

Living and dying with dementia in Scotland:

Barriers to care

Report
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Foreword

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

Progress has been made with the Scottish Government's two national dementia strategies, standards of care, post diagnostic support and a commitment to further work. However, more still needs to be done to ensure those with dementia at the end of life get the care that they need.

We hope that this report makes a contribution to how we address the challenge of improving care and support available to people with dementia at the end of life as well as their families. By focusing on the barriers we can begin to improve that care and ensure all those who might benefit from it receive it.

As a charity working to improve end of life care and strengthen the focus on dementia, we are committed to working with all those organisations which provide support and care to people in the final stages of the disease. This report sets out a series of principles which we believe should underpin high quality end of life care, no matter where it is delivered. We do recognise the successes that have been achieved in Scotland in supporting people with dementia, but we also highlight areas where improvements are needed. To that end, we have set out a number of recommendations, which we believe would help contribute to better care for people at the end of life with dementia.

Our 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
January 2015

Introduction

The [G8's dementia summit](#), held in London in December 2013, prompted a renewed focus on dementia. In particular it highlighted the challenge faced in the UK and globally from the projected '[explosion](#)' in dementia cases over coming decades.

Much of the focus of the summit and the resulting media coverage centred 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.

Contemporary debates about dementia, both in the UK and elsewhere, reflect the summit's focus, concentrating almost exclusively on early stages of the condition, on diagnosis and on the search for a cure. There is little reference to the final stages of the condition and the fact that dementia is a terminal condition.

Initiatives such as [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.

The Scottish Government and its partners have made good progress in caring for people with dementia. Scotland is currently implementing its second [National Dementia Strategy \(2013-16\)](#), which focuses on improving the quality, consistency and effectiveness of services for all types of dementia and at all stages of the illness, including end of life care.

End of life care is included in the [Standards of Care for Dementia in Scotland: action to support the change programme](#). The standards and accompanying framework outline the right to end of life care and the skills and knowledge health and social care staff should have when supporting people with dementia nearing the end of life.

However, overall there has been less of a focus on the inevitable conclusion of what is a progressive, terminal condition. Those with dementia will die and we must improve the care of people in the later stages. As it stands, the death and dying phase of dementia remains a largely overlooked aspect of what has previously been described as a '[silent epidemic](#)'.

This paper explores how we can ensure that there is a stronger focus on dementia as a terminal condition and the barriers which prevent many people 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

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. It also examines how we can reach those health and social care professionals who care for and support them. It focuses on what needs to improve in Scotland, drawing 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 symptoms³, 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 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, around 88,000 of whom live in Scotland⁵. The vast majority of those living with dementia are over the age of 65. There are, however, 3,197 people under 65⁶ with dementia in Scotland⁷.

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 condition⁸.

A recent cohort study in Northern Ireland concluded that:

'The cause of death documented for Alzheimer's disease (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'.⁹

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

In Scotland in 2013, 3,623 people had their death attributed to dementia and a further 1,196 had their deaths attributed to Alzheimer's. Of these, 1,434 were men and 3,385 were women. This represented 11.9% of all deaths for women in Scotland and 5.4% of men. This also represents a 4.6% increase in the number of deaths in total attributed to dementia and Alzheimer's from 2012 to 2013 in Scotland¹⁰.

The number of people in Scotland living with dementia is expected to double between 2011 and 2031¹¹ to over 160,000 people.

Dementia is therefore an important issue at the end of life for a growing number of people. According to the Scottish Government, in 2012 there were over 900,000 people living in Scotland over the age of 65: these individuals can be considered to be at the highest risk of developing dementia. This figure is set to rise in the future due to Scotland's rapidly ageing population. The Scottish Government's current projections suggest that the population will rise to 5.78 million by 2037, and that the population will age significantly, with the number of people aged 65 and over increasing by 59%, to 1.47 million.

Xie, Brayne et al (2008) estimate that one in three people over the age of 65 years who die will have some form of dementia¹².

As the proportion of the population aged 65 and over increases, so the number of people at risk of developing dementia increases. It is therefore 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 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 received¹³. 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 years¹⁴. Those diagnosed with vascular dementia can expect to live a shorter length of time after diagnosis – around five years¹⁵.

