

Living and dying with dementia in Northern Ireland:

Barriers to care

Report
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Foreword

Dementia is increasingly an issue of 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 the UK. Here in Northern Ireland, there are estimated to be nearly 20,000 people living with dementia and, of these, only 64.8% have been diagnosed.

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 in Northern Ireland have come together to write this report. We believe this 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 it.

As national charities working to improve care for people with a terminal illness and strengthen the focus on dementia, we are committed to providing leadership and to sharing insight and expertise with other organisations which provide support and care to people in the final stages of dementia, and their families. This report sets out a series of principles which we believe should underpin high quality end of life care, wherever it is delivered.

Over the coming months, we propose to 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 can work towards removing the barriers which currently prevent people with dementia and their families from accessing the highest quality care and support. Our collective goal is to ensure that everyone in Northern Ireland, regardless of their condition, where they live, or the services they use, gets the best possible care and support at the end of life.

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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 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.

The focus and subsequent media 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 illness.

Initiatives such as [The Prime Minister's Dementia Challenge](#) and [Dementia Friends](#) have helped to strengthen public focus on the need to enable people with dementia to live well for as long as they can. In February 2014 the Alzheimer's Society's [Dementia Friendly Communities Programme](#) in Northern Ireland secured commitment from more than a third of all members of the Northern Ireland Assembly to support the creation of dementia friendly communities through their work.

Northern Ireland's Dementia Strategy, [Improving Dementia Services in Northern Ireland \(2011\)](#) recommends building dementia specific requirements into the palliative and end of life care strategy for Northern Ireland¹.

The Dementia Strategy also gives Health and Social Care Trusts the lead in developing services for people with dementia and, whilst much work has been done, more focus is needed on the later stages of dementia as a serious, progressive and terminal condition. 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 end of life stage of dementia remains the forgotten aspect of what has previously 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 on the barriers which prevent many people with dementia in Northern Ireland from accessing and receiving appropriate high quality care at the end of their lives. There are three key barriers:

- 1) Identification and planning: People with dementia are not being appropriately identified for end of life care.**
- 2) Inequality of access: People with dementia have less access to care than people with other terminal illnesses.**
- 3) Quality of care: people with dementia receive poorer quality care than people with other terminal illnesses.**

It also explores how we can improve the care and support for people who are living and dying with dementia, and their families, carers and relevant health and social care professionals. It focuses on what needs to change in Northern Ireland and 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 dementia². Throughout the remainder of this paper, dementia is used as a shorthand term for this broad range of conditions.

Dementia is a progressive neurodegenerative disease. This means that the symptoms become more severe over time. Symptoms can include memory loss, confusion, speech difficulties, mood and behavioural changes³ and problems with self-care and other aspects of daily living. There are some treatments to alleviate the symptoms,⁴ but there is no cure for dementia and it is a terminal illness.

The final stage of dementia is comparable with other terminal illnesses as the prognosis is often similar⁵. 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 nearly 20,000 of these live in Northern Ireland.

Across the UK, the vast majority (almost 95%) of those living with dementia are over the age of 65.⁶ There are, however, 42,325 people under 65 who have dementia⁷. Dementia also has an interesting gender profile – two thirds of people with dementia are women.⁸ 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 co-existing condition.⁹ In Northern Ireland in 2013, 954 women and 451 men had their death attributed to dementia or Alzheimer's.

In the UK 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 men.¹⁰

A recent cohort study in Northern Ireland concluded that:

'The cause of death documented for dementia 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, across the UK, the number of deaths from dementia is currently being significantly 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'.

Dementia is therefore an important issue at the end of life for a growing number of people in Northern Ireland. According to the 2011 census, there were around 8.5 million people living in the UK over the age of 65, of whom 263,700 live in Northern Ireland. These individuals can be considered to be at the highest risk of developing dementia¹².

This figure is set to rise in the future because Northern Ireland has a rapidly ageing population. In addition, the number of people aged over 75 in Northern Ireland is expected to increase by 40% by 2020, and the number of people aged over 85 is expected to increase by 58%¹³.

