Hospice enabled dementia care
The first steps

A guide to help hospices establish care for people with dementia, their families and carers
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Foreword – Hope for Home

The charity Hope for Home was born out of the direct experience of people trying to look after a loved one with dementia in their own home. The mission of the charity is to help other people to do the same.

The home page of the Hope for Home website confronts that dilemma head on. It says:

“So, you suddenly find yourself looking after someone at home who has a diagnosis of dementia. You are absolutely determined to keep your loved one at home if at all possible, but you face an unknown future, with an unpredictable way forward.”

It is this ‘unknown future’ that frightens people and it is in facing it that they need most help. Carers need to be reassured that if they have the desire to look after their loved one at home it can be done. It does not matter if they live in cramped conditions; often it is better if the person with dementia is in a bed in the living room as they are then totally part of the life of the household. We know from the calls we get that there are many people living in this way and that support is what they need to continue to care for their loved one.

To succeed, carers need good support from their GP, access to an older person psychiatrist, palliation of the symptoms of problem behaviour where necessary to improve the comfort and quality of life of their loved one, provision of equipment in their home, eg commode, hoist, grab rails, and help from specialist teams. Support is also needed to improve carer resilience in the form of counselling to help carers cope with the emotional and behavioural changes in the person with dementia and their own anticipatory grief.

Hope for Home was delighted to fund this project as we feel that hospices are well placed to provide this kind of support, being the experts in end of life care and providing outreach support to people living at home.
Dementia is now one of the biggest global public health challenges facing our generation which can no longer be put out ‘into the long grass’. Notably there is now also overwhelming evidence of a need to redress the poor care towards the end of life people with dementia experience because of their diagnosis. It brings into focus the need for all leaders of care services to question the position they may currently hold of ‘doing nothing’ or limiting access to care due to diagnosis – now colloquially titled ‘diagnosis apartheid’ practice.

Dementia has emerged as a key issue for consideration by hospices as they consider their strategic direction for the future. While few people challenge the belief that dementia is a life-limiting illness, it has struggled to be accorded the same degree of service provision from within the palliative care domain as other life-limiting illnesses. To date, the overall investment by hospices in response to dementia has been relatively small, inhibited by concerns about impact on resources and a number of other perceived challenges.

This guidance stresses the important requirement for palliation of symptoms and provision of comfort for anyone with dementia regardless of anticipated prognosis, and suggests hospice care has much to offer people affected by such a diagnosis, in the light of suggested principles underpinning high quality care for people with dementia.

The document argues convincingly that hospices should build skills and relationships so they can offer “hospice enabled dementia care”. In addition, it identifies actions hospice leaders can take to introduce and develop such an approach. It offers a checklist for hospice boards and senior managers to help them assess their position and progress in supporting people with dementia, their families and carers. We hope this will encourage hospices to take new steps to consider their role in supporting people affected by a diagnosis of dementia. We, at Hospice UK, believe this is a journey hospices must consider and through which they could make a real difference.

Finally, we are most grateful to our funders, Hope for Home, for their initiation of this project and their support of its work. We look forward to working with them again in the future. We are profoundly grateful to Elaine and Norman McNamara, who offered their personal story and views to the work, and extend thanks to the steering group members, who have expertly overseen the development of this guidance.

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Executive summary

This is a guide to assist hospices consider their contribution as local players in the provision of care for people living with, and affected by, a diagnosis of dementia.

Dementia care is an increasingly important strategic consideration for palliative and end of life care providers including hospices. Hospices will therefore want to think carefully about whether they extend care to people with dementia, their families and carers for a whole variety of reasons. The anticipated changes in population size, age and related morbidity and mortality indicate dementia will call for increasing levels of health and social care, including end of life care. Its current marginalization, and growing awareness of the poor quality of care at the end of life for many people with dementia, will place legal and moral pressures on hospices to consider their role in supporting this emerging group of patients, families and carers. Finally, hospices will find it increasingly hard to ignore the call for their expert help from other health and social care providers, family carers and communities about how to support people at the end of life with dementia.

Many of these drivers already exist and yet the majority of hospices do relatively little to reach out and support people with dementia, their families and carers. Some hospices are understandably anxious about the level of need and also about whether they are skilled sufficiently to respond. Many are concerned about the implications on resources, which are already increasingly strapped. Some have simply not really considered the opportunities to extend care to people with dementia in any serious way to date, or have not yet engaged their governing bodies in discussion about taking this agenda forward as a strategic priority. The authors of this guidance believe the best way to proceed on the part of the hospices is to adopt a facilitative role, working in partnership with their local community and care providers, to ensure people affected by dementia have access to the necessary care and support where ever they live and whenever they need it. They have termed this ‘hospice enabled dementia care’.

While hospices may be unclear about what this would look like in practice, there is well developed knowledge within dementia care about what constitutes high quality care for people with this diagnosis, their families and carers. Such care is person centred and holistic in nature; recognises the central role of informal carers; is coordinated and consistent and draws on support from professionals and carers who are well trained and highly skilled. It requires attention to issues pertaining to mental capacity and advance care planning, the value of pharmacological interventions to manage agitation and distress, and ethical issues pertaining to the autonomy of the person with dementia.

Having identified the principles underpinning high quality care for people affected by a diagnosis of dementia, the guidance then considers their fit with hospice care. Drawing on a description of hospice care fit for the future, this publication confirms hospices are well placed to adopt a role in providing hospice enabled dementia care. The focus of hospice
care on death, dying and loss, its expertise, flexibility and timeliness and its interest in the individual needs of patients and those close to them makes hospices ideal providers of end of life care for people with dementia. Their history of serving as pioneers and innovators will enable them to develop and refine new models of end of life care to meet the specific needs and preferences of people affected by a diagnosis of dementia. Their interest in collaborative work and education and training of others positions them well within the local health and social care context and their local communities to work in a facilitative way to support the efforts of others.

If hospices are interested to grasp such opportunities, then there are key characteristics they must adopt to provide effective end of life care to people affected by a diagnosis of dementia. These include:

• a corporate commitment to engage with the agenda of dementia care
• efforts to establish new partnerships
• creativity in the provision of care and services to meet the specific needs of people with dementia
• an evidence-based approach to care and the care environment
• investment in training of staff and volunteers.

A checklist of questions in relation to each of these characteristics is included in the guidance along with a list of resources and useful references hospices may wish to access to guide their work locally to develop new services and partnerships.
Section 1: Why is dementia care an important strategic consideration for palliative and end of life care providers in the future?

Introduction

There are a variety of voices calling for action on the part of providers of palliative and end of life care, including hospices, to consider their role in supporting people affected by a diagnosis of dementia. Individuals affected by such a diagnosis extend beyond the person with the condition to their families and carers; for all, the consequence of such a diagnosis can be significant.

This section captures some of these voices that convincingly argue for the involvement of professionals and organisations who are expert in palliative and end of life care to extend their impact to include people affected by dementia. They include the views of someone living with a diagnosis of dementia and a family carer, as well as leaders, experts and academics who are aware of gaps in provision currently and who wish to redress them.

“We need help to continue enjoying life as much as we can”

Norman and Elaine McNamara talk about their response to a diagnosis of dementia. Norman received in 2007 and their experience of life since then. They make a strong plea to hospices to help others prepare for death as they have both done.

Norman was diagnosed with dementia in 2007, aged 50, and says that he is “still fighting it”. He has faced his diagnosis of a life-threatening condition head on and considers that vital to enjoying the rest of his life. He talks about “truth and tears – end of life care and arrangements”.

“As a person living with this awful disease, once I had got over the shock of diagnosis, the first thing we did was to sit the family down and tell them, warts and all. This may not suit everybody but it did us, but what we did next was so helpful to all – it took so much stress and worry away from an already horrible situation.

“As a loving husband, father, grandfather I couldn’t imagine leaving everything to my wife, Elaine, to sort out after I have gone. How selfish of me would that be, so one long night we sat down and decided to put our house in order, so to speak. It was a very long, emotional night, full of tears and truths, but we got there.

“We talked about wills, children, and most important of all, provisions for end of life care. We made plans about the kind of care I want, the songs at my funeral, how I want people dressed, what kind of wake, where I am to be buried and so on. We talked about even if Elaine passed away first and how we would (and now have) made arrangements for myself to stay in Torquay and be looked after here in Devon. We talked about my likes, my dislikes, Elaine’s likes/dislikes, etc and what should happen at the very end if I am that gravely ill and who decides when the time is right to say goodbye to each other, such a very hard conversation, but, looking back now, so very worth it.
“Looking back now, the amount of stress this has stopped, the amount of worry that has been taken off Elaine’s shoulders (she is also my full-time carer) is immense. I would never want Elaine to stand there after and think, would he have liked this, or that? It would be awful at such an emotional time for her. We chat every day about how we are going to live our life from now on, our priorities, and our hopes (yes we still have hope) for the future. Because when the time comes where I am too ill to understand what’s going on and facing my final days, Elaine will not have the worry or stress that goes with this situation, it’s all been sorted and talked about many times.

“If I dare say this, we can now get on with whatever time I have left and enjoy every minute of it. Hospices can help by asking families if these arrangements have been already made and if not, how they can help by approaching subjects I have just mentioned.”

Elaine McNamara (professional carer, Norman’s wife and now Norman’s family carer) adds:

“Finding out that your partner, husband, wife, loved one has dementia is a shock. Suddenly you have all these emotions and questions running around in your head. What will the future hold? How will I cope? You become a carer only for a little time at first, and then it becomes full time. You worry about the person with dementia and yourself. You have to put part of your life on hold, change some of your dreams and ambitions. Some people adapt to this more easily than others. Guilt creeps in, that’s okay, we are only human, not saints, its okay to shout sometimes, to feel down, to say ‘if only’.

“Your life doesn’t end; it just takes a different path. Take each day as it comes, make the best of each day, go out and enjoy your life. We live with dementia. Later on we (carers) would have to make all the decisions by ourselves, but, early on, we can make the same decisions together. This makes life easier later on as you know these are the things the person with dementia wants.

Put your house in order, make a will if you haven’t already, sort out power of attorney, finances and care. Talk about end of life care – not easy, but much harder later on if you have to make all the choices yourself. Ask the person what care they would like, where they want to live, do they want to be resuscitated if the case arises? Do they want to go into a hospice if staying at home is not always possible? What kind of funeral would they like? To be buried or cremated? What songs would they like playing at the funeral? Do they want a wake? Not easy questions, but once you have the answers, at the end, you will know you have done the right thing.

Then get on with living, laugh a lot and enjoy the most precious time of your life.”

**Dementia is a growing issue and increasingly part of national and international policy**

Dr Jacqueline Crowther, expert adviser to the Dementia Project, talks about the policy content and the requirements it makes on hospices.

Dementia is now one of the biggest global public health challenges facing our generation. Over 35 million people worldwide are currently living with a diagnosis of dementia. This is projected to double by 2030 and more than triple by 2050 to 115 million.¹ There is good evidence that as national and international levels increase attention is being given to the difficult question of how the challenge of dementia is best addressed.

