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## Building Consensus for the Future : Report of the Feasibility Study on Palliative Care for People with Dementia

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# Building Consensus for the Future

Report of the Feasibility Study  
on Palliative Care for People  
with Dementia

December 2012

### **Acknowledgements**

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"It is very difficult to talk about dementia and almost impossible to talk about end of life issues."

*Participant, health care professional*

# INTRODUCTION

Over the past three years, The Alzheimer Society of Ireland (ASI) and the Irish Hospice Foundation (IHF) have supported a number of local research and development projects in the area of dementia and palliative care. The Feasibility Project was established in order to build on this work in a strategic manner and to provide an opportunity for consultation with relevant stakeholders on their views of dementia palliative care in addition to signalling a future work programme in this area.

## **Aims of the Feasibility Project**

- To build a consensus on the vision and direction of dementia palliative care in Ireland with a range of stakeholders.
- To gain an understanding of the multiple perspectives involved.
- To identify and signpost a programme of work.
- To directly contribute to the policy and service agendas and the Department of Health's National Dementia Strategy.

## **The project was guided by a set of principles that included**

- A lifecycle approach reflecting the full journey for the person, their family members and carers following a diagnosis of dementia.
- The inclusion of all people impacted by dementia, for example, younger people, people with intellectual disability, co-morbidity, families and carers.
- Utilising an integrated care pathway approach to look at critical points where support/interventions are needed.
- A focus on adding value and integration into the existing health and social care systems, structures and services rather than creating 'new' ones.

This report applies an “exaggerated lens” on the current dementia landscape in order to highlight the dementia palliative care elements. This process has not been done to date and is critical to contributing to an understanding of, and informing, both the dementia and palliative care landscapes. For the purposes of this document we have used “dementia palliative care” as short hand to talk about ways to meet the end-of-life care needs of people with dementia, their families and carers and reflecting the qualities of person-focused dementia care and the holistic focus of specialist palliative care.

## Feasibility project work programme

The Feasibility Project, a joint partnership project with the Irish Hospice Foundation and led by The Alzheimer Society of Ireland, was conducted over a six-month period (October 2011–March 2012).

An Expert Advisory Group (See Appendix 1 for membership) was convened to meet over the course of the project in order to draw on key clinical, academic, policy and service expertise and to evaluate the findings of the project, advise on strategy and policy and guide the effective direction of future developments in line with the acting principles.

The Feasibility Project adopted a collaborative and consultative approach and included consultations and dialogue with the advisory group, specialists, frontline service providers and users, including family members, across a range of services and sectors to scope out and identify pertinent issues for shaping the development of dementia palliative care. (See Diagram 1 and further details in Appendix 2) This study adopted an exploratory approach in order to signpost a specific work programme as outlined in the recommendations.



Diagram 1: Consultation methods used

The delivery of dementia palliative care takes place in the much broader and more complex context of how dementia is understood, responded to and resourced. Some of the work that is ongoing in the dementia field including creating awareness, reducing stigma, providing education and training resources, developing services and care pathways, operating person-centred care services, promoting timely diagnosis and early intervention services and supports, are all significant in relation to dementia palliative care and form the overall backdrop. However, this work is beyond the scope of the signposting and recommendations of this Feasibility Project.

## Building consensus on what is dementia palliative care

The term 'dementia palliative care' has been adopted as a way of describing the means of appropriately addressing the palliative care needs of the person with dementia and their family throughout the disease trajectory. Dementia palliative care reflects the qualities of person-focused dementia care and the holistic focus of palliative care. The palliative care approach aims to promote both physical and psychosocial well-being. It is a vital and integral part of all clinical practice, whatever the illness or its stage is informed by a knowledge and practice of palliative care principles. The key principles of the palliative care approach focus on quality of life and includes good symptom control; a holistic approach that takes into account the person's life experience and current situation; care that encompasses both the dying person and those who matter to that person; and an emphasis on open and sensitive communication, which extends to patients, carers and professional colleagues.<sup>1</sup>