Over the next 40 years, as our society ages, dementia will become more common in Northern Ireland. An ageing population could see the numbers of people diagnosed with dementia rising to around 60,000 by 2051¹⁴. As our society ages, health and social care expenditure on services for people with dementia could be expected to double within 20 years¹⁵. In 2013/14, the cost of acute care (in-patient and day case only) for people with dementia in Northern Ireland was £913,091¹⁶.

Moreover, according to the Office for National Statistics, the number of dementia related deaths in Northern Ireland is predicted to increase by 29% by 2037 from that in 2014¹⁷.

As the proportion of the population aged 65 and over increases, so too does the number of people at risk of developing dementia. For example, the Alzheimer's Society estimates that by 2021, the number of people (both diagnosed and undiagnosed) in Northern Ireland will reach 24,980.¹⁸ 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 complex nature of dementia and the fact that 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 received¹⁹. 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 years²⁰.

Those diagnosed with vascular dementia can expect to live a shorter length of time after diagnosis – around five years²¹.

The period for which a person with dementia might require care is long compared with a number of other terminal illnesses, most notably cancer. 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. It is important they are well coordinated and aligned with social and palliative care services so that an individual can routinely access palliative care, regardless of where they live.

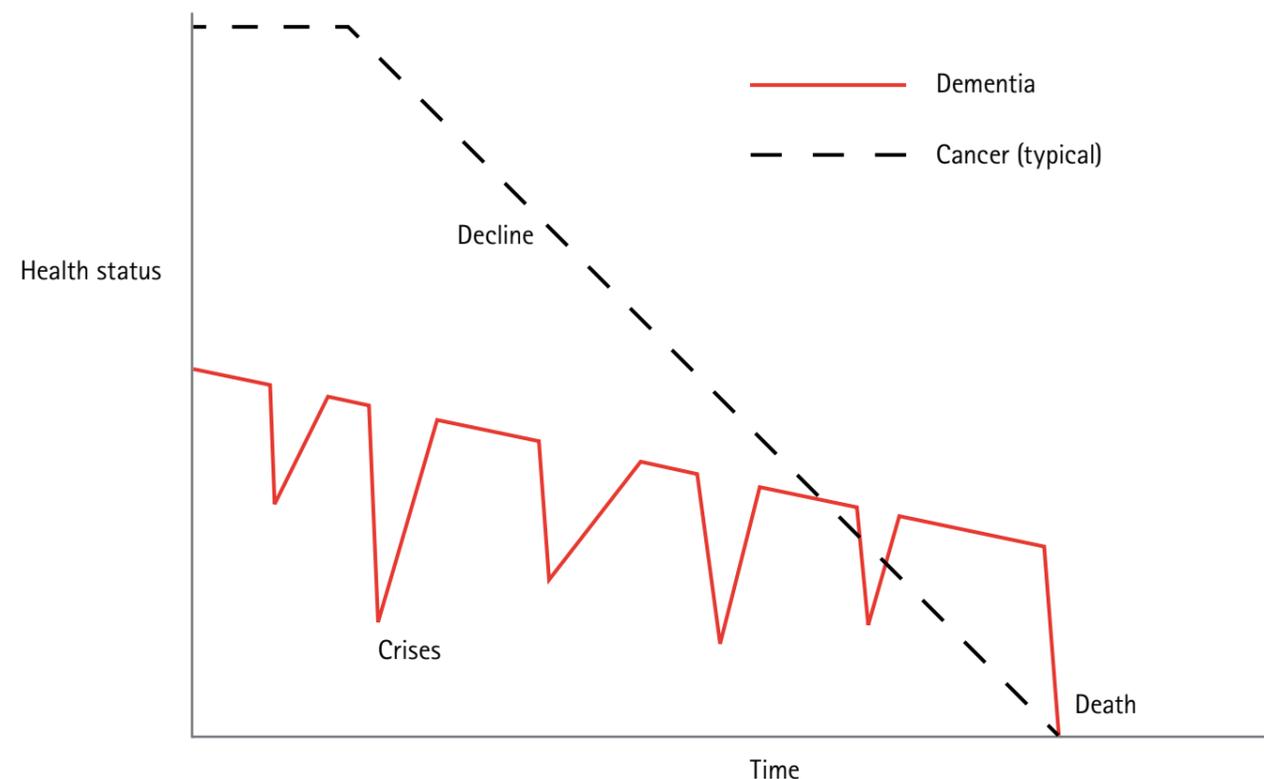


Figure 1 Terminal trajectory typical of cancer and dementia (adapted from Sachs, et al., 2004)

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

The length of time a person can expect to live with dementia also depends on the stage the disease has reached when they are diagnosed²². Dementia's relatively long and unpredictable disease trajectory (see Figure 1²³) 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 period²⁴.