The first Dementia Summit was held in the UK in 2013 and resulted in a call for global action and appointment of the first ever world Dementia Envoy by the UK government, in an attempt to support an international response to the problem. This person is working closely with Alzheimer’s Disease International to establish a World Dementia Council and generate new international funding streams which will help to sustain the crucial collaborative action required from all nations.¹
The European Association for Palliative Care (EAPC) produced the first definition of palliative care in dementia based on evidence and consensus from a range of experts in both the fields of dementia and palliative care.\(^2\) This suggested that creating a link between dementia and palliative care would result in comfort and improved care, with a core element being the anticipation of inevitable decline and death and needs related to this. The emergence of recommendations on palliative care and treatment of older people with Alzheimer’s disease and other progressive dementias are a valuable resource. The domains identified and recommendations within these can be used as a framework to help identify gaps and develop and implement policies.\(^3\)

Closer to home, a report published by the Alzheimer’s Society in 2007\(^4\) marked a change in awareness and gravity of the worrying inadequacies of UK policy to address the issue of the projected dementia epidemic. The report offered alarming estimates of the numbers of people with dementia in the UK including future predictions to 2051. It provided a review of services and treatments for people with dementia and an estimation of societal costs. It was instrumental in raising awareness among the public, government and key stakeholders of the oncoming projected increase in numbers with dementia and the challenges faced by the UK.\(^5\) The report has been fundamental to guiding policy makers and service providers in designing, planning and costing service innovations and monitoring diagnosis, treatment and care.

Since the Alzheimer’s Society report of 2007, progress has been made in the UK to address the issues it identified.\(^6\) During this time dementia has been accorded much greater national priority through the formulation and introduction of national strategies for England\(^7\), Scotland\(^8\), Wales\(^9\), Northern Ireland\(^10\) and most recently through the Prime Minister’s Challenge on Dementia\(^11\). However, these strategies give little attention to palliative care towards the end of life. In England, this gap may have been addressed through the introduction of the End of Life Care Strategy which encompassed palliative care, death and dying regardless of diagnosis. However, current levels of provision do not suggest that this has been sufficiently successful.

Dementia is now acknowledged as a life-limiting condition with most dementias being progressive in nature and no curative treatment to date.\(^4\) Estimations of deaths attributable to dementia within the UK are at around 66,000 per year.\(^5\),\(^12\) While definitions such as those developed by the EAPC confirm that those with dementia may benefit from palliative care, interpretation of how much care and when in the trajectory is less clear.\(^13\) A further challenge posed by co-morbidity is the “blurred distinction between death with dementia and death from dementia”.\(^14\)

In recent years we have witnessed increasing numbers of younger people diagnosed with dementia in the UK, perhaps as many as one in 10 new cases.\(^5\) These individuals present with many additional challenges relating to occupational impact and family caring responsibilities, which need to be acknowledged and addressed.

It is my belief that everyone, everywhere can and must help to redress the unmet suffering of people dying with and from dementia. It is crucial hospices find a role and position within this challenge. How individual hospices respond will differ according to local need, resources and the presence of other services pursuing similar aims. The vital next move for hospices on this journey is their acknowledgement of their role, whatever the shape and size. It is no longer an option for hospices to say “we don’t do dementia”.

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\(^2\) European Association for Palliative Care (2017). The European Association for Palliative Care produced the first definition of palliative care in dementia based on evidence and consensus from a range of experts in both the fields of dementia and palliative care.

\(^3\) European Association for Palliative Care (2017). The emergence of recommendations on palliative care and treatment of older people with Alzheimer’s disease and other progressive dementias are a valuable resource. The domains identified and recommendations within these can be used as a framework to help identify gaps and develop and implement policies.

\(^4\) Alzheimer’s Society (2007). A report published by the Alzheimer’s Society in 2007 marked a change in awareness and gravity of the worrying inadequacies of UK policy to address the issue of the projected dementia epidemic.

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\(^8\) Alzheimer’s Society (2007). During this time dementia has been accorded much greater national priority through the formulation and introduction of national strategies for England.

\(^9\) Alzheimer’s Society (2007). The national strategies for Scotland have also been introduced.

\(^10\) Alzheimer’s Society (2007). The national strategies for Wales have also been introduced.

\(^11\) Alzheimer’s Society (2007). The national strategies for Northern Ireland have also been introduced.

\(^12\) Alzheimer’s Society (2007). Estimations of deaths attributable to dementia within the UK are at around 66,000 per year.

\(^13\) Alzheimer’s Society (2007). Definitions such as those developed by the EAPC confirm that those with dementia may benefit from palliative care, but interpretation of how much care and when in the trajectory is less clear.

\(^14\) Alzheimer’s Society (2007). A further challenge posed by co-morbidity is the “blurred distinction between death with dementia and death from dementia.”
Dementia care is essentially about kindness, good palliation and comfort

Dr Adrian Treloar, Consultant and Senior Lecturer in Old Age Psychiatry, Trustee of Hope for Home and member of the project steering group, talks about the contribution of hospice care to specialist dementia care.

Dementia is a terminal illness, which brings a life expectancy less than most cancers. While for some people with dementia, life may be happier and better than it was before they got it, for others, dementia may bring severe distress and profound disability.

There should therefore be a focus upon good care in dementia, reducing distress and enhancing comfort. Those aims of distress reduction and enhanced comfort are the central planks of palliative care as well as to help people live well. Much of that work is currently done (often quite well) by specialist dementia services but hospices can bring to that work a better understanding of palliation, and care. Indeed, palliative care of dementia reflects in large part palliative care of terminal physical illness, and dementia services have a lot to learn from hospice care. But hospice care also has much to learn about dementia, which, alongside the imperative of caring for a terminal condition, brings with it challenges of physical pain, psychosis and depression as well the loss of decision-making capacity.

We know that really excellent care of advanced dementia is possible and often delivered. But doing that will need to combine the skills of dementia services, primary care services, acute hospital services and hospice services with new partnerships and ways of working.

But there is also a problem. While much is said about ‘end of life’ care in dementia, we know that individual prognosis and death is especially hard to predict and the term ‘end of life’ may be misunderstood as being mainly about dying. Consequently, people with dementia who have significant needs for palliation may not be seen as eligible, as they are not thought to be ‘at the end of life’.

‘Care towards the end of life’, or ‘palliative care for those living with dementia’ may be better descriptors.

Whatever the descriptor, people hope to live well with dementia, and the care they receive is about living as well as they can. Hospices and dementia services therefore need to become much better at identifying distress and promoting comfort in all that they do. The established expertise of the hospice movement in palliative care, means they have an excellent role in supporting established dementia services and working toward a much better joint understanding about what palliative care in dementia can do.

Dementia care requires a partnership approach between specialists

Dr Karen Harrison-Dening, Director of Admiral Nursing, Dementia UK, and member of the Dementia Project steering group, describes the work of a national organisation that is leading work in the UK to improve care for people with dementia. The vision and partnership is one that the hospice sector may wish to share. She makes a strong case for hospices supporting people who may die with dementia, as well as those dying specifically from the condition.

Improving end of life care for people with dementia has been the focus of UK policy and guidance for over a decade now. However, we still see many examples where people with dementia do not have fair access to palliative and end of life care services and support; or in their family carers’ access of bereavement support after their death. A difficulty for services, such as hospices, is in understanding what it is they can offer to this group of people and when.

Life expectancy is increasing so people often develop a range of conditions and disabilities in the years of old age before death. As dementia is largely a disease of old age, many people with dementia will also have other illnesses or disabilities. Multi-morbidity is characterised by complex interactions of such co-existing diseases where a medical approach focused
on a single disease does not suffice. People with dementia and cognitive impairment show high levels of multi-morbidity, common conditions including cardiovascular disease, diabetes, and musculoskeletal disorders such as fractures. Multi-morbidity is a positive predictor of mortality in dementia; however, dementia itself is the strongest predictor of mortality, with the risk being two to three times greater than those of other life-shortening illnesses. Multi-morbidity including dementia often presents clinicians with practical problems in following treatment regimes or in understanding prognosis.

Dementia UK, with its Admiral Nursing model, has been developing its own approach for people with dementia and their families to enable those with the disease to not only live well but to die well also. When considering dementia, frailty and complex multi-morbidity it can be difficult to identify when someone may enter the final stages of their life. Admiral Nurse Leaders have become very aware that providing good palliative and end of life care for people with dementia often requires knowledge, expertise and skills relating to both dementia and palliative and end of life care. There have been a few projects across the UK that have aimed their approach specifically to people with dementia, with varying degrees of success. Often the recruitment of individuals that have specialist knowledge and expert practice across both fields has been a significant barrier to filling the posts for such targeted interventions.

Dementia UK, with its Admiral Nursing, has a long track record of supporting generalist and other specialist clinicians in successfully working with and supporting people with dementia on their caseloads. This has been through education in dementia related issues, supervision and direct partnership working. We firmly support an approach whereby clinicians in areas of specialist practice work together, in partnership, to provide high quality and well coordinated care for people with dementia as they approach the end of their life, irrespective of whether they die from dementia or one of their co-morbidities.

We heartily endorse and welcome this valuable contribution to the field of palliative and end of life care in dementia.

**Access to hospice enabled end of life care for people with dementia is a human rights issue**

Linda McEnhill is Manager of Family Support Services at the Prince and Princess of Wales Hospice in Glasgow. She is also a member of the Hospice UK Care Strategy and Support Team and a member of the Dementia Project steering group. Here Linda presents the human rights position, explaining why hospices need to consider their service provision for people affected by dementia.

Most of the debate concerning access of people with dementia to hospice enabled care has appealed to the compassion and generosity of hospices, their history of pioneering care for a variety of groups in need of end of life care and the clear opportunity for transfer of expert skills to some of the most needy situations of the growing number of people affected by dementia. While all of this is both true and important, there is a sense in which it disguises or misses an important point. That point is that it is not only ethically dubious for any publicly funded (in part or whole) body to refuse to adapt its services for all those who need them, it is also unlawful.

The Disability Discrimination Act of 1995 and the more recent Equality Act of 2010 make clear that organisations which receive monies from the public purse or which set out to provide public services are legally bound to make them (through ‘reasonable adjustments’) accessible to all persons who need them, and since we now know that people do not only die ‘with’ dementia but die ‘from’ dementia the challenge for hospices is clear. Thus the language of choice or persuasion is somewhat at odds with the fact that families caring for someone with end-stage dementia would be quite within their rights to complain about or report the discrimination of those hospices that refuse to care for their loved one. In a context where commissioners are increasingly urged to use commissioning as a lever for increasing
equity of service provision, hospices who do not engage in the care of dying people who have a primary diagnosis of dementia may find that they pay a high price for a response which results in the majority of people with dementia dying, inappropriately, in hospital and as at 2010 only 1% dying in hospices.17

As is outlined fully in this resource, this is not to suggest that all people dying with or from dementia require admittance to a hospice inpatient unit; hospice enabled care is much more person centered than that and access a more multifaceted concept. The requirement is to proactively make the necessary relationships and, utilising the variety of aids available, to interrogate current working practices and wherever possible to make the reasonable adjustments required to ensure an equal and equitable approach to end of life care of all those who need it.

Previous work on access to hospice care18 suggests that there are four levels of access which hospices may wish to consider in ensuring their services meet the needs of the communities in which they are set (see Appendix 1). Consideration is also given to some of the tools hospices may use to help them achieve this, although how they do so will be as individual as their particular hospice is. From an equalities point of view, all hospices are required to ensure equitable access at the most basic level – Level 1 – but for those hospices committed to caring for all those that need them they will want to consider the higher three levels.