Both models share a person-centred philosophy and a set of underlying principles that focus on quality of life, whole-person care, a respect for autonomy and care of the person and their family. In Australia, "palliative dementia care" has been defined as that which "actively treats distressing symptoms (physical or psychological or emotional), to optimise the quality of life for the person with dementia, and their family, knowing that the underlying cause cannot be cured."<sup>2</sup>

A palliative approach to dementia care involves supporting both the person with dementia and their family, seeking to address and relieve the pain, distress and discomfort associated with advancing dementia and inviting the person and family to participate in making decisions about future care needs and where it is best delivered.

Dementia palliative care must be located in the mainstream services and be led by the dementia experts with support as required from the palliative care specialists. The inclusion of palliative care principles in services for people with dementia, will help staff in these services to have the capacity and competency to communicate, support and manage a spectrum of care domains ranging from advance care planning to decision making regarding clinical interventions and specific ethical dilemmas that present for people with dementia and their families. People with dementia and their families often need guidance and support about decisions that impact on their life, and end of life care, throughout the duration of the illness. However, it is accepted that as the palliative care principles are integrated into services for people with dementia, sensitivity is required with regard to the use of language.

Building a conceptual model of dementia palliative care is challenging given the complex nature of the condition itself and the co-morbidities that often accompany this disease. Whether people die "with" dementia or "from" dementia is still a contested point, however what is accepted is that dementia is a progressive irreversible disease and the associated co-morbidities are life-limiting. The challenge is for service providers to accept and introduce the palliative principles appropriately within the disease trajectory.

Historically, specialist palliative care has developed within cancer care. However, palliative care is increasingly understood as an appropriate approach for addressing end of life care needs for people with life limiting diseases<sup>3</sup>. When considering the role of palliative care in chronic diseases, Dementia is relatively unique as it is recommended that palliative principles be introduced early in the disease trajectory, when the person with dementia can engage meaningfully in discussions about their future care. Clearly more work is needed in order to fully understand and to begin building an agreed model for dementia palliative care.

## International Context

The need to address end of life care for people with dementia is most recently acknowledged by the World Health Organization in 2012<sup>4</sup>. The UK End of Life Care Strategy (2008) has recommended an end of life care pathway across a range of conditions, including dementia<sup>5</sup>. This has been reinforced by the UK Dementia Strategy (2009), which has a specific objective for addressing end of life care for people with dementia<sup>6</sup>. Both Alzheimer Europe<sup>7</sup> and the European Association of Palliative Care<sup>8</sup> have also supported the need for appropriate levels of palliative care throughout the disease trajectory and the need for more research in this area.

It is now accepted that applying palliative care principles to dementia care can help address many of the complex 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 issues relating to loss and bereavement<sup>2</sup>.

## National Context

Creating Excellence in Dementia Care<sup>9</sup> has reported that the population of people with dementia is forecast to increase by 63% from an estimated 41,447 in 2006 to 67,493 in 2021. By 2041, it is estimated that there will be 140,580 people living with dementia in Ireland (a 240% increase). This report has laid the foundations for the development of a National Dementia Strategy; a commitment which forms part of the current Programme for Government<sup>10</sup>.

Irish palliative care services are underpinned by the 2001 report of the National Advisory Committee on Palliative Care<sup>1</sup>, which recognises the need for palliative care for people with diseases other than cancer. In 2008, the HSE and the Irish Hospice Foundation published Palliative Care for All<sup>3</sup>, specifically addressing the relevance of palliative care for people with dementia, as well as for those with COPD and heart failure.

Following this report the Irish Hospice Foundation established the Palliative Care for All Programme<sup>11</sup> which has funded a number of initiatives, in partnership with The Alzheimer Society of Ireland, to support the development of palliative care within dementia services.

These projects, listed below, are generating greater awareness, as well as guidance documentation, to assist the integration of palliative care principles in dementia care.