There is a growing evidence base which suggests that people with dementia in Northern Ireland are prevented from accessing and receiving appropriate high quality care at the end of their lives. This has highlighted three key barriers which relate to identification and planning, inequality of access and quality of care (see page 4).

These 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 help²⁵. In the earliest stages, symptoms such as confusion and memory loss may be dismissed by patients, 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 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 with the Northern Ireland average of 64.8% comparing relatively well with that of England, estimated to be in the region of 48%. However, it still leaves close to 7,000 people with dementia in Northern Ireland without a diagnosis and considerable diversity of diagnosis across Health and Social Care Trusts. A Northern Ireland study of GPs' perspectives of the barriers and solutions to good quality palliative care in dementia included a lack of knowledge and understanding of dementia amongst clinicians²⁶.

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 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 with dementia have, historically, not had access to specialist palliative care.²⁷ In 2004, the World Health Organization (WHO) found that fewer 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 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 certificates²⁸. The underlying cause of death is often attributed to an infection or other common illness and is stated as such when the death is formally registered²⁹.

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 heart stops. 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.

Barriers: Ineffective advance care planning

Once a person is identified as having a terminal illness, advance care planning is crucial. This is particularly important for people with dementia and other degenerative cognitive conditions, who may gradually lose capacity to make decisions as their condition progresses. However, the reality is that for many people with dementia, advance care planning can be problematic. A study from the US indicates that people with dementia were less likely to have advance care directives than people with other conditions³⁰. This is supported by evidence from the UK.³¹

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 situation.³² Further, it is suggested that preferences change as the condition progresses.³³ 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 outcome³⁴. 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.³⁵

The wishes of a terminally ill person can also be expressed in the form of advance directives or 'living wills'. In England and Wales, the Mental Capacity Act (2005) makes legally binding provision for advance directives/decisions which detail a person's express wishes relating to care and treatment in specific circumstances.

The Mental Capacity Act (2005) does not extend to Northern Ireland, however a draft Mental Capacity Bill relating to decision making is expected to become law during the course of the current Assembly term, at the time of writing.

Advance directives are currently part of common law in Northern Ireland and may not be included in the Mental Capacity Bill statute. This could mean a reduced use of advance decisions/directives and it could inhibit the advance care planning process.

In the absence of advance instructions, decision making ultimately sits with healthcare professionals, who must ensure that the treatment is necessary either to save the person's life or to prevent a serious deterioration in health and must be in the patient's best interests. In a joint statement from Edwin Poots, then Health Minister, and Justice Minister David Ford in May 2014, it was stated that the draft Mental Capacity framework for Northern Ireland would include:

'Putting on a statutory footing the common law doctrine of necessity which applies where a decision needs to be made about the care, treatment or personal welfare of a person lacking capacity and no alternative decision making arrangements have been put in place by the person. The provision will provide those carrying out health and welfare interventions with protection against civil and criminal liability provided they have properly established that the person concerned lacks capacity, they act in the person's best interests, and other applicable safeguards are met.'³⁶

Theme two: Inequality of access

Barriers: Poor access to palliative care

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 would 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'³⁷.

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 cancer.³⁸

This data chimes with the widely held perception that palliative care services have historically failed to reach a significant number of people with dementia³⁹. The reasons for this can largely be found in the roots of the modern hospice and palliative care movement which was developed in response to the needs of people with cancer.

The National Institute for Health and Clinical Excellence has produced guidelines on dementia care including palliative and end of life care for people with dementia. 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.'⁴⁰

Importantly, palliative care is identified as a valid treatment approach for individuals with dementia from the point of diagnosis.