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Hospices must work collaboratively to achieve their potential in dementia care

Siobhan Horton, Director of Clinical Services, St Luke’s (Cheshire) Hospice and member of the Dementia Project steering group, shares her thinking on the potential to be realised for improved care when hospices work in partnership.

I believe our communities need us (the hospice movement) to become a bigger player within the health and social care system. We need new ways of working and to develop new forms of entrepreneurship that attend to the scale of the palliative and end of life care need of our population; ways of working and enablement of good care that are not as resource heavy as some of our current ways of working.

We have a role and responsibility to develop mature relationships with local care providers and commissioners, so we can challenge, campaign, influence plans, shape decisions and have an authoritative voice for palliative and end of life care issues. Our communities need us to be strong, confident yet humble: with self-belief and humility that allows us to learn from colleagues in other services. This is particularly relevant within the context of dementia.

We cannot or should not develop services and approaches alone. We need to identify the experts in the field; we need to identify who is doing the bulk of the care work already; we need to work with them to identify gaps in their service, knowledge or care approach in relation to end of life issues that maybe we can share with them. We need to gain everyone’s confidence that we are coming out of our world to join the care staff in all settings that are trying very hard to care in complex situations.

We need to find our place outside hospice walls in dementia care, so we can contribute to the huge social problem. We cannot wait for people to come knocking on our doors; we must go more than half way to engage with others. We need to be excited to find our place. But have we, as 21st century hospices, got the organisational culture, drive, confidence and humility to partner, educate, influence and disseminate good care?
Summary

- Dementia has been described as a global problem; an effective response will require collective social responsibility.

- Dementia is considered to be a life-limiting illness, and one that will often exist alongside other chronic conditions. For this reason, it is a fair assumption that many people with this diagnosis could benefit from palliative care. Policy at national and international levels supports this.

- Palliative care for people with dementia is about effective palliation of symptoms, kind care and comfort. It is also about helping people plan for the future, in order that they can live well until death.

- Attending to the needs of family carers is also important. The demands on them are significant. They play a vital role in enabling people with dementia to continue to live at home, if this is their wish.

- The number of people who die with dementia is high and likely to increase substantially in the future; current palliative and end of life care provision is inadequate. Urgent and significant action is required if the gap between level of need and services available is to be reduced.

- Hospices could be an important part of the solution. They could make a significant contribution in providing care and support for people affected by dementia. This will be best achieved through collaborative effort and local partnership working.

- If hospices take on this challenge, they will need to work towards greater access for those affected by a diagnosis of dementia who could benefit from their expertise.
Section 2: To what degree has the hospice sector started to acknowledge the dementia challenge?

Introduction

There are good reasons, as described in the previous section, to indicate hospices should be considering their role in supporting people with dementia. The Commission into the Future of Hospice Care document ‘Future ambitions for hospice care: our mission and our opportunity’ has already explicitly identified dementia care as a potential priority for hospices in the future. What is less clear is the degree to which hospices have recognised and responded to this new beneficiary group (and their related needs) and how.

This is hard to ascertain. The Minimum Data Set related to specialist palliative care in England, Wales and Northern Ireland does not collect data related to the numbers of people with dementia specifically. Longstanding failure to record dementia as cause of death on death certificates further reduces availability of robust data from other sources. This is now changing but has affected statistics and information required across caring contexts to assist service planning.

Introducing a national project to help hospices consider their role in dementia care

Hospice UK, in response to the Commission recommendations, has sought to support its member hospices to address dementia care as an emerging strategic priority. With the financial and practical support of a funder, a charity called Hope for Home, work started in November 2013 to provide guidance that would help hospices extend their reach to care for people with dementia and also to their families and carers. Specifically it wanted to offer bespoke information about how hospices, and specifically their leaders, might grasp this opportunity and make a real difference to a growing group of people within their local community.

The current picture

Our project has confirmed there are a number of hospices reaching out to people with dementia, providing a variety of care and services to meet their needs and those of their families and carers. We have heard from hospices who are undertaking some innovative work to extend their reach and skills to people affected by a diagnosis of dementia. However, we believe the number of hospices engaging with this issue is relatively small.

Our conclusions in this respect are based on anecdotal evidence and stories of service development provided by hospices. In addition, we undertook a survey of hospices advertised via our e-communications channels, including ehospice. A total of 25 responses were received. This very low level of return is significant in itself. Even so, the responses we did receive have enabled us to begin to identify areas of good practice and issues of concern.

The findings from the survey suggest:

- Over three quarters (88%) of hospices who did respond stated they are caring for people with dementia. Just under a quarter of those hospices caring for people with dementia use dementia specific assessment tools or models of care. Hospices using these tools and models had good links with dementia specialists in their areas.
Over half of the hospices (64%) who responded had accessed training that focused specifically on dementia care, offered by other organisations in the main. A number of hospices that responded described frustrations in establishing working relationships with dementia experts outside of the hospice.

Nearly all hospices who responded (92%) provide support for family carers of people with dementia. The services family carers receive is the same as that provide to carers of people with other diagnoses – including counselling and complementary therapies. One hospice used a carer’s assessment tool focusing on carer needs. While this is a generic carer’s assessment tool, the hospice considered it appropriate for carers of people with dementia.

Hospices supporting people affected by a dementia diagnosis are changing their workforce. Some have begun to employ staff with dementia knowledge and expertise gained prior to employment at the hospice, such as dual registered (RGN and RMN) nurses. A number of hospices have introduced a dementia champion role, which may or may not be a nurse.

Many of the hospices engaged in dementia care provided examples of collaborative relationships established with a variety of local and national organisations including NHS organisations, local authorities and voluntary organisations. An example of a successful partnership can be found in Section 4, where the hospice is working in partnership with primary care to identify individuals who may have a diagnosis of dementia.

Many hospices described barriers and areas of concern around extension of their care to people affected by a diagnosis of dementia. The concerns identified within the survey were reiterated by other hospices during the course of the Dementia Project. The key areas of difficulty highlighted by hospices were:

- **Limited applicability of the existing model of care to respond to the specific needs of people with dementia** – There was a perception by some hospice staff that the needs of the person with dementia could not be met within current models of hospice care due to the lack of clinical skills and relevant expertise.

- **People with dementia are not seen as people who would typically benefit from hospice care** – Some hospice personnel described a relatively low degree of empathy for such people compared to the patients with which they are more familiar – particularly people dying with cancer.

- **Weak working relationships with external professionals**, such as mental health specialists, with subsequent lack of clarity around the role and function that each can play in achieving high quality end of life care for someone with dementia. This has major implications for timely referral to hospice services resulting in poor planning and delivery of care according to the wishes of the person who is dying, their families and carer.

- **The unsuitability of the hospice physical environment** – Many acknowledged reluctance, even within their own teams, to refer people with dementia to inpatient hospice wards due to limitations in the physical environment. There were specific concerns around the safety of the ambulant but confused individual on open wards and the impact of caring for someone who was unsettled, noisy or agitated in a bay occupied by other patients.

- **Concern about growing levels of needs and demand for hospice services**, particularly when the disease trajectory of someone with dementia is unpredictable in nature and may extend over many years. This concern is heightened as hospices take on increasing numbers of people with conditions other than cancer, many of which also share the characteristic of an extended trajectory. One senior nurse working in hospice care described a fear of a ‘tsunami’ effect with ever growing numbers of people with dementia needing support, a concern shared by some hospice boards also.
The future – hospice enabled dementia care

This guidance, while acknowledging the range of challenges facing hospices, shows how hospices can respond to the needs of people with dementia. It suggests an approach hospices may wish to adopt of ‘Hospice enabled dementia care’. This positions them as:

“key partners working with their local community and care economy to ensure people affected by dementia have access to optimum palliative care and support wherever they live and whenever they need it, regardless of anticipated prognosis.”

The guidance proposes this on the grounds that:

• Hospices have something valuable to offer people affected by a diagnosis of dementia in the light of their expertise in alleviating distress and promoting comfort – key needs for improving dementia care towards the end of life. Section 4 of this guidance highlights the areas of congruence between hospice care and the needs of people with dementia.
• This offering will be most effective when planned and delivered in partnership with others, including dementia specialists.
• There is a strong moral reason why hospices should help redress the poor quality of care experienced by many people with dementia, their families and carers.
• Hospices may be obliged to widen access to care for people with dementia in response to legislation around equality and diversity.

It is suggested hospices establish a plan to become dementia friendly that spans a number of years as a minimum. This plan will incorporate work to amend models of care and develop new relationships that will help the hospice achieve better outcomes and experience of care for people with dementia, their families and carers. This work will ideally reflect the principles of good care for people with dementia described in Section 3 of this guidance. The checklists in Section 5 can be used annually to help hospices assess their progress towards this end. The many resources available to hospices to help them in this endeavour are described in Section 6.

Summary

• The majority of hospices are not engaged in the agenda of dementia care for people who are approaching the end of life. They do not have a strategy in place to extend their care to this growing group of potential users and are concerned about their capability or capacity to do so.

• A minority of hospices have started to respond to this agenda and examples exist of good practice, often in partnership with other providers.

• There are important reasons for all hospices to begin to work towards a position where they are offering hospice enabled dementia care. This is unlikely to be a quick development and hospices are advised to work towards it over a period of years.
Section 3: What are the principles underpinning high quality care for people with dementia, their families and carers?

Introduction

There is growing knowledge regarding dementia and its impact on people with this disease, their families and carers. This section of the guidance draws heavily on that knowledge to introduce dementia to hospices, and to describe how its consequences are best managed. In addition, this section describes the trajectory of the condition and when hospices should become involved and to what end.

Introduction to dementia and its trajectory

Dementia is an umbrella term used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop what is sometimes referred to as the Behavioural and Psychological Symptoms of Dementia (BPSD) or non-cognitive features. This may include symptoms such as depression, psychosis, aggression, increased movements and activity levels, all of which may cause problems in themselves, occur at any stage and complicate care further. Further information and details about the course and symptoms of the different types of dementia can be found on the Alzheimer’s Society website, details of which are in Section 6 of this guidance.

Disease progression

While the progression of dementia is often difficult to predict, there is clear guidance that care from the point of diagnosis can benefit from a palliative care approach. Appendix 2 provides an overview of the trajectory of dementia with its related needs and opportunities for hospice involvement.

The progressive nature of dementia means symptoms will ultimately worsen over time. How quickly this occurs varies from person to person. As identified earlier, along with impaired cognitive symptoms affecting thinking and memory, other symptoms may arise, affecting behaviours that seem unusual or out of character for the person with dementia. These may include repetitive questioning, pacing, agitation, disturbed sleep and physical aggression. Such associated behavioural changes can sometimes be very difficult to manage and upsetting for the person with dementia and their carers. In the later stages, other symptoms such as muscle weakness, changed appetite and weight loss may appear which can be as equally distressing and upsetting for carers as the symptoms experienced earlier in the trajectory.