- *Opening Conversations, The Alzheimer Society of Ireland<sup>12</sup>*
- *Planning for the Future Project, Le Cheile, St Vincent's, Athy (in progress)*
- *Palliative care and dementia – developing frameworks for palliative care and dementia, Clare Mental Health Services for Older People (final report in preparation)*

# FEASIBILITY PROJECT: CONSULTATION AND DIALOGUE PHASE

The Feasibility Study set out to capture the views of a range of stakeholders through a process of consultation and dialogue across the spectrum of dementia clinical and care specialists, regions and environments. Discussions were also held with specialists in palliative care, representatives from the national clinical programme for older people and family members. Group consultation sessions were held to explore the views of service providers across a range of services and regions in both Dublin and Sligo, to capture some of the potential regional and urban rural differences. A presentation and consultation was also held with the Hospice Friendly Hospitals Community Hospital Network in Dublin and this was attended by representatives from community residential settings and others involved in end of life care for older people.

During this consultation and dialogue phase participants highlighted a number of good practice initiatives, developments and resources that currently support the delivery of palliative care in dementia care in addition to identifying some current challenges.

## Good practice initiatives and developments

A number of good practice initiatives and developments were identified during the consultation phase summarised as follows:

- The development of interfaces between hospital and community services at a structural level has eased pressures in both environments. For example, at Connolly Hospital collaboration between the Liaison Team for Older Persons and the specialist palliative care services at Beaumont Hospital have utilised documentation and procedures to include nursing home patients. The Connolly Hospital\* outreach (community geriatric) service has also reduced the length of stay and number of potentially avoidable emergency admissions from residents in nursing homes.
- Local development of integrated pathways, for example Nazareth House, Sligo and the North West Hospice, have developed a programme of end of life care planning involving case conferences, phone support and family conferences that has reduced the number of potentially avoidable emergency admissions.
- Development of collaborative models of care, such as, the specialist palliative care services in the North West, which have established close links with the GPs and public health nurses in certain geographic areas. Where there is primary care support, patients are discharged back to primary care if they are not in need of specialist palliative care services. A collaborative model of care has also developed with some intellectual disability services in the North West.

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\* Connolly Hospital Liaison Medicine for the Elderly Project is a community-led service to enhance communication systems between primary care providers and the hospital-based team. The service also aims to enhance and augment secondary care provision to frail elderly at the site of care most appropriate to them in addition to providing specialist in-reach / outreach services to patients in residential care in the catchment area.

- Hospice Friendly Hospitals Programme (HfH) resources and initiatives. For example service providers cited the establishment of end of life committees, internal leadership and champion work, education programmes and training resources as supportive of staff and services. Hospice Friendly Hospitals Programme resources such as the symbol, Final Journeys training and the Think Ahead form were also considered valuable.
- The use of guidelines for staff in advance care planning and end of life care discussions with people with dementia and their families. Developed by the Planning for the Future Project in St. Vincent's Hospital in Athy these were identified as good practice tools and supports in the context of dementia palliative care.

## Current challenges

Health care service providers and families identified a number of challenges across service and societal domains and these are presented as follows.

- 1. Service and societal issues pertaining to dementia and palliative care**
- 2. Perspectives of family members**
- 3. Perspectives of health care professionals**

## Service and societal issues

Dementia is a highly stigmatised condition with serious implications for the lived experience of the person with dementia and their carer, that can lead to withdrawal from social and community life, family and friends. The stigma associated with the illness can present challenges in seeking and accessing a diagnosis. Dementia can be difficult to diagnose and often remains undetected. Previous research has also demonstrated reluctance among some GPs to diagnose dementia in their patients<sup>9</sup>. While services will continue to encourage early diagnosis of dementia, there will be a cohort of people who will only receive their diagnosis late in the disease trajectory. Mechanisms need to be put in place to ensure that these people are provided opportunities to avail of services to meet their needs and assist them plan for their future care.

Once a diagnosis is received, adjustment to the diagnosis and coping with transition points will vary amongst individuals, and this can influence how people with dementia and their families will engage with services.