In its vision statement, [Living Matters; Dying Matters](#), the palliative and end of life care strategy for Northern Ireland, states that:

'Any person with an advanced, non-curative condition lives well and dies well irrespective of their condition or care setting.'⁴¹

Elsewhere in the UK, Standards of Care for Dementia in Scotland (published in 2011) 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 life⁴². In Northern Ireland, currently there are no dementia specific standards for care in any care setting and these must be developed.

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 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, their 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

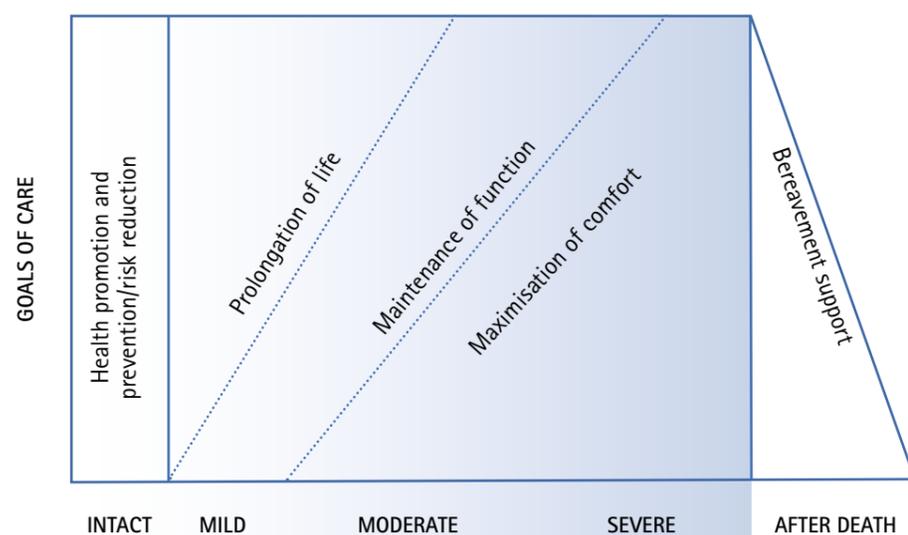
similarly well developed. There may be additional barriers in the divide between providers of health and social care. As previously noted, decision making about the move from active treatment to palliative care is complex.⁴³ For people with dementia there is usually no single point equivalent to the conversation which someone with cancer may have with an oncologist about the transition from active treatment to palliative care. We have to find a way to better identify people with dementia at the point at which they need support 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.

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, fewer than 2% of hospice in-patients had a primary

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



diagnosis of dementia.⁴⁶ Sleeman et al found that in England just 0.3% of people whose cause of death included a reference to dementia died in a hospice.⁴⁷ This reflects the wider picture of hospice use which is still most commonly perceived to apply to people with cancer.

It is important that we explore why hospice use is so low for people with a dementia diagnosis.

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 task as hospices.

Given the complex 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 settings.⁴⁸ 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 design 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 additional confusion and distress at a stage in the disease when the person may be less able to cope with change. This may partly explain why people in the latter stages of dementia rarely use hospice services⁴⁹.

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 dementia focused end of life care, resource it fully and encourage the development of hospice care principles within local care homes.

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.

As their dementia progresses people 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 NHS Continuing Health Care (CHC). 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 CHC⁵⁰. In Northern Ireland approaches to funding CHC even vary across Health and Social Care Trusts.

The recent Age NI report [The Denial of Continuing Healthcare in Northern Ireland](#), illustrates the detrimental impact of the absence of guidance or clarity in the provision of CHC in Northern Ireland. The report includes the response from the then Health Minister's office to an Age NI request for clarification on CHC in Northern Ireland, which includes the view that drafting guidance would be 'to interfere unnecessarily with professional and clinical judgement'⁵¹.

The lack of clarity or transparency around NHS-funded CHC eligibility produces considerable confusion for those who are responsible for assessing need and those who might and do apply for it. The experience of seeking CHC funding can be harrowing and the outcomes are unsatisfactory for many service users and their carers and families. Those effects are aggravated for a person with dementia, as their condition becomes more marked. Their health will deteriorate and they will have increasing health and social care needs, requiring a greater degree of personal care as well as specific healthcare services, all of which are directly attributable to their dementia.