All or any of these signs and symptoms described may occur at different time points in the disease trajectory. As already highlighted, dementia is an unpredictable disease and how long people can live with it also varies. Some may live for many years with several transition points over the course of time. Some problematic and distressing behavioural aspects associated with the disease, such as agitation or constant purposeful walking, may even abate over time – which may offer respite to the person’s carer.
Impact of a diagnosis of dementia

The impact of a diagnosis of dementia on the person receiving this, families and significant others cannot and should not be underestimated. Many people, regardless of age at time of diagnosis report loss of friendships, loss of roles in communities and society, feeling a burden upon their families and experiencing loneliness. Many people with dementia can become depressed and quite literally can give up living, overwhelmed by the uncertainty of their almost definite future demise. It is important to remember that, while dementia can be a debilitating illness with devastating consequences for many, a number of people with dementia are settled within their own dementia world.

As dementia progresses and the person with the disease becomes more dependent on others for his/her care, families and those close to the person with dementia may start to experience physical and mental health problems. These arise from the relentless nature of meeting care needs, coupled with an anticipatory sense of ‘loss’ of the person as their personality and behaviour changes and indeed the loss of all the ‘what might have beens’. More positively, the literature reports there are ways of re-connecting with the person with dementia and locating the ‘enduring self’ within. Life history work, music and other sensory approaches are excellent ways of doing this. Further information about these approaches in dementia care can be found in Section 6 of this guidance.

Carers share how such feelings of loss and grief can begin early in the disease process as they see the person with dementia losing recognition of their family and loved ones. Often the carers of people with dementia and others close to them witnessing the changes feel powerless to help, and thus experience increasing levels of distress and anxiety.

Introducing palliative care for people with dementia

There is a wide range of guidance available at national, European and international levels, all of which propose that dementia care incorporates a palliative care approach from time of diagnosis until death. According to these documents, such an approach will:

- alleviate distress and promote comfort, enabling people with dementia to live well
- enable people with dementia to die with dignity and in a place of their choice
- support carers throughout the illness and following death.

The European guidelines, developed from a Delphi methodology, describe what optimal palliative and end of life care for older people with dementia should encompass. These guidelines offer 11 domains of care:

**Domains of care**

1. Applicability of palliative care
2. Person centred care, communication and shared decision making
3. Setting goals and advance care planning
4. Continuity of care
5. Prognostication and timely recognition of dying
6. Avoiding overly aggressive and burdensome and futile treatment
7. Optimal treatment of symptoms and providing comfort
8. Psychological and spiritual comfort
9. Family carer involvement
10. Education of healthcare team
11. Societal and ethical issues

While hospices focus effort on meeting the needs of the increasingly elderly population, they must also consider the needs of younger people being diagnosed with the condition:
an estimated 40,000 in the UK and increasing.\textsuperscript{5} While a number of their needs may be similar, there will also be distinct differences. Of note are the common requirements of young people to maintain employment, manage financial commitments and the responsibilities associated with a young dependent family.\textsuperscript{27} Again, many of these areas are ones that hospices are familiar with and can help with as part of their portfolio of support.

**The principles of high quality care for people with dementia**

In reviewing the literature several themes emerged around what constitutes high quality care for people with dementia and those dear to them. For the purposes of this guidance, they have been brought together in the form of six key principles. They are augmented through the use of some “I” statements, developed by the Department of Health\textsuperscript{7}, to represent the needs and wishes expressed by those affected by a diagnosis of dementia.

**Principle 1: Care is person centred**

“I am treated with dignity and respect.”

Person-centred care, pioneered by renowned psychologist Thomas Kitwood\textsuperscript{28} and relationship-centred care espoused by gerontologist Dr Mike Nolan\textsuperscript{29} are the cornerstones of best practice in dementia care. Kitwood’s person-centred model of dementia care offers a way of thinking about and approaching dementia which is both practical and based on the view that the person with dementia remains a whole person throughout the disease trajectory. His work broke the negative link between ‘no cure’ and ‘no hope’ by introducing a new culture of care in which the person with dementia and their wellbeing remained central. The introduction of relationship-centred care moved person-centred care in a slightly different direction. It acknowledges the influence and impact that relationships (significant and otherwise) have on the person with dementia and their state of wellbeing. These two models of care serve to confirm that it is not only the symptoms of the condition that affect the person with dementia but also their access to a social network and behaviour of others. These can have both positive and negative impacts on the wellbeing of people with dementia.

A focus on the person calls also for a shared approach to decision making about goals and plans for care. Shared decision making is an approach where clinicians and patients make decisions together using the best available evidence. Patients are encouraged to think about the available screening, treatment or management options and the likely benefits and harms of each so they can communicate their preferences and help select the best course of action for them. Shared decision making respects patient autonomy and promotes patient engagement.\textsuperscript{30}

The practice of shared decision making from the outset enables the person affected to retain as much control as they wish in their desire for knowledge and future planning possibilities. We know that people affected by dementia are often asked too late in terms of their capacity to make an informed choice about future care options.\textsuperscript{31}

**Principle 2: Plans for care of people with dementia acknowledge the vital contribution made by the family carer to their wellbeing**

“I am confident those around me and looking after me are well supported.”

Guidance developed on dementia care confirms the importance of the family.\textsuperscript{2,7} They are central to the care of the person with dementia and are responsible for large amounts of care hours, reducing the financial costs to the state in the UK by significant amounts.\textsuperscript{5} The longevity of the disease trajectory can result in family carers being primary carers for several years. This often places significant financial, emotional and physical burdens on them.\textsuperscript{32}
Research suggests carers of people with dementia experience greater strain and distress than carers of other older people. A survey undertaken by the Alzheimer’s Society in 2012 found that 52% of carers for people with dementia were not getting sufficient support to enable them to carry out their caring role. There are significant perceived repercussions of this, including impact on mental and physical health and earlier admissions to long-term care. When carers are well-supported, they provide better care to the person they care for and report better outcomes in relation to their own wellbeing. Despite this knowledge, there is limited access to carer support services, with nearly a third of carers receiving no services.

Professionals must make an effort to build the resilience of carers, which is essential. An example of training to this end is offered in Figure 1 below.

Other opportunities include the use of social media to increase access to peer support. In 2004, the Alzheimer’s Society launched Talking Point, an online chat forum for carers of people with dementia. This now has over 29,000 members. The key benefit of Talking Point is it is accessible 24/7, which means people can seek help and advice whenever they need it.

Further efforts are required to support carers in terms of financial support and time off work for caring.

**Figure 1: START – Programme of support for carers**

Family carers attended an eight-session programme during a period of two to four months, depending on their availability. They were required to fill in and keep their own manual. The programme comprised several components, including:

- education about dementia, caregiver stress, and understanding patient behaviours
- behaviours the caregiver finds difficult and generating solutions
- communication skills
- challenging negative thoughts
- skills to take better care of themselves, including relaxation CDs
- getting emotional and practical support
- planning for the future
- increasing pleasant activities
- maintaining learned skills.

Two years after completing the START programme, the investigators found that individuals in the treatment-as-usual group were seven times more likely to be anxious or depressed compared with those who received the intervention.

The cost analysis revealed that the cost of the intervention was £232 per caregiver. Findings showed that overall, caregiver costs during a two-year period were £170 higher in the intervention group. However, overall patient costs were £571 lower in the intervention group, owing to less utilization of services.

"Many, many people in the adult population are family carers of someone with dementia. It is not something we necessarily grow up having an ambition to do, but it is something we are doing. Policy is that families will remain frontline providers of unpaid support for people with dementia. This intervention is cost neutral, it significantly improves family carer mental health, and it should be widely available," said Dr G Livingston.
Principle 3: Plans for care of people with dementia focus on delivering coordinated and seamless care from the point of diagnosis

Continuity in care along the disease trajectory is possibly the most important and valued component of care for both the person with dementia and their family carers. Too often people with dementia live as part of a hidden population, only coming to the attention of the statutory services at the later phase when the carer may no longer be able to meet his/her physical care needs or manage distressing behavioural changes. From diagnosis it is essential the person with dementia and those who care for them have access to professional expertise over the whole care continuum to pre-empt such changing needs. Coordination of such care is also vital and often found wanting. A pilot study undertaken by a dementia specialist service found some patients accessing up to eight services concurrently with no coordination.

Dementia UK advocates all people living with dementia should have access to and ongoing support from a dementia specialist such as an Admiral Nurse who can coordinate care and provide vital relational support and practical help for carers. While Admiral Nurses are growing in numbers, demand for their help outstrips supply significantly. In the absence of Admiral Nurses there may be others with dementia knowledge and expertise; subject to receipt of specific training new roles are emerging, for example ‘care navigators’. These individuals will support someone throughout the dementia journey and help navigate them through systems and care services. Information on how this service has been implemented in the Merseyside region of England is included in Section 6 of this guidance. A similar project is to be introduced in Scotland in line with their Dementia Strategy.

Information about services provided by Admiral Nursing can be found on the Dementia UK website, details of which are included in Section 6 of this guidance.

Principle 4: A holistic, needs-based approach considering legal, ethical and moral implications is adopted for both the treatment of symptoms and in the provision of comfort

“I got the treatment and support which are best for my dementia and my life.”

Holistic assessment and treatment is the essence of good clinical care. Despite the similarity of presentation people with dementia and their carers, all will experience the impact of dementia differently depending on their circumstances and environments and will therefore present with varying degrees and range of needs. Scrupulous assessment of needs is required using validated assessment tools. Once assessment of need has been completed, individuals require access to a range of treatments or care interventions to mitigate distress, whatever its nature. This process should follow a cyclical process that identifies and meets different needs as and when they arise, change or abate along the dementia journey. Such assessment is likely to identify needs that call for palliation.

Principle 5: Legal considerations regarding care, compassion and neglect are considered in the assessment and review of people who have a diagnosis of dementia

Poor services and neglect are common among dementia sufferers. Those who lack the ability to make independent choices continue to have a right to be provided with excellent care and treatment to enable them to live and die well and in comfort. At times professionals will want to draw on guidance from the Mental Capacity Act, Deprivation of Liberty Safeguards and even the Mental Health Act to ensure the rights of someone without capacity are being observed.

Further details on addressing legal issues and information on all the legislation and guidance mentioned above can be found on the Department of Health website, details of which are in Section 6 of this guidance.
Principle 6: The therapeutic value of pharmacological interventions

Pharmacological interventions are an important element of the care on offer to individuals who have a diagnosis of dementia. Those prescribing for people with dementia will need to be knowledgeable and skilled in pharmacological treatment and management of the non-cognitive symptoms such as depression, psychosis and distress. In particular, they will need to be confident about the use of antipsychotic medication; when used appropriately to reduce distress, their benefits are weighed favourably against side-effects. Indeed some argue it is unethical not to use antipsychotics when they provide an effective response to severe distress in someone with dementia.44

Further information and guidance on the use of antipsychotic medications for dementia can be found on the National Institute for Clinical Excellence in Health and Social Care (NICE) website, details of which are in Section 6 of this guidance.

Principle 7: Care is delivered by dementia aware and appropriately trained staff and volunteers

“I am confident my end of life wishes will be respected; I can expect a good death.”

In order to ensure dementia care is compassionate, empathic, responsive and appropriate, all members of the team, including volunteers require, an agreed level of skills and knowledge. They will need to learn to deliver care in different and more creative ways, and will often have to adapt current practice to meet the specific requirements for someone with dementia. There is evidence this shift can be difficult and the workforce may be reluctant to do so.7

Staff and volunteers also require support to sustain delivery of high quality care over time. The degree of emotional labour experienced by some members of the staff delivering care cannot be underestimated.34,45 Organisations such as hospices need to be vigilant in assessing staff and volunteer resilience and ensuring effective support mechanism are in place.