The needs of people with dementia and their families can be complex and may cross several service providers over the duration of the illness. The range of interaction with health care personnel and services that people with dementia and their families may have during their disease trajectory<sup>12</sup> is illustrated below in Diagram 2. Specialist services include gerontology, psychiatry, neurology and specialist palliative care.

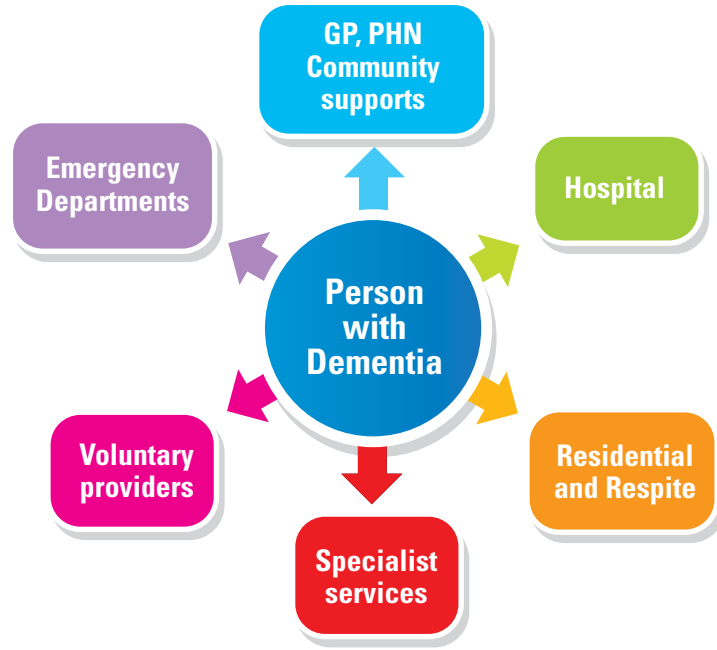


Diagram 2: Range of services involved in dementia care delivery

It can be difficult for people with dementia and their family members to negotiate and navigate the various health services as very often there are multiple services involved. In addition, it is likely that people with dementia will need to engage with a range of health service structures (See Diagram 3 below); frequently these services will not have established links or networks with each other.

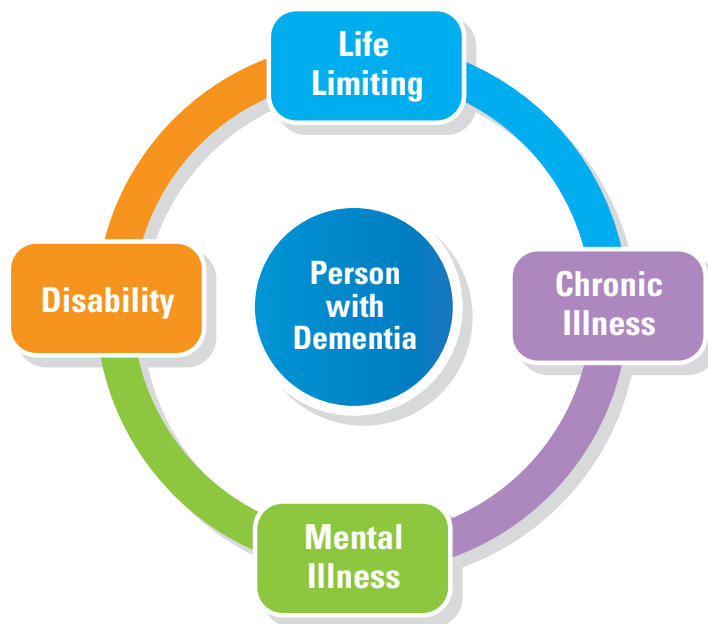


Diagram 3: Multiple services responding to people with dementia

Dementia services have been under resourced and under developed[9]. This provides a challenge when considering the introduction of additional components or service dimensions, including palliative care principles.

The dearth of education and training provision in dementia care at under-graduate and post-graduate level has contributed to the difficulties in enabling service development<sup>9</sup>.