Though people in the later stages of dementia will have considerable health needs, their access to NHS-funded CHC does not appear to reflect the situation.

There are serious questions about who carries out the CHC 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 dementia? There are clear issues relating to training and understanding of specific conditions and involvement of appropriate health 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.

Barriers: Discrimination

The Alzheimer's Society has argued that individuals with dementia face discrimination in the care they receive because there is a lack of targeted services and care standards vary across care providers⁵².

The Alzheimer's Society argues that those with dementia may experience 'poor rates of diagnosis and a lack of appropriate services' because dementia occurs at a later stage in life and is sometimes wrongly 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 ageist attitudes. Furthermore, dementia may affect a person's ability to challenge discrimination⁵⁵, which may go uncontested.

Conversely younger people with dementia may also experience disadvantage in terms of access to dementia services. Since most people with dementia are aged over 65, services are targeted at older individuals and there could be a risk of younger people with dementia being excluded. There are estimated to be over 1,140 people in Northern Ireland (from a UK total of 42,000) with early-onset dementia⁵⁶. Specialist services for younger people with dementia are rare, and dementia services targeted at older people may not be appropriate for them - which means it can be difficult for younger people to access help⁵⁷. There is a need to ensure dementia services targeted at young people are in place so that these people get the support they require and are not excluded from services because of their age.

Connolly et al have suggested that people with dementia who are from minority ethnic groups might face a 'double disadvantage'⁵⁸. Marie Curie commissioned research by Kings College London into the Palliative and end of life care for Black, Asian and Minority Ethnic (BAME) 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

On any day in Northern Ireland, a sizeable proportion of those living with dementia are in acute hospitals, often staying for longer than other people⁵⁹. The Alzheimer's Society's Counting the Cost report (2009) shows that in England, Wales and Northern Ireland, it was estimated that people with dementia over 65 years of age account for 25% of hospital beds at any one time and, when admitted because of another condition, spend longer in hospital than those with the same condition who don't have dementia.⁶⁰

A number of studies in England have identified the considerable variation in care on offer for people with dementia in hospitals.

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 dementia.⁶¹

A key problem appears to be the inadequate identification of dementia when people with dementia are admitted to hospital. A Care Quality Commission review of hospital episode data in England found that in 29% of cases a person's dementia was not recorded, despite having been recorded during previous admissions.⁶²

As the Care Quality Commission notes:

'An NHS Confederation briefing on dementia in England 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.'⁶³

Barriers: Inappropriate hospital admissions

According to a Care Quality Commission update, people with dementia in care homes are more likely to experience inappropriate admissions to hospital:

'In more than half (78 out of 151) of Primary Care Trust areas, people in care homes with dementia were admitted to hospital with "avoidable conditions" significantly more than people without dementia.'⁶⁴

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. 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 dementia⁶⁵. In addition, in 2013/14, 86% of all dementia admissions to hospital in Northern Ireland were emergency admissions⁶⁶.

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. Improved and increased training and awareness on dementia in the care home setting could also help to address unnecessary admissions to hospital for people with dementia at the end of life, where an infection could readily be identified and treated within the care home. With almost half of people in Northern Ireland with dementia living in care homes⁶⁷, any additional training and support for care home providers could substantially reduce inappropriate admissions for people with dementia.

It is also important that we learn from those many care homes which are providing appropriate 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.

In Northern Ireland in 2013, out of a total of 1,403 deaths registered with underlying cause of death of Alzheimer's or dementia, 29% people died in hospital, 60% in nursing homes and 10% at home⁶⁸. This clearly demonstrates 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 this⁶⁹. However, a significant proportion of people with dementia are likely to die in hospital⁷⁰. 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 admission⁷¹.

Barriers: Lack of continuity of care

Continuity of care is extremely important as changes in health or social care staff can create unnecessary distress⁷². 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 longer.⁷³

Similarly, unnecessary transfers from an individual's usual place of residence can have a disconcerting impact, causing confusion and exacerbating 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.

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 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 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.