A range of resources and suggestions to help with this are included in Section 6 of this guidance.

Principle 8: The impact of dementia on the mental capacity of individuals affected is recognised and addressed in care plans

“I understand so I make good decisions and provide for future decision making.”

As the disease progresses, the person with dementia is very likely to experience changes and ultimately deterioration in their mental cognition to the point where it may be impossible to have a sense of the person’s wishes. It is therefore imperative to preserve their identity and to strive to maintain communication with them through adopting a range of creative strategies. When communication is especially difficult it is vital the care team has established a strong sense of ‘who’ the person is and has clarity about their wishes related to future care. This enables them to care accordingly. Research46 has demonstrated people with dementia often receive sub optimal care at the end of life because their wishes are unknown. For this reason information collected through the process of advance care planning is to be strongly encouraged.
Summary

- Dementia is an unpredictable disease. Many will live for a number of years with this diagnosis, with several transition points over the course of that time.
- Care planning and delivery is best approached using a person-centred model.
- Family carers are central to the wellbeing of the person with dementia. Their requirements for care and support must be acknowledged and efforts made to build their resilience.
- The need for coordination and continuity of care from diagnosis is considered paramount.
- A holistic approach to assessment and treatment is required, which also considers legal, ethical and moral issues.
- Care is delivered by dementia aware and appropriately trained staff and volunteers.
- The impact of dementia on the mental capacity of individuals with dementia should be considered from the outset and efforts made to get to know the individual and their wishes so the unique identity and their preferences can be embraced, even when it is impossible to communicate with the person as his/her condition worsens.
Section 4: What strengths do hospices have to take forward this agenda?

The Commission into the Future of Hospice Care confirmed a vital role for hospices in the delivery of palliative and end of life care in the future – extending to individuals regardless of diagnosis. It described hospice care that is fit for the future, many of its characteristics reflecting the principle of high quality care for people affected by a diagnosis of dementia.

“Hospice care is palliative and end of life care provided by hospices for people of all ages with life-shortening illnesses, their relatives and family carers. It is delivered in partnership with others including local communities, so as to reach out to more of those who could benefit from it, and into the many different settings where care is needed. It is a dynamic and innovative response by hospices, which are constantly adapting to meet the palliative and end of life care needs of the communities they serve.”

This section highlights some of the characteristics of hospice care that relate closely to the needs of people with a diagnosis of dementia, their families and carers (formal and informal). It also describes work already being undertaken by hospices that confirms this fit and provides examples of how hospices utilise their skills to respond to the needs of a new user group.
Hospice care is about dying, death and bereavement and about living with these realities

One of the defining strengths of the hospice movement is its concern with care for people who are coming to the end of their life, their families and their carers. Hospices are seen as beacons of good practice around the care of the dying and the bereaved and have set a standard of care which is observed by many within the UK and beyond as the best. Hospice care is focused on helping people cope with many challenges associated with terminal illness and loss through the delivery of individualised and compassionate care. There is no reason to believe individuals who are dying with dementia, and those close to them, will not face many of the challenges people dying from other conditions experience. For this reason it is equally likely they will benefit from being supported by professionals and volunteers who are confident in this area of care.

Hospice staff are often accomplished in recognising when people are dying, in having difficult conversations with patients and families and providing relief from distressing symptoms. They are also well versed in supporting people to live well, even when they have a condition which is advancing. This focus on quality of life, regardless of prognosis, is an approach to care which would be highly complementary to the care provided by dementia specialists and other related professionals. Hospices are increasingly concerned about working well with informal carers – supporting them pre and post bereavement while also acknowledging their expert carer role. Informal carers of people with dementia have significant needs, and could benefit from much of the help available from hospices including expert carer programmes.

A growing area of expertise on the part of hospices is that of advance care planning for people who are coming to the end of their life. This has particular relevance to people with dementia as an advance care plan, established early in someone’s illness, could be crucial in guiding decisions about their place of care and levels of intervention as they become more unwell and find communicating their preferences more difficult.

In 2012, Willow Wood Hospice in the North West of England appointed a Dementia Specialist Nurse, Ann Regan. Ann will visit and assess the person ideally wherever they are most ‘at home’. There is strong emphasis on recognising and treating pain effectively and minimising distress. Ann undertakes advance care planning with people with dementia and their carers using an ACP toolkit developed by the hospice. The need to provide support to carers is paramount and Ann has seen the benefit of early Best Interest meetings, involving family, professional carers and medical staff. This enables decisions to be made to avoid futile interventions and for the family carer to accept a possibly shorter length of life for their loved one in return for improved quality of the life that remains.
Hospice care is expert, flexible and timely in nature

The expert nature of hospice care is derived from its exclusive focus on helping people who are approaching the end of their life and those close to them. This focus is supported by multiprofessional team work, a corporate commitment to the principles of palliative care, ongoing skills development on the part of staff and volunteers and often purpose built physical facilities. The flexibility and timeliness of hospice interventions is one of the characteristics of hospice care – in recognition of the high stress and changing nature of needs of people facing death or bereavement.

This expertise is highly complementary to that provided by specialist dementia teams and others involved in the diagnosis and support of people with dementia across primary and secondary health and social services. Together they are in a strong position to address the multiple and often changing needs of people with such a diagnosis and their families and carers, throughout the trajectory of the illness. Getting the best out of such partnerships will only be possible if all involved recognise their relative strengths and gaps in knowledge and work together with generosity to design and deliver care.

East Cheshire Hospice has partnered with one of the largest care home providers in the UK caring for people with dementia to introduce a scheme in which hospice and care home clinical staff exchange care environments for a period of two weeks. This approach has enabled many anxieties and myths to be dispelled about work in the ‘other care environment’. The scheme has proved very popular and mutually beneficial for the staff who, in addition to gaining awareness of the other care environment, have acquired important skills and insight into caring for people with dementia at the end of life.
Hospice care is led by people’s needs

The history of hospice care confirms that at its best it is constantly changing in response to the needs of local people and groups. To this end it must seek to gain an understanding of the needs of individuals within their local community in an ongoing way.

Over the years, hospices have moved from caring almost exclusively for people with cancer to providing care for people with heart failure, respiratory disease and neurological conditions, among others. There is also evidence they are beginning to respond to new needs in established beneficiary groups – for example providing rehabilitation opportunities for people with chronic debilitating illness, alongside the provision of more traditional symptom management for people with progressive life-threatening conditions.

So a new shift now to reach out to people affected by a diagnosis of dementia, given the current and anticipated levels of need for high quality end of life care for people affected by this diagnosis, would appear to be appropriate for hospices to embrace.

At patient level, hospices work hard to identify and respond to a person’s specific needs and preferences and those of their family members and carers. This is clearly vital for someone with dementia. Specific dementia tools may assist hospice staff in their assessment of patient’s needs, to which their care plan will respond.

The Memory First service operates across 41 GP practices. The new partnership between a GP Federation, St Giles and Douglas Macmillan Hospices aims to deliver a holistic memory service and improve end of life care for people with dementia. The hospices’ role is to manage a team of care facilitators (CF) who operate as part of the primary care team. The CF receives referrals for people concerned about their memory and offers a holistic home assessment, during which they also conduct a memory assessment and decide whether the patient should be referred to a memory clinic. The CF provides assurance and signposting to a range of services if required; for those requiring a Memory Clinic appointment the CF supports them during and after diagnosis.

The service ensures the CF has time to spend with a patient. The CF can discuss any issues affecting the patient’s physical or psychological wellbeing. The patient can consent to their carer or family member becoming a key part of the care team and also access support from the service.

Since January 2014, over 1,200 patients have accessed the service. Evaluation is via patient and family reported outcome measures in addition to a range of KPIs. The service is evaluating a level of quality we expect from hospice services. A carer said: “It was very reassuring to have someone listen to the problem and understand. The CF was very caring and patient.” A patient said: “Relieved I am alright. I could speak easily. I am more at ease, not worried.” Another carer said the CF had done more to help him cope than anyone else had.
Hospice care is pioneering and innovative

The hospice movement was founded to redress the poor experience of end of life by patients with cancer dying in hospital through investment in brave and creative solutions. This interest to do things differently to improve the lot of people who are dying or bereaved remains a hallmark of hospice care. For this reason, there is good reason for hospice boards to consider investment in developments designed to improve the care available to people with dementia, their families and carers living in their local area. There is no doubt successful solutions will need to be innovative – reshaping existing provision to meet the unique needs of people affected by this diagnosis. Having said that, there is evidence many aspects of hospice care only need minor amendment to become highly suitable for this user group – arguably demanding relatively little resource.

St Christopher’s Care Home Project Team and the South London and Maudsley NHS Foundation Hospital Trust have implemented and evaluated the Namaste Care Programme through an action research study with five London care homes. ‘Namaste’ is the Indian greeting meaning ‘to honour the spirit within’. The care programme was developed in the USA by Professor Joyce Simard (2007) to meet the needs of people with dementia at the end of their lives.

Namaste Care is a seven days a week programme integrating compassionate nursing care with individualised, meaningful activities. The Namaste Care worker seeks to engage people with advanced dementia through sensory input and life review, and to enrich their quality of life. Therapeutic touch, music, colour, food treats and scents are provided in an attractive welcoming environment and family members are encouraged to join the programme. Relatives are supported to acknowledge the progression of dementia in the positive context of seeking to provide quality of life to the end of life.

Namaste Care reduced the severity and frequency of behavioural symptoms in people with advanced dementia, reducing distress and increasing comfort. Care staff, managers and relatives welcomed Namaste Care and judged it had a positive impact on the quality of life of care home residents with advanced dementia. Neither additional staff nor significant expenditure was needed. This sensory based model of care is easily transferable across care environments, including family homes, and has been successfully trialled in an acute hospital ward.
Hospice care is integrated and provided in partnership with others

Much of the success of hospice care lies in the independent status of the majority of hospices. By being established outside the National Health Service they have enjoyed an autonomy that enables them to design new ways of caring and to advocate on behalf of those whose needs may remain unmet in swift and imaginative ways. Having said that, the Commission into the Future of Hospice Care confirmed hospices must be highly integrated into existing systems of health and social care in order that they can influence plans, decisions and care provided by others while also listening and learning in a reciprocal way. There is strong evidence that improvement in end of life care for people with dementia will only happen in a significant way when hospices work in strong partnership with other experts in dementia care to develop new services that draw on the strengths of both.

St Luke’s (Cheshire) Hospice, in collaboration with Dementia UK, undertook a palliative and end of life care population-based needs evaluation for people with dementia and their carers. This work, spanning three CCG’s, considered the current and projected local dementia population and their essential palliative care needs. The resulting report recommended the formation of an innovative Practice Development team to help address the palliative and end of life care service for people with dementia and their carers. The Practice Development team comprises a team leader, speech and language therapist, educational lead post, Admiral Nurse and administration support role.

The new team and its evaluation is being pump primed for two years by East Cheshire Hospice, St Luke’s Cheshire Hospice (the two hospices are forming a funding partnership called Hospice Together) and Dementia UK with a contribution from one of the CCG’s.