Greater acceptance, awareness and education is required regarding the benefits of palliative care for all life limiting diseases, including dementia and its role early in the disease<sup>3</sup>.

## Perspectives of family members

Individual interviews were held with three family members who were caring, or had cared for, their parent or spouse. Families did not readily identify with the palliative phase of dementia care for their loved one, but they all expressed a need for good quality dementia care. It is likely that families do not think about dementia from a palliative perspective so when the dying phase comes they may not be prepared. The points they raised helped to identify some of the challenges they face and what would make their experience easier. GPs and community services were seen as a vital component to accessing the services throughout the illness. There was a lack of clarity about what resources and services were available to families and therefore it was difficult to think about, discuss and plan for the future. The lack of information and support resulted in each of the families feeling alone, isolated, let down, uncertain, vulnerable and distressed at different times.

The transition to residential care from a home setting proved traumatic for one of the family members interviewed, as well as for other members of her family. They felt uncertain of their role in the residential setting and unsure of how the illness would progress and how they could help and support their parent. Access to advice and services from a specialist palliative care team proved problematic for one of the families when their loved one was imminently dying.

### Addressing needs

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- Clarity about services available and entitlements—in various formats and delivered in a timely and a sensitive manner.
- Comprehensive information on the disease trajectory.
- Staff available to anticipate and signpost service options, to assist in planning for the future, plan and support for the transition to long term care and to be available when a crisis or a critical event takes place.
- Guidance and advice about benefits and consequences of treatment decisions with regard to end of life care.
- The services provided to people with dementia and their families should be responsive and reliable, ensuring their palliative care needs are assessed and responded to in a meaningful way.
- Specialist advice and support available for complex needs of patients and support of family throughout the disease journey and into bereavement.

## Perspectives of health care professionals

Consultations and discussions with health service providers, including individual and group discussions at the two regional consultation meetings have highlighted numerous challenges.

### Communicating and planning throughout the illness trajectory

There was a good overall understanding of the illness progression and the level of future planning that is required for people with dementia and their family. However, most of those who participated noted that it was a difficult conversation to broach with the person with dementia and their family. This is particularly so for those who are still living at home as there is intermittent contact with services, and families are often focused on short term needs and have a difficulty in seeing and understanding what lies ahead.

As the symptoms of dementia progress, people with dementia and their families are introduced to new service providers for e.g. day care, home care, respite care, acute care, and long term care. It is understandable that these changes may cause some initial stress and uncertainty for all concerned, however these transitions can provide opportunities for those with dementia and their families to discuss future care plans, preferences and anxieties with existing or new service providers.

### Addressing challenges

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- More resources, training and guidance should be available for people with dementia, their families and for staff to support discussions about end of life care and planning for care transitions.
- Specific information should be available about medical care, treatments, pharmacological interventions and Enduring Power of Attorney to assist family members anticipate future decisions.
- Particular focus is required to build cohesive services for those with dementia still living in their own home, to assist the introduction of advance care planning and develop a method of consistent and shared communication across services.

### Access to Specialist Palliative Care

Some health care professionals based in residential settings noted the benefit of access to advice from specialist palliative care services, for example where existing relationships exist between services to support symptom management for people with dementia. While this is clearly of benefit, not all services had access to specialist palliative care services.

Staff caring for people with dementia reported that often the guidance and direction received from specialist palliative care provided reassurance to their practice and increased their confidence and professional competence when they had to deal with the same situation in the future.

Specialist palliative care staff indicated their preference for a collaborative approach when responding to referrals for people with dementia, respecting the expertise that dementia staff can bring to symptom assessment while acknowledging that the primary responsibility for the care of the person with dementia needs to be clearly identified.

Reaching an understanding about aspects of care such as hydration, nutrition and appropriate treatments at the end of life requires a lot of time and skills from a range of disciplines, including specialist palliative care.

