



**Submission from the Irish Hospice Foundation
to the Department of Health
for the National Dementia Strategy**

National Strategy on Dementia
Department of Health,
Hawkins House - Room 2.04,
Dublin 2.

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The Irish Hospice Foundation (IHF) is a national charity dedicated to all matters relating to death, dying and bereavement. Our work centres on development, support and advocacy and we work in partnership with statutory providers and the voluntary sector to deliver our programmes.

We welcome the invitation from the Department of Health to submit to the development of a National Strategy on Dementia.

Summary

Ensuring that people with dementia and their families are afforded opportunities to discuss and plan for their future care throughout their disease trajectory, may relieve some of the anxieties and apprehension that people with dementia and their families face, and help them get on with living.

Supporting the delivery of appropriate levels of palliative care within dementia services will take place in the wider context of health service enhancement for people with dementia, as well as the increasing accommodation of Irish society to ensure ongoing inclusion of people with dementia and their families.

Providing a framework that supports the inclusion of palliative care principles into routine dementia care will support staff in delivering a model of care that is consistent with a public health palliative care approach.

This submission sets out the specific priorities of the the Irish Hospice Foundation to be addressed by the National Dementia Strategy in Section 2, page 4.

The Irish Hospice Foundation will continue to take a lead role in advocating and supporting the need for dementia palliative care within all health care settings, so that people with dementia and their families can live their life with dignity and receive quality end of life care that is already available to other people with life limiting diseases. We look forward to the guidance and direction emanating from the forthcoming strategy to support us in this task.

Background

Whilst dementia is recognised as a progressive chronic condition, it is not always understood or accepted as a life limiting disease. Many people with dementia will experience age-related life limiting co-morbidities such as heart failure, COPD and cancer. The essence of palliative care encompasses both the needs of patients and their families, and although traditionally associated with cancer and for those who are imminently dying, is now increasingly being linked to all life limiting diseases and can be introduced for holistic symptom management throughout the disease trajectory. It is thus appropriate that the National Dementia Strategy would ensure a strong focus on ensuring that the palliative care needs of people with dementia and their families are recognised and responded to.

The relevance of palliative care for people with dementia has grown momentum in the past decade, with key international organisations recommending appropriate levels of palliative care for people with dementia (Alzheimer Australia 2006, Alzheimer Europe 2008, European Association of Palliative Care 2010 and the World Health Organisation 2012). From UK perspective, in 2007, the UK NICE Clinical Guidelines developed to support people with dementia and their carers recommended that dementia care should incorporate palliative care principles from diagnosis and throughout the disease trajectory, and since then the UK Department of Health Strategies on End of Life Care (2008) and Dementia (2009) have recommendations to support this approach.

In Ireland the need to introduce a palliative approach to dementia care has been recognised most recently by Cahill et al in *Creating Excellence in Dementia Care* [1].

The Irish Hospice Foundation, since 2005, as part of the Palliative Care for All Programme, has taken a lead role in supporting the provision of palliative care for people with dementia in Ireland through the funding of the following dementia palliative care research projects and service developments: ASI - Opening Conversations (2010); St Vincents Hospital Athy - Future Planning (2010 – 2013); Clare Mental Health Service for Older People – Action research in Dementia and Palliative care (2010 – 2012) and ASI/IHF – Feasibility Study on Dementia Palliative Care (2012).

These projects and developments have assisted in creating greater recognition of the relevance and need for people with dementia and their families to have access to appropriate levels of palliative care throughout their disease trajectory. This submission will be based on the findings of these projects, as well as the learning from the IHF Hospice Friendly Hospital programme.

Section 1 of this submission will provide an outline of the relevance of palliative care for people with dementia and their families, and Section 2 will list the priorities to support the delivery of palliative care for people with dementia, that should be contained within the National Dementia Strategy.

1. The relevance of palliative care for people with dementia

Introducing palliative care principles within a dementia care framework, will help to ensure that people with dementia will receive the person-focussed and relationship-centred care that is traditionally associated with dementia care, alongside the care associated with the palliative approach which emphasises holistic care, focussing on quality of life, respecting patient autonomy - for both the person with dementia and their family throughout their disease and into bereavement. Palliative care promotes the identification of a range of physical, psychological, emotional and spiritual symptoms for all those with life-limiting disease and advocates for appropriate treatment and responses, and considers the needs of both the person with the illness and their family members.

Applying palliative care principles in routine dementia care can help address many of the complex symptom management and ethical care issues that present for people with dementia and their families throughout their illness, including decisions relating to hydration and nutrition, burdensome physical interventions, advance care planning and addressing issues relating to loss and bereavement.

This section will outline the rationale for palliative care from perspectives of people with dementia, families, society and health care professionals.

- Throughout their disease trajectory, people with dementia can experience difficult transitions related to symptom progression and loss of independence. These difficulties can be compounded by the varying degree of support their family and friends can provide. Whilst focussing on maintaining independence, the introduction of palliative approach early in their disease trajectory will help to ensure that people with dementia will receive opportunities to plan their future care, seek to address any fears and apprehensions by providing appropriate information and guidance with regard to decisions about future care needs and an outline of the disease trajectory.
- As the principles of palliative care extends to families, the introduction of a palliative approach in dementia care will support family members as they become the advocate for the person with dementia. The complexities and burden of decision making that family members experience can be overwhelming, and a dementia palliative care framework would ensure that the services can support and guide family members by providing information and advice with regard to the potential disease trajectory and anticipating decisions and care needs. This approach would also recognise and support the loss and bereavement that family members experience as their relationship with the person with dementia changes during the disease progression and after their death.
- The stigma associated with this illness can present challenges for people with dementia to seek a diagnosis, and then communicate to their friends and family about the impact of this illness on

their life, leading to withdrawal and isolation. Adopting a public health palliative care approach to the disease will acknowledge and create greater understanding about the impact of the disease trajectory – from diagnosis to death and bereavement - amongst the general public and health and social care policies [2]. This will, in turn, generate increased consideration and support from all aspects of society for people with this disease and potentially reduce the burdens and seclusion associated with this disease.