The future funding is being picked up by three CCG’s from 2016. The hospices are excited to be working with the local mental health trust that enabled a year’s secondment for the Admiral Nurse position into the team. The secondment leads to tremendous opportunity for cross organisational learning for mental health and hospice and palliative care services. The team is based within the End of Life Partnership and will work with staff in all care settings to enable appropriate high quality care for this increasing sector of our population.
Hospice care is influential in the quality of care provided by others

The founder of the first modern hospice, Dame Cicely Saunders, had a vision of an organisation in which the complementary activities of compassionate care, good symptom control, teaching and research would thrive. Over the years hospices have been true to her vision of them being sources of education and training – often providing a variety of learning opportunities for colleagues in primary and secondary care, the NHS and more recently social care. Many hospices are also working with care homes – in supportive and educative roles.

There is a clear opportunity for hospices to help educate the wide variety of professionals and organisations involved in the support of people affected by a diagnosis of dementia. They have much to offer in terms of planning and delivering holistic care, focused on enabling people with dementia to live and die well and providing support to families and carers before and after the death of someone close to them. They could also share well honed communication skills with professionals working in dementia care.

By the same token, hospices much have to learn from others that in turn will affect their practice. This reciprocal relationship has been at the heart of this project and hugely influential in arriving at its conclusions.

The Education Team at Bolton Hospice work closely with their local Admiral Nurse. Together they have developed and deliver a training package for all hospice personnel, including volunteers, and to date have trained over 500 individuals. Accreditation for this from a higher education institute is being sought.
Hospice care engages with the community

The relationship between hospices and the communities in which they sit are well established. Very often hospices have been conceived and established by local people who have had a vision for a different kind of experience for people facing the end of life and loss. Even when hospices are well established, local communities continue to play a crucial role in the provision of hospice care via fundraising, volunteering and other forms of community participation in care.

Hospices are well placed to galvanise community efforts to support people with dementia and their families and informal carers. They are in a strong position to train volunteers to reach out to these individuals and to help establish new models of care characterised by engagement of local people and communities. Given the substantial burden of care on informal carers and the multiple challenges of living with a diagnosis of dementia – including social isolation – input by volunteers could be particularly valuable.

As noted earlier in the St Christopher’s Hospice contribution, Namaste is a Hindu term meaning ‘to honour the spirit within’. The Namaste Care Service honours people who can no longer tell us who they are or who they were, or care for themselves without assistance. Namaste care is not a medical treatment but a programme designed to improve the quality of life for people with advanced dementia.

The Nasmate project run by St Joseph’s Hospice is funded by Hope for Home. This service is volunteer led and working in a deprived area of East London where people with advanced dementia and their carers are often finding it difficult to cope at home with the increased burden of poverty, social isolation and an inability to access appropriate services and benefits, made more challenging by poor literacy levels or language barriers.

Volunteers have been recruited, trained and matched to work with service users and carers in their own homes and provide emotional support, as well as teach carers how to use massage with someone with dementia.

Evidence has been gathered via case work notes and case work sharing sessions to illustrate often very moving and positive experiences for the service user, carer and volunteer. As one volunteer said: “I can’t believe he managed to open his hands with the massage; I was crying, his wife was crying and he then said thank you to me, and he hasn’t spoken English for years… I can’t wait to get back to the family.”
Summary

• Hospice care has significant strengths and attributes that position it as a valuable element of the care required by people affected by a diagnosis of dementia across the disease trajectory.

• Its focus on end of life care and bereavement could augment care provided by other health and social care professionals.

• Its expert nature means it can help identify when someone is approaching the end of life, engage in difficult discussions about end of life care and offer highly effective palliation of symptoms.

• Its attention to people’s needs means care is highly individualised. This is a key driver in encouraging hospices to extend their care to people with dementia as a new user group.

• The innovation and pioneering spirit of hospices means they are ideally positioned to lead on developments in care that will meet the unique needs of people with dementia, their families and carers.

• When hospices are well integrated in their local health and social care systems they will be highly effective facilitators of end of life care for people with dementia.

• Hospices are renowned for their education and training. If this is undertaken in a reciprocal way with providers of dementia care, then all can expect to be upskilled.

• Hospices’ engagement with their communities ideally places them to call on the time and expertise of local people to better support people with dementia.
Section 5: What must hospices do to support people with dementia, their families and carers?

There is good evidence hospice enabled dementia care for people with a diagnosis of dementia, their families and carers could be a huge benefit. In order to deliver this, hospice leaders will need to assess their organisational readiness and current practice.

Hospices in a position to deliver hospice enabled dementia care will require the following:

1. **A corporate commitment to reach out to people affected by dementia**

   It is vital the Board of Trustees, or relevant governing body, of the hospice give consideration to the question of how the hospice responds to local people who have dementia and could benefit from their service. Explicit confirmation of the importance they place on such a development will be key. Their intentions in this regard will influence the vision for care and relevant strategic and operational plans that guide service development and improvement in the future.

   The board’s consideration is ideally informed by knowledge about the local population served by the hospice and specifically those affected by a diagnosis of dementia. Knowing the numbers currently diagnosed, how these are likely to change in the future and any particular needs or characteristics arising from local demography, are key to identifying the size and shape of the response required on the part of the hospice. Engaging with other knowledgeable providers, those affected by dementia and the broader general public will help the hospice establish services that reflect the needs of those who could benefit from the service. Once the needs of the local population are identified, a gap analysis is possible to assess the degree to which the needs of people with dementia are met by other providers and the hospice.

   If gaps exist in local provision for people with dementia approaching the end of life, the board may want to identify the development of dementia care as a priority for the hospice for the foreseeable future. Boards should seek to satisfy themselves of the skills of the staff in managing dementia related problems and be assured of robust collaborative working practices.

   A shared aspiration to reach out to people affected by dementia and deliver effective and appropriate care must be adopted by the whole hospice, once agreed by the board. This will need to be accompanied by a commitment on the part of the executive team to allocate time and resource to related developments. Periodically, checks are required across the organisation to assess the degree to which this aspiration is shared by staff and volunteers.

   It is suggested establishing dementia champions at board, senior management and clinical levels can be helpful. Their role is to help identify and lead on dementia initiatives, ensuring a commitment to providing dementia-related care remains embedded in hospice plans and any barriers to care identified and addressed.
Checklist 1: A corporate commitment to reach out to people with dementia

- Is there a commitment from the board and executive team with designated leadership to take forward the dementia agenda?
- Do you have dementia champions at board and clinical level to help identify and lead on dementia initiatives, ensuring dementia is embedded in hospice strategies and part of its mission and values?
- Do you know how many of your staff have carer responsibilities for someone affected by dementia? If so how can you support them?
- Are there resources allocated to support the agreed strategy?
- Do you have sufficient intelligence of your local demographics?
- Do you know the current needs of your population in relation to people living with dementia?
- Have you considered how your population is likely to change in the next 5-10 years?
- How much do you understand about the gap between the needs of people with dementia and the degree to which they are being met by the wider care community and your hospice?
- To what degree is your vision of hospice enabled care shared and demonstrated by the knowledge and practice of board members, hospice staff team and volunteers?
- Are you registered as a dementia-friendly community with the Alzheimer’s Society?

- What information does your hospice have in relation to those from marginalised groups locally who may have dementia, ie homeless, prisoners, gay, lesbian, transgender, BME communities, learning disabilities?

2. A collaborative approach to the development of services and skills in response to the needs of people affected by a diagnosis of dementia

Hospices need to ensure they meet and talk with local specialist dementia services and that they are identifying the needs of people in acute hospitals and care homes who may face poor care towards the end of life. Eighty per cent of people living in care homes have dementia and are frail with complex comorbidities, thus making the case for their meriting a more palliative care approach.

Hospices need to develop/contribute to a broad portfolio of services for people with dementia, their families and family carers. Individuals affected by a diagnosis of dementia require a wide range of support to maximise independence, social connections and opportunities for activity as well as the more traditional care as their condition deteriorates.

Such a portfolio can only be achieved for individuals in any area when a whole range of providers and members of the local community work together. By far the strongest innovations observed during the Dementia Project were multi-agency in nature with the focus squarely on the needs of people living with a diagnosis of dementia. Such a shared focus is achieved through ongoing dialogue with potential users of the service and those that represent them. Various organisations exist locally and nationally to do this and hospices must establish strong, open relationships with them. It is vital hospices work with other providers in the statutory and voluntary sector, across health and social care, to establish an integrated and seamless approach to care. They must recognise they are one very small
element of dementia care and as such cannot support everything and everyone; however, they can make a significant contribution in the right place at the right time.

In addition, hospices should engage in partnerships that allow reciprocal exchange of learning whereby hospices offer training around end of life care and learn about specific aspects of dementia care from experts outside their organisation.

Checklist 2: A collaborative approach to the development of services and skills in response to the needs of people affected by a diagnosis of dementia

- What links to you have with current providers of dementia support and services in your locality?
- Do you meet and discuss strategy and service development with them?
- Have you involved or consulted with people in your locality living with dementia including carers?
- Are there mechanisms within partner organisations to facilitate this, or systems you could adopt?
- What do you know of the objectives and quality of service and reach of these organisations?
- Are you engaged /could be engaged as co-designers of services?
- Have you explored or are aware of how other hospices are contributing to the dementia agenda?
- Could you adopt or replicate any of these approaches and models?
- What barriers do people with dementia and their carers face when wanting to participate and access services from the hospice?

3. A creative approach to adapting existing models of care to meet new needs and preferences

Hospices must use their established expertise in the palliation of distress and pain alongside their skills enhancing comfort creatively to further develop models of care which are person and family centred and emphasise the importance of self-management wherever possible. Hospices can play a vital role in informing people affected by a diagnosis of dementia about the services available, helping to coordinate input and providing holistic care and support as required – including care in the community. They will often have well developed models of 24 hour access to advice for families and carers; they are expert in helping individuals plan ahead when faced with a diagnosis of a life-threatening illness and are becoming increasingly confident about helping people to manage their own conditions. Their knowledge of symptom management is finely honed. With some adaption these services could enhance and augment provision by others.

Hospices may wish to identify some initial developments or ‘quick wins’, reflective of gaps in local provision, which they could support. Some possible areas could be:

- upskilling dementia professionals’ knowledge in care towards the end of life, and communication/having difficult and sensitive end of life conversations
- training in the identifying and managing distress and pain
- linking into the memory assessment and treatment services to be possible link to support advance care planning
- offering symptom assessment and management in care homes, supporting the use of assessment tools, interpretation and subsequent symptom management
- facilitating ‘best interest’ discussions with care home staff groups
• establishing relationships so as to be able to provide support via telephone to care home staff
• undertaking joint working between the hospice and specialist dementia service.

Checklist 3: Creative efforts to adapt to existing models of care to meet new needs and preferences

• To what degree are your models of care evolving to incorporate the needs of individuals affected by dementia?
• Are you exploring creative models of care in order to extend your reach and build care capacity in the community, ie attending dementia cafes, information giving/signposting sessions?
• Is there a co-coordinator role function built into the model of care operating in your area?
• Is there an opportunity to provide care for the carer/family in a range of options?
• Are there opportunities for partnership and collaboration in building new models/pathways locally, eg participate in joint visits with a dementia expert?
• What are your partners doing? What dementia specific models of care do they use?
• Do you have access to an Admiral Nursing Service?
• Can you identify any areas of practice in your hospice you could change that would bring benefits to people with dementia and their carers quickly?
• What barriers do people with dementia and their carers face when wanting to participate and access services from their local community?