## Addressing challenges

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- Guidance and information with regard to responding to pain and symptom management for people with dementia would assist in clarifying service responsibility and more responsive service delivery.
- Draw on emerging and existing tools to support collaborative working, for example the HSE Palliative Care Competency Framework [13] which will provide for core competencies in palliative care whilst also detailing individual competencies for each health and social care discipline.

## Planning for a crisis

Crisis events will still take place, for example admission to acute settings for fractures following a fall. People with dementia and their families will find themselves among the care of those who are not familiar with their care needs.

In order to prevent unnecessary tests or interventions that may cause undue distress, every effort must be made to ensure that the needs and wishes of the person with dementia are communicated to the staff with responsibility for their care. This would meet the expectation of those with dementia and their families that there would be a quality and consistent level of service provision regardless of care location.

## Addressing challenges

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- Personalised care protocols to support the care of people with dementia should accompany the person with dementia if they require treatment by staff not familiar to them or accustomed to caring for people with dementia.
- Staff working in acute hospitals and emergency care should receive education and training about how to optimally support people with dementia.



## Consensus, Signposting and Recommendations

1. Services
2. Education and Training
3. Research
4. Policy and Advocacy

# BUILDING CONSENSUS, SIGNPOSTING AND RECOMMENDATIONS FOR A PROGRAMME OF WORK

The Feasibility Project set out to build consensus for dementia palliative care in Ireland through a process of dialogue and consultation with specialists, service providers and families. Through this process, a commonality of view emerged across a range of services and sectors regarding the need for palliative care in the care of the person with dementia. There was clear agreement for the need to build understanding, knowledge, skills and sectoral capacities in order to respond to the specific need of people with dementia. Finally, there was a shared eagerness and willingness among both dementia and palliative expert groups to engage and learn from each other to begin to deliver a palliative care agenda.

The Feasibility Project has focused on signposting a number of key issues. These have generated a set of specific recommendations as they relate to dementia palliative care.

The targeted recommendations will add value and complement the broader dementia policy and practice agenda. The Feasibility Project has highlighted several examples of good practice and resources, in particular the Hospice Friendly Hospitals programme that forms a central part of the recommendations in order to progress work in this area.

The signposting and recommendations are broken down into four thematic areas:

1. Services
2. Education and Training
3. Research
4. Policy and Advocacy

## Services

There is a multiplicity of sectors, service domains and service providers involved in the care of the person with dementia throughout the illness. “Navigating the system” is challenging and families have identified the need for some sort of support service to help them reach the services they need and in a timely fashion. Primary care, and specifically the GP, play a critical role throughout the disease trajectory. There is a real need to engage with the person with dementia and the family in a meaningful way and to also support and inform them about the range of services available.

This study has identified that ‘transitions’ to services including acute care, residential care, respite care, community care, as key milestones in the disease trajectory and when palliative care principles should be particularly considered. Families and healthcare professionals have identified that more supports and help are needed to make the transitions successful and as seamless as possible. Using integrated care pathways models to support the delivery of dementia care in general and dementia palliative care in particular are needed.

The study also indicates there is currently a lack of capacity and resources to respond to the person's needs including palliative care needs, not only at the transition stages but also throughout the time the person is involved with the various services.

The acute hospital is a place where many people with dementia and their families find themselves, often in times of crisis, with little evidence of future planning having taken place and staff have limited knowledge about the person and their wishes. It was identified in the Feasibility Project consultation that people with dementia, where possible, should be diverted away from the acute hospital setting, including A&E, and these facilities should only be used in cases where there is a real need for hospital admission, based on a comprehensive assessment, with systems and protocols in place to ensure the proper response. The concept of a dementia friendly hospital emerged where the whole hospital has the capacity, skill, knowledge and expertise to respond to the needs of the person with dementia.

Residential care is an essential service for all people with dementia and a critical service for those people with advanced dementia. Throughout the Feasibility Project, residential care service providers indicated their strong desire to respond to the dementia palliative care needs of their residents but also identified that there are capacity and resource issues at play. Service providers in these settings are also key to helping and supporting families to plan and to come to terms with what the future holds.