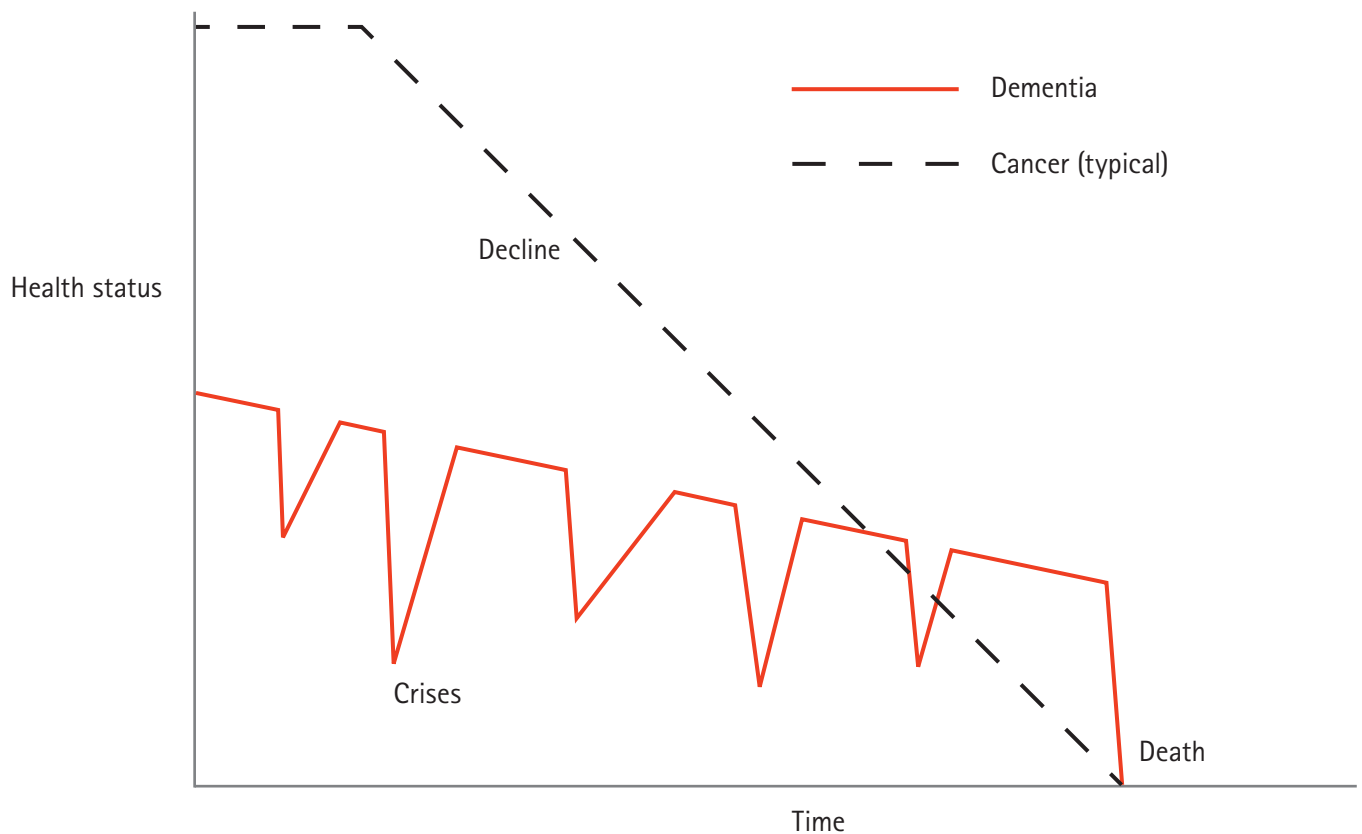


Figure 1. Terminal trajectory typical of cancer and dementia (adapted from Sachs, et al., 2004)

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 diagnosed¹⁶. Dementia's relatively long and unpredictable disease trajectory (see Figure 1¹⁷) 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.

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 symptoms¹⁹. 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 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, 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 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. Scotland's dementia diagnosis rate is higher than the other parts of the UK. In Scotland the estimated average rate of dementia diagnosis is 64% (56,320 people with dementia diagnosed) compared to England where the estimated rate is 48%²¹. This is a mark of progress in Scotland, but there is still further work needed to sustain and improve this figure. A new standard has been introduced in

Scotland to maintain the proportion of people with a diagnosis of dementia on the Quality and Outcomes Framework (QOF) dementia register and other equivalent sources.

Timely diagnosis has a major potential impact on subsequent access to support, treatment and appropriate care. In Scotland, everyone diagnosed with dementia from 1 April 2013 is entitled to a minimum of one year's worth of post-diagnostic support, coordinated by a link worker.

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

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 is likely to 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. Over the same period in Scotland the number of cases where cause of death was recorded as vascular dementia, unspecified dementia or Alzheimer's disease also almost doubled from 3.7% in 2001 to 6.3% in 2010²⁶. This further rose in Scotland to 8.8% in 2013.