4. An evidence-based approach to care and the care environment

‘Optimum care’ is a term coined by an EAPC dementia white paper. It describes care that is person centred and considers the best and most favourable approach, taking into account the individual and their needs. Optimum care should be reflective of research evidence and formal guidance, wherever it exists and is the practice standard.

Dementia care enjoys a growing body of evidence about what is effective and considered best practice. Hospices need to become familiar with this body of literature and consider its application to their work and services. The Commission into the Future of Hospice Care (2013) has described in some detail a model of research activity on the part of hospices. At the minimum, it suggests hospices are aware of relevant research and are able to consider the relevance of its findings. At its best, hospices will be engaging in research of their own, and seeking collaboration with others to undertake research that supports ongoing development of care.

There is some evidence in end of life care, such as the VOICES survey, which confirms a good experience of many who die having accessed hospice care. Hospices have some knowledge of the contributory factors to this experience and are in a strong position to ‘export’ this success to other providers and into other settings. Which aspects of care and how they are successfully transferred could be a very interesting area of collaborative research to be undertaken by hospices in, partnership with colleagues with dementia expertise such as Admiral Nurses, dementia nurse specialists and dementia nurse consultants and interested academic centres.
Recent research illustrates the huge importance of a dementia friendly environment to those affected with the disease (see Section 6 for guidance and useful references about this). Such an environment will give consideration to the contents and use of rooms, lighting, signage, colour contrast, floor covering, stairs, lifts, outside spaces and entrances. Some of the modifications may be quite simple, e.g. wall colour is used to demarcate room changes. The use of technology can also contribute to providing a safe environment by monitoring the person’s movement.

Increasingly we must remember that many visitors to a hospice may have impaired, cognitive ability so a dementia-friendly environment will ensure all feel welcomed. It must also be said that such changes to the physical environment alone do not make it dementia friendly, it is as much about the dementia awareness and welcoming attitude of the staff and volunteers they encounter.

Checklist 4: An evidenced-base approach to care and the care environment

- Is your hospice a dementia-friendly environment (DFE)?
- What training have you done with staff in dementia awareness?
- Do you need to access specialist architectural advice/support on DFEs?
- Are you building your practice with reference to key national and international guidance?
- Are you seeking opportunities to build the current body of knowledge by undertaking research yourself?
- Are you collaborating with others to establish new intelligence and promote knowledge transfer to other groups of professionals and settings?
- Do you have links with higher education institutions or other organisations locally who engage in research activity, i.e. Age UK, Alzheimer’s Society?
- Have you identified any physical limitations and constraints i.e. listed building status?
- What is the purpose, and contents, of rooms? Are these clear? Are there sufficient visual cues to guide patients and visitors with dementia around environments? Visual cues can influence behaviours in both a positive and negative manner.
5. Investment in the development and support of its workforce (staff and volunteers)

It is essential for hospice staff and volunteers to be educated and trained to deliver the optimum standard of care for people living with dementia across a range of care settings. Setting up a dementia interest group may be one way to provide in-house learning and ownership in developing practice. The need to build and maintain dementia awareness and empathic practice organisation wide (including retail shops) is an area that requires regular review. The potential emotional burden experienced by staff and volunteers, as they may experience perplexing or difficult behaviour and perceived unrewarding responses, cannot be underestimated. For this reason, proactive approaches to staff support are required.52

Checklist 5: Hospice staff and volunteers to be educated and supported to deliver the optimum standard of care for people living with dementia and their carers

- How are you building awareness, knowledge, skills and confidence throughout the organisation, including your retail shops?
- Do your staff/volunteer induction programmes incorporate dementia awareness and friendliness? If not how can you build on this?
- Does your mandatory training include upskilling staff/volunteers to ensure dementia awareness and skills are fit for purpose?
- Do you have recognised tiered levels of training and skills supported by core competencies and, as needed, specialist competencies?
- Are you confident you have the right skills, in the right place, at the right time?
- Are there support mechanisms for staff and volunteers to access so as to strengthen their resilience?
- Where do you access your dementia awareness and beyond training? Is this fit for purpose? How are you evaluating the impact of this?
- Is there sufficient financial support to enable study leave for those taking higher level courses/training in building dementia expertise?
Summary

Hospices interested in becoming effective in the delivery of hospice enabled dementia care need to establish and maintain:

• a corporate commitment to reach out to people affected by dementia
• a collaborative approach to the development of services and skills in response to the needs of people affected by a diagnosis of dementia
• a creative approach to the adaption of existing models of care to meet new needs and preferences
• an evidence-based approach to care and the care environment
• investment in the development and support of its workforce (staff and volunteers).
Section 6: Resources to help hospices achieve high quality care for people with dementia, their families and carers

1. General dementia information (including organisations)

Age UK
General information and advice on finances, capacity and other legal issues.
http://www.ageuk.org.uk

Alzheimer’s Society
Useful for general information on all types of dementia. They offer a range of publications to aid population-based needs assessments, as well as the ‘This is me’ booklet to aid person-centred care. Access to the Society’s dementia training is available from the website along with information on the Dementia Champions and Friends initiative.
http://www.alzheimers.org.uk

Dementia UK
General dementia information. Dementia UK is now predominantly supporting the introduction of Admiral Nurses and their practice nationally; their website contains a useful directory of local Admiral Nurses. They also run a dementia advice line.
http://www.dementiauk.org

E–PAIGE
An electronic palliative and end of life care website. Predominantly developed with Cheshire in mind, this website is now available to all. It is linked to the End of Life Partnership in Cheshire. It has information on local and selected national training opportunities and a dementia portal with lots of information on dementia and end of life care that is applicable across the board and caring contexts. Documentation on the site pertains to local specification and need but can be used and adapted by others with acknowledgements to the original source.
http://www.cheshire-epaige.nhs.uk/SitePages/Home.aspx

2. Vision, strategic planning, commissioning and partnership working

*All nations have their own dementia strategies; individual hospices will need to locate and explore the content of these depending on their location within the UK.

Health Scotland
http://www.healthscotland.com

Investing for Health in Northern Ireland
http://www.dhsspsni.gov.uk/ifh

NHS England
http://www.england.nhs.uk

NHS Wales
http://www.wales.nhs.uk

Department of Health (DoH) UK
The DoH website contains many publications and guidance including: Dementia Strategy; Mental Capacity and Deprivation of Liberty (DoLS); Human Rights Act; The Care Act and the Dementia Challenge.
https://www.gov.uk/government/organisations/department-of-health

Dying Matters
General information on death and dying.
http://www.dyingmatters.org

European Association for Palliative Care
General information and dementia publications including the ‘EAPC guidelines for palliative care for older people with dementia’ 2013.
http://www.eapcnet.eu/
Health Guides
A Map of Medicine is available but a licence is required to benefit from the full version; a limited number of pathways, including dementia, are made available free of charge via NHS Choices and this website.

National Council for Palliative Care
Offers dementia-specific publications.
http://www.ncpc.org.uk

National End of life Care Intelligence Network
General demographic information and demographics pertaining to dementia numbers/statistics in England; useful for population-based assessments. There is also a mental health, dementia and neurology network linked to this. Data pertaining to dementia is limited to date.
http://www.endoflifecare-intelligence.org.uk

National Institute for Health and Care Excellence
Lots of information on many aspects of dementia including: pathways; quality markers; care guidance including palliative and end of life care; commissioning guidance; guidance on use of cognitive enhancers; guidance on the use of antipsychotic medications in dementia.
http://www.nice.org.uk

Nuffield Trust
Offers dementia-specific publications.
http://www.nuffieldtrust.org.uk

Primary Care Web
A Dementia Prevalence Calculator can be found on this site which is useful for population-based assessments. An NHS mail address is needed to access this site, however restricted access will be granted to none NHS organisations such as hospices.
https://www.primarycare.nhs.uk

3. Care specific resources
Gold Standard Framework Prognostic Indicator Guideline for dementia and frailty
http://www.goldstandardsframework.org.uk

Supportive and Palliative Care Indicators Tool
Prognostic Indicator Guideline developed in Edinburgh (alternative to GSF PIG above).
http://www.spict.org.uk

Evidenced-based dementia specific symptom assessment tools:
CNPI (Checklist of Non-verbal Pain Indicators)
Measures pain behaviours in cognitively impaired older adults.

DisDAT (Disability Distress Assessment Tool)
Observational assessment tool initially designed for use in people with learning disabilities. Now used to help identify distress cues in people who, because of cognitive impairment or physical illness, have severely limited communication. Distress can be a sign of pain in dementia.

DOLOPLUS 2
French behavioural assessment tool which includes pain assessment.

NOPPAIN (Non-communicative Patients Pain Assessment Instrument)
Observational pain assessment tool.

PACSLAC (Pain Assessment Checklist for Seniors with Limited Ability to Communicate)
Observational pain assessment tool.

Pain Assessment guidelines
http://www.guidelines.co.uk/central_nervous_system_wp_dementia_jun14#.VQgYbI6sWPb

PAINAD (Pain Assessment in Advanced Dementia)
Observational pain assessment tool adapted for use in dementia from the Dis-DAT above.

Quality of end of life care in dementia assessment tools:
SWC-EOLD (Satisfaction with Care at End of Life in Dementia)
10 item questionnaire administered to family carers.

SM-EOLD (Symptom Management at End of Life in Dementia)
10 item questionnaire for care staff.
CAD-EOLD (Comfort Assessment at End of Life in Dementia)
10 item questionnaire for care staff and family carers.