Finally, in terms of service supports, there is a clearly identified need for information products that are targeted and timely for the person with dementia, carers and family members as well as the range of health and social care professionals. There is a wide range of issues which information products need to address, all of which need to be tailor-made for the variety of audiences.

## Recommendations

- 1.** In conjunction with relevant HSE clinical care programmes, carry out case study analysis of selected sites with existing good dementia palliative care practices including examining the partnerships, interdisciplinary/multi-disciplinary working and networks that takes place both in acute and residential settings, to be disseminated as models of good practice for shared learning.
- 2.** Engagement with the residential care sector in order to identify ways to build capacity and begin to resource dementia palliative care interventions in residential settings.
- 3.** Support acute hospitals and primary care via the relevant clinical care programmes in the introduction of interventions to support palliative care in dementia and to include working with the IHF Hospice Friendly Hospital Programme and IHF/HSE/ICGP Primary Palliative Care Programme.
- 4.** Engagement with the Department of Health's newly established Special Delivery Unit to explore how to develop responsive and fast tracking protocols for people with dementia to prevent admissions in the first instance, to fast track people if admission is needed and to significantly reduce the number of days the person is in hospital.
- 5.** Building on work emerging in this area, to produce a suite of information products to meet the information needs of people with dementia and their families, as well as guidance materials for staff to include a focus on palliative care.

## Education and Training

The Feasibility Study has identified that there is limited awareness, knowledge and skill-base at present across the disciplines and services in relation to dementia palliative care. However, there are a range of initiatives and programmes in place. Building on these existing initiatives and resources is an essential first step.

Mixed learning methods and resources are needed to build the knowledge and skill base in dementia palliative care. This needs to take place at all the different levels of education and training across the total spectrum of the health and social care professions.

### Recommendations

- 6.** Evaluation of the existing training and educational materials and modules in order to establish a baseline to determine how to advocate for the inclusion of dementia palliative care in the training of healthcare professionals and to strengthen the educational components on 'dementia', 'palliative care' and 'dementia palliative care' at all levels of health and social care professionals' education and training.
- 7.** Development of a dementia palliative care web-based training and education site to include on-line self-directed training and education, resources and information portal/repository.
- 8.** Establishment of a peer-to-peer learning network to bring together dementia experts and palliative experts.

## Research

There is a dearth of research in the area of dementia palliative care. There is a need for significantly more research that informs the understanding of the dynamics, parameters and elements for further building a concept and paradigm for dementia palliative care. There is also a clear need for research to take place to understand the policy, services, education and training responses required. In addition to this, researching and mapping what is currently happening in Ireland around existing and developing initiatives as needed.

### Recommendations

- 9.** Formulation of a research agenda that spans the policy, services, education and training needs to promote dementia palliative care as a unique element within both spheres.
- 10.** Carry out a prevalence study of people with dementia in one of the major acute public hospitals at any one point in time and to ultimately move towards investigating the parameters and feasibility of a Dementia Friendly Hospital.
- 11.** Research and develop a range of guidance documents/good practice guidelines/decision making trees for healthcare professionals dealing with the specific aspects of end of life care for example PEG feeding, nutrition and hydration and communication etc.
- 12.** Research the palliative care needs of the person with dementia, their carer and family including anticipatory grief and bereavement counselling.
- 13.** Building on existing tools and frameworks, research ethical dilemmas that present at end of life care for people with dementia and build a framework for informing ethical decision-making.
- 14.** Dissemination of these research findings across a range of stakeholder groups.

## Policy and Advocacy

There is a need to recognise from a policy perspective that dementia is a life-limiting condition which requires an appropriate multi-disciplinary service response. Dementia policy needs to recognise that dementia palliative care/end of life care is a central part of the dementia journey and that capacity building is needed to grow the expertise and skills among key health care professionals. There is also a need to recognise that families play a crucial role in the dementia palliative care process. Specialist palliative care services need to develop appropriate support for people with dementia and their service providers, in line with the recommendations of the Report of the National Advisory Committee on Palliative care, 2001<sup>10</sup>.