However, as around 850,000 people live with dementia in the UK, around 88,000 of whom live in Scotland, it is clear that there is still work to be done to improve death certification processes. Sleeman et al (2014) argue that 'improved death certification is essential to fully understand place of death in dementia'²⁷.

Following a review in 2011, the Scottish Parliament passed the Certification of Death (Scotland) Act 2011 to improve the accuracy of

death certification in Scotland. This introduced the setting up of a new national review system, and created the roles of Medical Reviewers and a national Senior Medical Reviewer. These new positions aim to improve the accuracy of death certificates by conducting reviews of Medical Certificates of Cause of Death (MCCDs) and provide training, guidance and support to doctors who certify the cause of death. From April 2015, Healthcare Improvement Scotland will implement the Death Certification Review programme and run the service, with the review of MCCDs carried out by experienced and trained doctors.

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 conditions²⁸. This is supported by evidence from the UK²⁹.

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 situation³⁰. Further, it is suggested that preferences change as the condition progresses³¹.

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 outcome³². 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'³³.

In Scotland, the wishes of a terminally ill person can also be expressed in the form of advance statements. There are two types of advance statements. The first is a general advance statement and the second is only for treatments if a person becomes mentally unwell and needs to receive compulsory treatment under the Mental Health (Care and Treatment) (Scotland) Act 2003.

A general advanced statement, sometimes described as a 'living will', can be developed to record a patient's wishes over their physical care and most of their dementia care. They can also make an advanced statement concerning compulsory treatment for the future.

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

In Scotland, a person with dementia may also nominate a 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 caregivers will usually be discussed with the relevant health professionals and a consensus reached on the best way to proceed³⁸.

Theme two: Inequality of access

Barriers: Poor access to palliative care

As discussed above, 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 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 can largely be found in the roots of the modern hospice and palliative care movements which 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 homes.

In Scotland, the Scottish Government has published Standards of Care for Dementia in Scotland⁴¹, which has been developed by the Mental Welfare Commission for Scotland. These standards, underpinned by the Charter of Rights for People with Dementia and their Carers in Scotland, include the right to end of life care that

respects the wishes of a person with dementia. This states 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**
- **receive the support they need to die with dignity and in the place of their choosing wherever possible**
- **receive care towards the end of life that respects their previously expressed wishes**

And people with dementia will not:

- **experience inhuman or degrading treatment at the end of their life**

The standards set out requirements on NHS Boards, local authorities and other care providers to ensure that palliative and specialist palliative care is provided in a variety of settings including hospitals, care homes and a person's own home. It also states that people with dementia should receive:

- **a multi-disciplinary assessment advice and support on advanced care planning, including instructions about resuscitation**
- **pain relief and support**
- **respect for their faith and cultural preferences**
- **care and support in the last days and hours of life**
- **support to family and carers, as well as bereavement support for the family**

To date there has been little assessment or audit carried out against some of these standards. This has made it difficult to understand what progress is being made in Scotland in end of life care for people with dementia beyond that the vast majority of dementia patients are not accessing palliative care.

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 dementia⁴².

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.

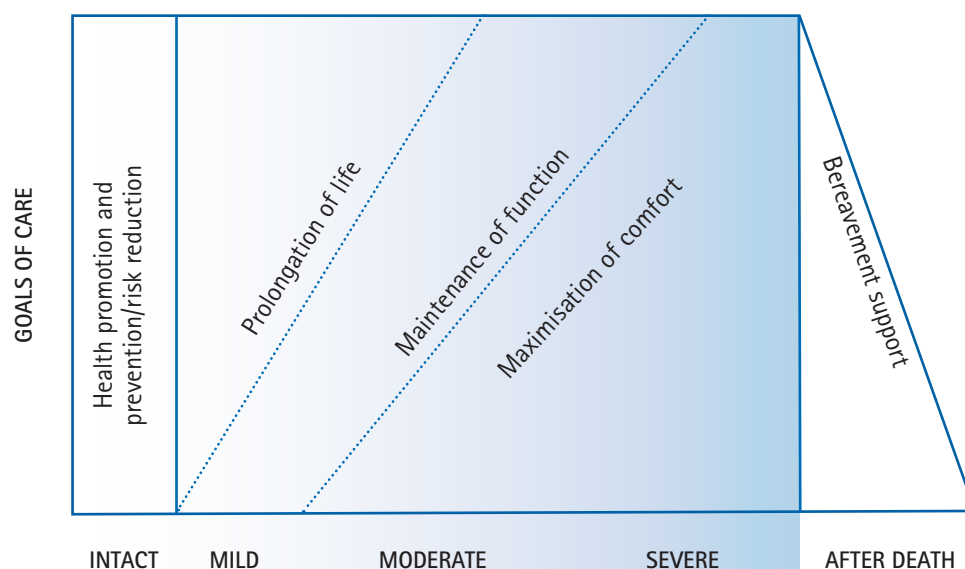
It is therefore vital that we enhance the role of palliative care for people with dementia, not just in the last few days of life, but much earlier in the development of the condition because of its emphasis on symptom management.