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 do⁷⁴. 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.'⁷⁵

They conclude that clinicians should bear this in mind when assessing patients with dementia for pain.⁷⁶

Health professionals tend to have to rely on close observation of changes in people's behaviour to identify the level of pain they are experiencing and to manage it correctly.⁷⁷ As the dementia progresses, reporting of pain by the person generally decreases and becomes less accurate⁷⁸.

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 PAINAD*, 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.'⁷⁹

Managing pain is more complicated for people with dementia and this means they are more likely to experience inadequate pain management than people with some other terminal conditions.⁸⁰

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 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 as 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, 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 advanced dementia is common and can include tube feeding and antibiotic treatment for infections⁸¹. Evidence suggests, however, that this treatment is inappropriate and does not improve survival⁸². A study into family satisfaction with nursing home care suggested that aggressive treatments such as feeding tubes decreased satisfaction with care⁸³. It would appear that such interventions are not what most families want nor do they benefit the person with dementia. Families desired a focus on improving patient comfort and an increase in advance care planning, both of which could be provided under a palliative care strategy⁸⁴. Palliative care is a more appropriate intervention for people at this stage.

*Pain Assessment in Dementia Scale (PAINAD)

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.

What is required is a fundamentally different approach 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 dementia⁸⁵.

Those with moderate or advanced dementia can be physically aggressive, experience hallucinations, be agitated or anxious and have sleeping disorders⁸⁶. These symptoms can cause emotional and physical stress for the terminally ill person and their carers⁸⁷. People with dementia and their carers can have some very specific support needs which those affected by other terminal conditions do not have. For this reason it is essential that people have appropriate and timely referral to organisations which provide dementia-specific support services which are tailored to their particular needs.

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 them⁸⁸. 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 Northern Ireland 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 largely 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 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 in Northern Ireland are committed to working with a range of partner organisations, including representatives from the statutory and voluntary sectors, to raise awareness and understanding of key aspects of dementia and end of life care and to address the barriers identified throughout this report.

Our task over the course of 2015 and beyond will be to take action to address these barriers. 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 wish 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 help them to do this.

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

References

- 1 DHSSPS. Improving Dementia Services in Northern Ireland: A Regional Strategy. 2011. <http://tiny.cc/Nlstrat>
- 2 Alzheimer's Society. What is dementia? Factsheet. 2012
- 3 *ibid*
- 4 *ibid*
- 5 Sampson EL. Palliative care for people with dementia. *British Medical Bulletin*. 2010;96:159-174.
- 6 Alzheimer's Society. Dementia 2014 infographic, text only version. <http://tiny.cc/dementiainfo>
- 7 *ibid*
- 8 Dementia 2013 infographic <http://tiny.cc/dementia7>
- 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 AP. 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 Health and Social Care Board. Transforming Your Care: A Review of Health and Social Care in Northern Ireland. 2011.
- 14 DHSSPS. Improving Dementia Services in Northern Ireland: A Regional Strategy, 2011. <http://tiny.cc/Nlstrat>
- 15 *ibid*
- 16 DHSSPS. Hospital Information Branch
- 17 Office for National Statistics: Interactive Download Table Tool – National Population Projections (2012-based). <http://tiny.cc/popstats>
- 18 Alzheimer's Society. Mapping the Dementia Gap 2013
- 19 Alzheimer's Society. The progression of Alzheimer's disease and other dementias. <http://tiny.cc/dementia16>
- 20 *ibid*
- 21 *ibid*
- 22 *ibid*
- 23 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.
- 24 Bayer A. Death with dementia – the need for better care. *Age and Ageing*. 2006;35:101-102.
- 25 Alzheimer's Society. Diagnosing Dementia. <http://tiny.cc/dementia24>
- 26 Carter G, Galway G, van der Steen J and Brazil K. GPs' Perspectives of the Barriers and Solutions to Good Quality Palliative Care in Dementia. 2014.
- 27 Hughes JC, Jolley D, Jordan A and Sampson EL. Palliative care in dementia: issues and evidence, <http://tiny.cc/dementia26>
- 28 Todd S, Barr, S and Passmore AP. Cause of death in Alzheimer's disease: a cohort study, *QJM: AN International Journal of Medicine*, 2013. <http://tiny.cc/dementia27>
- 29 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.
- 30 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.