- Health care professionals support people with dementia and their families with complex decision making with regard to treatment options relating to end of life care and advance care planning. To date there is a dearth of guidance or frameworks available to staff to respond to these needs with competence and confidence, often resulting in staff experiencing inadequacy in their care delivery and patients and families feeling unsupported. Findings from the IHF research and development projects have demonstrated a demand from health care professionals working with people with dementia for more support in the area of advanced communication skills, ethical decision making and clinical guidance with regard to hydration and nutrition. Specialist palliative care staff have indicated that a collaborative model of care would benefit from those patients with dementia who have specialist palliative care needs.

2. Supporting the delivery of appropriate levels of palliative care for people with dementia

There are a number of issues that present when seeking to ensure that people with dementia receive appropriate levels of palliative care, including: the terminology and language used; referencing the benefit of palliative care on dementia information material; provision of education and training; policy and clinical support; efficient communication systems across the many health care settings that people with dementia interface; and research. These themes are elaborated below.

2.1 Language and terminology

The development of conversation prompts and guidance documents to enable discussion in relation to addressing palliative care needs of people with dementia, will assist staff in this aspect of care delivery, and will support meaningful and constructive dialogue with people with dementia and their families in this sensitive yet fundamental aspect of care. The Alzheimer Society of Ireland Report - Opening Conversations [3] outlined how difficult it is for staff, people with dementia and families to talk openly about dementia; introducing conversations related to palliative care is even more challenging. The use of palliative care terminology can be daunting and invoke anxiety amongst people with dementia, their families and staff.

2.2 Information material for people with dementia and their family

Information material that is developed for people with dementia should have appropriate references to the benefit of a palliative care approach throughout the disease and specific leaflets should be developed on topics such as advance care planning, hydration and nutrition, loss and bereavement.

In general the information material that is developed to support people with dementia and their families focuses on memory coping strategies, access to services and financial planning. There is an absence of material available describing the potential disease trajectory that lies ahead, and suggestions on how to prepare for transitions and complex decisions as the disease progresses. The availability of such material in the UK has supported people with dementia with conversations and discussions about their future care needs so that they can 'get on with living', as demonstrated by the quote below:

'The thing is once you've spoken about these things (as hard as it might be) you can put them away and focus on enjoying things'[4]

2.3 Education and training

Formal and informal education and training to support the delivery of palliative care in dementia settings is required. Formal review of existing course curricula should be carried out and cross referenced to the pending [HSE palliative care competence framework](#). This needs to be considered at undergraduate and postgraduate level as well as inclusion in the continuing professional development programmes. Opportunities for informal and responsive training inputs in relation to the delivery of palliative care for people with dementia must also be made available as staff often require immediate support to deal with increasing complexity of care of certain people with dementia and respond to family needs, enabling continuity of care. These opportunities will be enhanced where there is local leadership and collaboration between the specialist teams.

2.4 Policy and clinical support

It is essential to establish a clinical directorate in dementia within the existing health care structure, in order to champion the necessary policy service developments for people with dementia and their families. Such a dedicated resource will assist in the implementation of the National Dementia Strategy and ensure that the relevant aspects of this strategy are cross referenced with the other clinical programmes in the HSE as appropriate. Based on the success of the IHF Hospice Friendly Hospital initiative, this directorate could examine and support the development of a Dementia Friendly Health Service initiative, and establish integrated dementia care pathways in acknowledgement of the significant patient numbers with dementia being cared for in acute settings. In light of the increasing number of people with dementia who will be cared for in community settings, this directorate should prioritise resources towards flexible dementia orientated community based services.

2.5 Communication systems

Efficient communication systems across all health care settings are required to ensure consistent and safe care of people with dementia, as they are challenged in their capacity to communicate their own health and social care needs across the various care settings they interface. In addition to up to date electronic patient records that can be accessible in the various health care settings that people with dementia access, the development of a patient passport for people with dementia should also be considered.

2.6 Building a research platform

Formal opportunities for dissemination and networking are required to assist in sharing the emerging research and service developments in dementia palliative care. This could be supported by the All Ireland Institute of Hospice and Palliative Care. Such a research platform could also support quality initiatives and monitoring to support the effective delivery of appropriate levels of palliative care for people with dementia and their families.

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1. Cahill, S., O'Shea, E., Pierce, M., *Creating Excellence in Dementia Care 2012*, TCD & NUI Galway: Dublin p. 170.
2. Libby Sallnow, S.K., Allan Kellehear, ed. *International Perspectives on Public Health and Palliative Care*. ed. R.S.i.P. Health. 2011, Routledge. 224.
3. McConville, U., *Opening Conversations: Developing a model for The Alzheimer Society of Ireland of best-practice palliative care interventions for people with dementia and their carers 2011*, Alzheimer Society of Ireland: Dublin. p. 54.
4. NCPC, *Difficult Conversations: making it easier to talk to people with dementia about the end of life*, ed. NCPC. 2011. 12.