We need to ensure that examples of excellent links between local palliative care services and care homes and hospital services are replicated across the UK and potentially over a much longer time period. We also need to ensure that those people in the last days of life, whether they are in their own home, care home or in hospital can access palliative care specialists who can 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. As previously noted, decision making about the move from active treatment to palliative care is complex⁴³. For people with dementia there is usually no equivalent conversation which someone with cancer may have with an oncologist about the transition from active treatment to palliative care. The degenerative nature of 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 death⁴⁴.

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



Barriers: Access to hospice care

The picture of poor 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 hospice⁴⁵. In 2005, less than 2% of hospice in-patients had a primary diagnosis of dementia⁴⁶. Sleeman et al found that in England just 0.3% of people whose cause of death included a reference to dementia died in a hospice⁴⁷. This reflects the wider picture of hospice use which is still dominated 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 them to hospices and palliative care teams when there is no further active treatment? 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 differing needs of those with the condition, it is perhaps not surprising that there are relatively few dementia specialists working in palliative care settings⁴⁸. 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 will require 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 partly explain why people in the latter stages of dementia rarely use hospice services⁴⁹. 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 communicate 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 those commissioning services to prioritise end of life care focused on dementia, resource it fully and encourage the development of hospice care principles within local care homes.

Barriers: Access to funding

Access to funding for those approaching the end of life can be complex. In Scotland, healthcare is free, as is personal and nursing care for those over 65 years of age. For those diagnosed with dementia under 65, there have been issues around accessing personal care. However, the Scottish Government has committed to ensuring that all those with early onset dementia will get free personal care when they need it.

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.

In Scotland, the majority of NHS continuing care beds are for dementia patients⁵⁰. There are around 1,500 NHS or NHS-paid-for dementia continuing care or dementia specialist beds.

This complex care is currently provided in a number of hospital and community settings. The Scottish Government recently accepted the recommendations of an independent review of NHS continuing care, which proposed that the NHS will only pay for the accommodation costs of patients in NHS hospitals and NHS nursing homes⁵¹.

This means that those receiving complex care in other settings, such as care homes, will be required to pay their accommodation costs. Although the Government has committed to maintaining the existing arrangements for patients currently receiving continuing care, the new arrangements will come into force from 1 April 2015. This could result in many dementia patients being forced to pay for home costs or possibly move into unsuitable and unfamiliar NHS facilities in order to ensure they do not pay costs they cannot afford.

Barriers: Discrimination

The Alzheimer's Society has previously argued that people with dementia face discrimination in care they are given due to a lack of targeted services and variation in standards of care⁵². 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 old⁵³.

It has also been suggested that those with dementia have poorer access to mental health services compared with younger people with mental health conditions⁵⁴. Older people with dementia may, therefore, not be getting optimum care simply because of their age. Dementia also affects people's ability to defend themselves against discrimination⁵⁵, 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 usually targeted at older people and there could be a risk of younger people with dementia being excluded. Around 3,200 people aged under 65 are living with early-onset dementia in Scotland⁵⁶. 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 support⁵⁷. More 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 also face a 'double disadvantage'⁵⁸. Marie Curie commissioned research by Kings College London into 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

Nearly 60% of Scottish people die in hospital. Almost 30% of people in hospital at any one time are in their last 12 months of life⁵⁹. It is likely that many people with dementia are spending some of their last 12 months of life in hospital and many will be dying there. It is not only crucial that people receive care that is appropriate to their needs, but that they receive that care in an appropriate setting. This raises the question of whether they should be in hospital at all.

In Scotland the chief nursing officer is leading a programme of improvement activity with NHS Boards and others involved in the care of older people, including those with dementia in hospital settings. Improving care in acute hospital settings was a key element of the first national dementia strategy – along with improving diagnosis and post-diagnostic support. The Standards of Care for Dementia in Scotland, published in 2011, and the 10 Care Actions identified in the 2013-16 National Dementia Strategy, have been used to support inspection regimes. There has, however, been little national data collected to show signs of progress against the standards and actions.