References

- 31 Sampson EL and Burns A. 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>
- 32 *ibid*
- 33 *ibid*
- 34 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).
- 35 Livingstone G, Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK, *BMJ* 2010; 341 <http://tiny.cc/carersdecisions>
- 36 Northern Ireland Executive. Joint Written Statement to the Assembly by Health Minister Edwin Poots and Justice Minister David Ford, 27 May 2014, Mental Capacity Bill <http://tiny.cc/mentalcapacity>
- 37 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.
- 38 Zheng L, Finucane AM, Oxenham D, McLoughlin P, McCutcheon H and Murray SA. How good are we at identifying patients who need palliative care? <http://tiny.cc/dementia44>
- 39 NICE. Dementia: Supporting people with dementia and their carers in health and social care. National Institute for Health and Clinical Excellence. 2012.
- 40 *ibid*
- 41 DHSSPS. Living Matters; Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland. 2010. <http://tiny.cc/dyingmatters>
- 42 Scottish Government. Standards of Care for Dementia in Scotland, June 2011. <http://tiny.cc/govscot>
- 43 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>
- 44 Rexach L. Palliative care in dementia. *European Geriatric Medicine*. 2012;3:131-140.
- 45 Bayer A. Death with dementia – the need for better care. *Age and Ageing*. 2006;35:101-102.
- 46 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.
- 47 Sleeman KE, Ho YK, Verne J, Gao W and Higginson IJ 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>
- 48 Harris D, Forget me not: palliative care for people with dementia <http://tiny.cc/dementia53>
- 49 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.
- 50 Alzheimer's Society. NHS Continuing Healthcare. <http://tiny.cc/dementia55>
- 51 Age NI. The Denial of NHS Continuing Healthcare in Northern Ireland. <http://tiny.cc/ageNI>
- 52 Alzheimer's Society. Equality, discrimination and human rights. <http://tiny.cc/dementia60>
- 53 *ibid*
- 54 *ibid*
- 55 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.

References

- 56 Alzheimer's Society (2014). Dementia UK: update. <http://tiny.cc/alzupdate>
- 57 *ibid*
- 58 Connolly A, Sampson EL and 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>
- 59 DHSSPS. Improving Dementia Services in Northern Ireland: A Regional Strategy, 2011. <http://tiny.cc/Nlstrat>
- 60 Alzheimer's Society, (2009) Counting the cost: caring for people with dementia on hospital wards <http://tiny.cc/dementia69>
- 61 National Audit of Dementia Care in General Hospitals 2012-13: Second Round Audit Report and Update
- 62 Care Quality Commission. Care Update, March 2013.
- 63 *ibid*
- 64 *ibid*
- 65 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>.
- 66 Admissions, emergency admissions, individuals admitted and total bed days for admissions to HSC hospitals in Northern Ireland for Dementia, 2013/14. Hospital Information Branch, DHSSPS.
- 67 DHSSPS. Improving Dementia Services in Northern Ireland: A Regional Strategy, 2010. <http://tiny.cc/Nlstrat>
- 68 Number of deaths registered in NI with underlying cause of death of Alzheimer's. Demography and Methodology Branch, NISRA
- 69 Bayer A. Death with dementia – the need for better care. *Age and Ageing*. 2006;35:101-102.
- 70 *ibid*
- 71 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.
- 72 *ibid*
- 73 Southwest Dementia Partners, Improving Domiciliary Care for People with Dementia
- 74 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.
- 75 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>
- 76 *ibid*
- 77 Rexach L. Palliative care in dementia. *European Geriatric Medicine*. 2012;3:131-140.
- 78 *ibid*
- 79 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>
- 80 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.
- 81 Candy, B, Jones, L, Sampson, E. Enteral tube feeding for older people with advanced dementia.

References

- <http://tiny.cc/dementia89>
- 82 *ibid*
- 83 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.
- 84 *ibid*
- 85 Rexach L. Palliative care in dementia. *European Geriatric Medicine*. 2012;3:131-140.
- 86 *ibid*
- 87 *ibid*
- 88 Chan, Sampson, Jones and Livingston 2012. Grief reactions in dementia carers: a systematic review. <http://tiny.cc/dementia96>

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