4. Personal experiences

Common sense caregiving discussions: having that end of life conversation with your loved ones when dementia is involved
Twenty-eight minute long open discussion with two people with dementia about death and dying.
http://vimeo.com/87399807

**Essential Conversations – Talking about death and dementia**
Alzheimer Scotland video talking about death, dying and dementia. Emotional resource to help enhance confidence and skills in supporting people with dementia and family carers to have conversations about death and dying.
http://www.essentialconversations.org.uk

**Glorious opportunity**
Retired GP recounting her experience of living with early onset dementia.
http://gloriousopportunity.org

**The Caregiver’s Voice**
“I want to go home” narrative.
http://t.co/sSp8aY8HxS

**Video about end of life care**
Eight minute long video of a person with dementia talking about living and dying with dementia and what people can do to help.
http://youtu.be/Y_QT9cas37k

5. Education and training for all levels of staff

**Bradford University – Bradford Dementia Group**
Offers undergraduate and postgraduate online, distance and taught courses including end of life care.
http://www.brad.ac.uk

**Dementia Services Development Centre**
Offers online, distance and taught courses which include end of life care. Some courses and modules here are suitable for care home staff and healthcare assistants/support workers.
http://www.dementia.stir.ac.uk

**Dementia Services Development Centre**
Bangor (linked to Psychology Department)
Offers postgraduate courses.
http://d IDC bangor.ac.uk

**e-Learning for Healthcare (includes dementia)**
http://www.e-lfh.org.uk

**Essential Conversations**
Alzheimer Scotland video talking about death, dying and dementia. Emotional resource to help enhance confidence and skills in supporting people with dementia and family carers to have conversations about death and dying.
http://www.essentialconversations.org.uk

**Gold Standards Framework**
Dementia end of life care specific training available aimed at all care staff in different environments.
http://gsfcentre.co.uk

**Kings College University**
Offers full and part-time taught MSc in Advanced Dementia Care.
http://www.kcl.ac.uk

**NHS England**
Different levels of training, awareness and information on dementia.
http://www.england.nhs.uk
Northern Ireland Dementia Services Development Centre
Offers various courses, leadership skills, meaningful activities for people with dementia, assessment skills and best practice.
http://www.dementiacentreni.org

Skills for Care
Social care training in dementia and end of life.
http://www.skillsforcare.org.uk

Skills for Health
Focus more on workforce development but there is some dementia training.
http://www.skillsforhealth.org.uk

Social Care Institute for Excellence
E-learning open dementia programme includes dementia and end of life training.
http://www.scie.org.uk

University of Manchester
Offers bi-annual taught MSc in Dementia, with different exit points, ie postgrad cert, postgrad dip or MSc
http://www.manchester.ac.uk

University of Salford – Institute for Dementia
Offers taught MSc in Dementia, with different exit points, ie postgrad cert, postgrad dip or MSc.
http://www.salford.ac.uk/salford-institute-for-dementia

Worcester University – Association of Dementia Studies
Offers undergraduate and postgraduate taught dementia specific courses.
http://www.worcester.ac.uk

6. Dementia friendly Environments (DFEs)

Dementia Services Development Centre
Offers specific training and courses on developing dementia friendly physical environments. Also offers dementia design checklist, audit tool and publications on design and dementia. Some items incur a cost.
http://www.dementia.stir.ac.uk

Housing Learning and Improvement Network
Guides to buildings and environments friendly for a number of conditions including dementia. Also has a dementia specific portal.
http://www.housinglin.org.uk

Kings Fund guidance on building DFEs including residential workshops.
http://www.kingsfund.org.uk

Social Care Institute for Excellence
Practical tips and advice for making existing living spaces safer, user-friendly and more enjoyable for people with dementia.

Innovations in Dementia
Access to advice and checklists on design and dementia.
http://www.innovationsindementia.org.uk

Dementia Without Walls
Advice and guidance on DFEs and dementia friendly communities.
http://www.jrf.org.uk/topic/dementia-without-walls

Pioneer Network
Offers advice and tips on how to change existing physical environment to DFEs on a budget.
http://www.pioneernetwork.net/DesignOnADollar/

7. Other useful resources

And still the music plays: stories of people with dementia

Alzheimer’s Research UK
http://www.alzheimersresearchuk.org

Contented dementia: a revolutionary new way of treating dementia: 24 Hour wraparound care for lifelong wellbeing.

Dementia Nursing Research Taskforce
Updates on research and progress within the Royal College of Nursing.
http://www.rcn.org.uk/development/research_and_innovation
Dementia revealed: what primary care needs to know
Department of Health (2014).

Dementia: the one stop guide: practical advice for families, professionals and people living with dementia and Alzheimer’s disease

Digital life story and occupation in dementia
http://www.mylifesoftware.com

Ethical issues in dementia care: making difficult decisions

Haylo Theatre: Over the Garden Fence
Hour-long play looking at fractured memories and altered perception of reality in dementia. Portrays a relationship through dementia between a grandmother and her grand daughter. Plays can be adapted to suit training needs and can include different aspects of dementia.
http://haylotheatre.co.uk

Hope for Home
Hope for Home is a charity aims to help elderly people with dementia and/or advanced Parkinson’s disease and their carers who are looking after their loved ones in their own homes.
http://www.hopeforhome.org.uk

House of Memories – National Museums Liverpool
NHS England supported dementia training for all.
http://www.liverpoolmuseums.org.uk/learning/projects/house-of-memories

How would I know? What can I do? How to help someone with dementia who is in pain or distress
The National Council for Palliative Care (2012).

Innovations in Dementia
Lots of up to date information on work in dementia.
http://www.innovationsindementia.org.uk

Mersey Care NHS Trust
Care Navigation in Dementia service which has had positive evaluation.
http://www.merseycare.nhs.uk

Palliative care in severe dementia in association with Nursing and Residential Care.

Playlist for Life
Highlights the importance of music in dementia care. Similar to life history work but life history in music.
http://www.playlistforlife.org.uk

Royal College of Nursing dementia work
Offers SPACE good practice in dementia guidelines.
http://www.rcn.org.uk/development/practice/dementia#dig

Seeing beyond dementia: a handbook for carers with English as a second language

St Christopher’s Hospice Education and Training
Dementia end of life care training available, as well as information on the Namaste in Care Homes research.
http://www.stchristophers.org.uk/education

The enduring self in people with Alzheimer’s: getting to the heart of individualised care

The forgetful Elephant
An illustrated book for children on forgetfulness in adults as a result of dementia and other illnesses. Could be useful in hospice generally and not just for dementia alone.
http://www.irenemackay.com/forgetful-elephant

The Lifestory Network
Organisation dedicated to the importance of lifestory work in the case of people with dementia.
http://www.lifestorynetwork.org.uk
The Triangle of Care
Model for dementia care that supports a partnership approach between the person with dementia, the staff member and carer.
http://www.rcn.org.uk/development/practice/dementia/triangle_of_care

The validation breakthrough: simple techniques for communicating with people with “Alzheimer’s-type dementia”

University of Tasmania
Offers a free open online course in dementia awareness. If embarking on this course, be mindful of different legislations and services in the UK.
http://www.utas.edu.au/wicking/wca/mooc

University of Wollongong
Australian work on younger onset dementia. Includes literature reviews.
References

2. European Association for Palliative Care (EAPC) (2013). EAPC White Paper: Recommendations on palliative care and treatment of older people with Alzheimer’s disease and other progressive dementias. EAPC.

20. The future of hospice care for people living with dementia (ehospice article). http://www.ehospice.com/uk/Default/tabid/10697/ArticleId/10538/


Glossary of terms

**People with dementia**: People we are aware of with a formal diagnosis of dementia.

**People affected by dementia**: Includes all those around the person with dementia.

**Carer**: All informal carers be they partners, spouses, family member, friends who are providing support and care for the person living with dementia.

**DFE**: Dementia Friendly Environment.

**ACP**: Advance Care Plan.
## Appendix 1: Levels of access to hospice enabled dementia care

<table>
<thead>
<tr>
<th>Level of access</th>
<th>Issue</th>
<th>Available tools/aids</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary access</strong></td>
<td>Where access is denied to a particular social group or type of condition, eg people with a primary diagnosis of dementia</td>
<td>Includes all tools which facilitate a population-based model of care, eg census data, Marie Curie Atlas of Care, End of Life Care Observatory</td>
</tr>
<tr>
<td><strong>Secondary access</strong></td>
<td>Where referral for an individual from a minoritised group is accepted but when explored their journey through the service is unequal to that of other mainstream users, ie they are not offered the full range of holistic services, eg day services, complementary therapies or counselling</td>
<td>Public and Service User Involvement Group – which can inform as to the experience of trying to gain access or why they refused access when offered it Undertaking a process – map of individuals or groups through services and comparing this with mainstream users process map will highlight differences</td>
</tr>
<tr>
<td><strong>Tertiary access</strong></td>
<td>Where all referrals are accepted but the service that is offered is the same despite different groups or individuals having different needs. In this sense the service offered is ‘equal’ but not ‘equitable’ NB: ‘Equity is the principle of treating equal things equally and unequal things unequally’ (Aristotle)</td>
<td>Undertaking an Equality Impact Assessment of services, policies and personnel will highlight barriers to primary and secondary access Need for partnerships with community groups and individuals with specific expertise in the needs of these clients/patients, eg Age UK, Admiral Nursing Literature search required to develop evidence base Developing a Compassionate Communities approach</td>
</tr>
<tr>
<td><strong>Ultimate access</strong></td>
<td>Where service user feedback is sought but although the same themes arise they are never addressed ‘we’re the experts’ model of care promoted</td>
<td>Need to involve potential service user and refusers of service in commissioning, designing, delivering and evaluating services Tools: Co-production principles and Patient Leadership models need to be researched, piloted and established</td>
</tr>
</tbody>
</table>

Appendix 2: Dementia trajectory supported by hospice enabled dementia care

### Finding out it’s dementia: ‘Nothing has changed yet everything is different’

**Person with dementia’s needs/wishes:**
- Information; Communication; Assessment; Treatment; Inclusion; Consultation; Coordination; Supportive care; Signposting; Enabling choice; ACP.

**Carers’ needs/wishes:**
- Information; Communication; Assessment; Signposting; Inclusion; Consultation.

**Hospice contribution**
- Link with memory assessment services to support staff by enabling/facilitating difficult conversations; Complementary therapies; Develop partnerships with local providers including voluntary and Third Sector; Supportive care; Contribute to Public Health partnerships, consultations and education awareness raising of services on offer; Support Dementia Friends initiative; Support Dementia Action Alliance; Identify local dementia populations and needs.

### Living well

**Person with dementia’s needs/wishes:**
- Coordination; Information; Communication; Inclusion; Consultation; Review (mental/physical health/ACP); Occupation; Supportive care; Enabling choice; Signposting; ACP.

**Carers’ needs/wishes:**
- Information; Communication; Review of needs; Supportive care/guidance; Signposting; Inclusion; Consultation.

**Hospice contribution**
- Information; Communication; Future planning (ACP); Enable/facilitate difficult conversations; Public Health initiatives; Consultations; Signposting; Complementary therapies; Education for families and professionals; Promote dementia awareness raising; Support Dementia Friends initiative; Support Dementia Action Alliance; Ensure dementia patients have access to ‘out of hours’ advice services; Engage with local partners to develop services based on needs assessment.
<table>
<thead>
<tr>
<th><strong>Living well with help and support</strong></th>
<th><strong>End of life, dying well</strong></th>
</tr>
</thead>
</table>

### Person with dementia’s needs/wishes:
- Coordination; Information; Communication; Review (mental/physical/ACP); Inclusion; Consultation; Support with choices; Support with accepting changes; Support with accepting help and care; Bereavement/grief/loss support (both).

### Person with dementia’s needs/wishes:
- Coordination; Information and communication where possible; Review; Symptom assessment; Symptom management; Review of choices (ACP); Respect for wishes/choices; Comfort care.

### Carers’ needs/wishes:
- Information; Communication; Inclusion; Consultation; Review of needs/practical help; Support with future choices/Best Interest decisions; Support with accepting change; Bereavement support; Respite options; Complementary therapies; Support with navigation through care.

### Carers’ needs/wishes:
- Information; Communication; Inclusion; Consultation; Support with Best Interest choices; Complementary therapies; Bereavement support; Practical advice.

### Hospice contribution
- Information; Communication; Enable/facilitate difficult conversations; Support organisational partners/providers; Education for families and professionals; Signposting; Complementary therapies; Respite options; Dementia buddies (volunteers); Dementia cafes, information/support sessions; Continued engagement with partners to review and develop services.

### Hospice contribution
- Information; Communication; Complementary therapies; Enable/facilitate difficult conversations; Advice on symptom assessment/management; Best Interest decisions at end of life; Education of families and professionals on end of life care; Practical advice on death; Bereavement support; Volunteering opportunities.
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