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 dementia⁶⁰. A report published earlier this year has found that the introduction of dementia champions and nurses has already led to improvements in approach and culture of care in acute settings⁶¹.

However, a key problem appears to be the inadequate identification of dementia when people with dementia are admitted to hospital.

Barriers: Inappropriate hospital admissions

People with dementia are more likely to be admitted to hospital compared with older people who do not have dementia⁶². There is, however, little data to highlight the full extent of the problem in Scotland.

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 dementia⁶³.

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.

In Scotland the 8 Pillars Model of Community Support, developed by Alzheimer Scotland, sets out an integrated and comprehensive, evidence-based approach to supporting people with dementia living at home during the moderate to severe stages of the illness. This model is designed to support NHS Boards and local authorities to provide integrated care, and allowing people to stay at home or in their communities for as long as possible. This model is currently being piloted in five areas in Scotland.

In England, 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%)⁶⁴. This compares with just 4.8% who died at home and 0.3% in hospices⁶⁵. Although there is no data to show the same in Scotland we would expect to see a similar picture. 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, such as a care home. Research indicates that patients' families would also prefer this⁶⁶. However, a significant proportion of people with dementia are likely to die in hospital⁶⁷. 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 admission⁶⁸.

Barriers: Lack of continuity of care

Continuity of care is extremely important as changes in health or social care staff can create unnecessary distress⁶⁹. It is clear that familiarity benefits both the person with the dementia (and their family) and those providing care, by helping people to stay in their own homes for longer⁷⁰.

Similarly, unnecessary transfers from a person's usual place of residence can have a disconcerting impact, causing confusion and increasing uncertainty. As most people wish to die 'at home', investment in care in their usual place of residence and enabling people to die there is potentially most beneficial.

Work is also needed to ensure that nursing and care home staff, social care and local GPs are confident about working with people with dementia. They should be 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.

The first pillar of the 8 Pillars Model is a Dementia Practice Coordinator. Each person with dementia will be accompanied throughout their journey by a coordinator who will provide an individualised approach to lead the care, treatment and support of the person and their carer. They will be an appropriately skilled worker with the ability to provide, commission and control interventions⁷¹. It is hoped that these coordinators will help address some of the continuity of care issues identified.

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 do⁷². Researchers have shown that as dementia progresses, people become less able to identify pain. They conclude that clinicians should bear this in mind when assessing patients with dementia for pain⁷³.

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 correctly⁷⁴. As the disease progresses, reporting of pain by the person generally decreases and becomes less accurate⁷⁵.

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 PAINADi, 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'.⁷⁶

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 conditions⁷⁷.

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

We need to build on existing expertise and resources such the National Council for Palliative Care's *How would I know? What I can 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. This is particularly relevant in the last few days of life, but also throughout the progression of their dementia.

In Scotland, *Good Life, Good Death, Good Grief* also provides a range of information and online resources to support professionals.

Barriers: Inappropriate interventions

The use of aggressive treatment for people with dementia is common and can include tube feeding and antibiotic treatment for infections⁷⁸. Evidence suggests, however, that this treatment is inappropriate and does not improve survival⁷⁹. A study into family satisfaction with nursing home care suggested that aggressive treatments such as feeding tubes decreased satisfaction with care⁸⁰.

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 approach⁸¹. Palliative care is 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 chronic obstructive pulmonary disease (COPD). In most instances, people 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.

A fundamentally different approach is required to care for 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.

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 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 dementia⁸².

Those with moderate or advanced dementia can be physically aggressive, experience hallucinations, be agitated or anxious and have sleeping disorders⁸³. These symptoms can cause emotional and physical stress for the terminally ill person and their carers⁸⁴. 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 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 them⁸⁵. 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 Scotland 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 and palliative care approach 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 Scotland in the care of people with dementia. We recognise that significant work has been done by the Scottish Government and others in developing two national dementia strategies. There has also been success with the development of post-diagnostic support. We also recognise that further work is ongoing and in development. However, there now needs to be a greater focus on those with dementia who are approaching the end of their lives.

We ask the Scottish Government to consider a number of recommendations:

- **Make end of life care for people with dementia a core part of its third national dementia strategy starting in 2016.**
- **Ensure the Scottish Government's planned Strategic Framework for End of Life Care focuses on ensuring that all people who might benefit from palliative care are accessing it regardless of diagnosis.**
- **Focus on collecting robust data to ensure there is a clear national picture of the level and quality of care being received by those with dementia at the end of life.**

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

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