http://tiny.cc/dementia48>
- ⁴⁵ Rexach L. Palliative care in dementia. *European Geriatric Medicine*. 2012;3:131-140.
- ⁴⁶ Bayer A. Death with dementia – the need for better care. *Age and Ageing*. 2006;35:101-102.
- ⁴⁷ Robinson L, Hughes J, Daley S, Keady J, Ballard C, Volicer L. End-of-life care and dementia. *Reviews in Clinical Gerontology*. 2005;15:135-148.

References

- ⁴⁸ Katherine E Sleeman, Yuen K Ho, Julia Verne, Wei Gao, Irene J Higginson and on behalf of the GUIDE Care project Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001–2010 <http://tiny.cc/dementia52>
- ⁴⁹ Dylan Harris, Forget me not: palliative care for people with dementia <http://tiny.cc/dementia53>
- ⁵⁰ Robinson L, Hughes J, Daley S, Keady J, Ballard C, Volicer L. End-of-life care and dementia. *Reviews in Clinical Gerontology*. 2005;15:135–148. <http://tiny.cc/dementia55>
- ⁵¹ <http://tiny.cc/dementia55>
- ⁵² All Party Parliamentary Group on Parkinson's (2014), Failing to Care: NHS Continuing Care in England, <http://tiny.cc/dementia56>
- ⁵³ *ibid*
- ⁵⁴ *ibid*
- ⁵⁵ <http://tiny.cc/dementia59>
- ⁵⁶ Alzheimer's Society. Equality, discrimination and human rights <http://tiny.cc/dementia60>
- ⁵⁷ *ibid*
- ⁵⁸ *ibid*
- ⁵⁹ Bond J, Stave C, Vincenzino O, O'Connell B, Stanley RL. Inequalities in dementia care across Europe: key findings of the Facing Dementia Survey. *International Journal of Clinical Practice*. 2005;59:8–14.
- ⁶⁰ Alzheimer's Society. <http://tiny.cc/dementiainfo>
- ⁶¹ *ibid*
- ⁶² Connolly A, Sampson EL, Purandare N. End-of-life care for people with dementia from ethnic minority groups: a systematic review. *Journal of the American Geriatric Society*. 2012;60:351–360. <http://tiny.cc/dementia66>
- ⁶³ Katherine E Sleeman, Yuen K Ho, Julia Verne, Wei Gao, Irene J Higginson and on behalf of the GUIDE Care project Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001–2010 <http://tiny.cc/dementia67>
- ⁶⁴ Royal College of Physicians, Marie Curie, (2014) National Care of the Dying Audit for Hospitals, England <http://tiny.cc/dementia68>
- ⁶⁵ Alzheimer's Society, (2009) Counting the cost: caring for people with dementia on hospital wards <http://tiny.cc/dementia69>
- ⁶⁶ National Audit of Dementia Care in General Hospitals 2012–13: Second Round Audit Report and Update, <http://tiny.cc/audit1>
- ⁶⁷ <http://tiny.cc/dementia71>
- ⁶⁸ *ibid*
- ⁶⁹ *ibid*
- ⁷⁰ Sampson EL, Leurent B, Blanchard MR, Jones L, King M. Survival of people with dementia after unplanned acute hospital admission: a prospective cohort study. <http://tiny.cc/dementia74>. Sampson EL, Blanchard MR, Jones L, Tookman A, King M (2009). Dementia in the acute hospital: prospective cohort study of prevalence and mortality. *British Journal of Psychiatry*, 195(1), 61 – 66.

References

- ⁷¹ Katherine E Sleeman, Yuen K Ho, Julia Verne, Wei Gao, Irene J Higginson and on behalf of the GUIDE Care project, Reversal of English trend towards hospital death in dementia: a population-based study of place of death and associated individual and regional factors, 2001–2010 <http://tiny.cc/dementia75>
- ⁷² *ibid*
- ⁷³ Bayer A. Death with dementia – the need for better care. *Age and Ageing*. 2006;35:101-102.
- ⁷⁴ *ibid*
- ⁷⁵ Sampson EL, Gould V, Lee D, Blanchard MR. Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing*. 2006;35(2):187-189. Sampson et al 2009 and 2013
- ⁷⁶ *ibid*
- ⁷⁷ Southwest Dementia Partners, Improving Domiciliary Care for People with Dementia <http://tiny.cc/dementia81>
- ⁷⁸ Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*. 2004;19(10):1057–1063.
- ⁷⁹ Oosterman JM, Hendriks H, Scott S, Lord K, White N, Sampson EL. When Pain Memories Are Lost: A Pilot Study of Semantic Knowledge of Pain in Dementia. <http://tiny.cc/dementia83>
- ⁸⁰ *ibid*
- ⁸¹ Rexach L. Palliative care in dementia. *European Geriatric Medicine*. 2012;3:131-140.
- ⁸² *ibid*
- ⁸³ K Lord, N White, S Scott and E L Sampson, The Behaviour And Pain (Bepaid) Study: Dementia Patients Who Die In The Acute Hospital, 2013 <http://tiny.cc/dementia87>
- ⁸⁴ Sampson EL, Gould V, Lee D, Blanchard MR. Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing*. 2006;35(2):187-189.
- ⁸⁵ Candy, B. Jones, L. Sampson, E. Enteral tube feeding for older people with advanced dementia. <http://tiny.cc/dementia89>. Evers MM, Purohit D, Perl D, Khan K, Marin DB. Palliative and aggressive end-of-life care for patients with dementia. *Psychiatric Services*. 2002;53(5):609-613.
- ⁸⁶ *ibid*
- ⁸⁷ Engel SE, Kiely DK, Mitchell SL. Satisfaction with end-of-life care for nursing home residents with advanced dementia. *Journal of the American Geriatric Society*. 2006;54(10):1567-1572.
- ⁸⁸ *ibid*
- ⁸⁹ Rexach L. Palliative care in dementia. *European Geriatric Medicine*. 2012;3:131-140.
- ⁹⁰ *ibid*
- ⁹¹ *ibid*
- ⁹² Chan, Sampson, Jones and Livingston 2012 <http://tiny.cc/dementia96>. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*. 2004;19(10):1057–1063.

For more information

To learn more or speak to someone about this paper, please contact:

Sharon Manwaring
sharon.manwaring@mariecurie.org.uk
020 7091 4182

Martina Kane
martina.kane@alzheimers.org.uk

Marie Curie Cancer Care gives people with all terminal illnesses the choice to die at home. Our nurses provide them and their families with free hands-on care and emotional support, in their own homes, right until the end.

mariecurie.org.uk

Alzheimer's Society is the UK 's leading support and research charity for people with dementia, their families and carers.

alzheimers.org.uk