### Recommendations

- 15.** The forthcoming National Dementia Strategy in 2013 gives full policy recognition to dementia palliative care as an area that requires skilled expertise and that dementia palliative care interventions have relevance right throughout the illness trajectory.
- 16.** The various professional groupings are informed and influenced to include dementia palliative care in their education and training initiatives, especially the GP, the primary care teams and legal professions.
- 17.** The Department of Health's Special Delivery Unit is urged to consider protocols and specific policy measures that direct acutely ill people with dementia away to the most appropriate setting.
- 18.** The HSE clinical care programmes that specifically relate to dementia palliative care (care of the elderly, primary care and palliative care) promote and support the development of appropriate policy leading to interventions across the clinical care programmes.
- 19.** There is an assessment of the forthcoming mental capacity legislation conducted using a palliative care lens and its implications for advanced care planning, living wills and Enduring Power of Attorney.

# IMPLEMENTATION OF THE RECOMMENDATIONS

The Irish Hospice Foundation and The Alzheimer Society of Ireland will develop a work plan around the recommendations. One of the essential elements of this work will be to identify and link with the key stakeholders, actors and structures which are critical to supporting the roll out the recommendations. These include the HSE, private and voluntary agency service providers, specialists in dementia and palliative care, researchers and academics and the All Ireland Institute for Palliative Care. In particular, the two organisations will link the implementation of the recommendations with the relevant HSE Clinical Care Programmes and complement/add to the work that is already planned or underway including the development of the competency framework, quality and safety standards and efficiency programmes.

As the project moves into the development phase, an appropriate project structure will be devised, most likely to include the development of an overall advisory group with project specific working groups established.

# APPENDIX 1

## MEMBERSHIP OF THE DEMENTIA PALLIATIVE CARE EXPERT ADVISORY GROUP

Mr Maurice O'Connell	CEO, The Alzheimer Society of Ireland (Chair)
Ms Sharon Foley	CEO, Irish Hospice Foundation
Dr Patricia McCormack	Consultant Geriatrician, Care of the Elderly Programme
Dr Regina McQuillan	Consultant in Palliative Medicine, Palliative Care Programme
Dr Joe Clarke	GP, Primary Care Programme
Ms Ann Coyle	National Planning Specialist for Older People, Health Service Executive
Mr Matthew Gibb	Acting Director, Dementia Services, Information and Development Centre (DSIDC)
Kate Irving, PhD	Mental Health Nursing Specialist, School of Nursing and Midwifery, DCU
Ms Marie Lynch	Programme Development Manager, Palliative Care for All, Irish Hospice Foundation
Ms Gráinne McGettrick	Policy and Research Manager, The Alzheimer Society of Ireland,
Una MacConville, PhD	Feasibility Project Officer

# APPENDIX 2

## DETAILS OF THE CONSULTATIONS CONDUCTED

### **Meetings with 5 Individual specialists**

(Specialist Palliative Care, Medicine of the Elderly, Intellectual Disability, Psychiatry of Old Age, Community Liaison Services)

### **Meetings with 3 Family Members**

#### **3 Consultation Sessions**

- Community Hospitals Network: 23 participants.
- Sligo Session:  
27 participants drawn from Specialist Palliative Care, Community Services, Primary Care, Psychiatry of Old Age, The Alzheimer Society of Ireland's Services, Medicine for the Elderly, intellectual disability services, The Carers Association, nursing homes and the education sector.
- Dublin Session:  
23 participants drawn from intellectual disability services, The Carers Association, acute hospital services, nursing homes, dementia specialists and The Alzheimer Society of Ireland and Irish Hospice Foundation staff.

# REFERENCES

1. Department of Health and Children, *Report of the National Advisory Committee on Palliative Care*. 2001, Department of Health and Children: Dublin p. 157.
2. ACH, *Planning for Palliative Dementia Care: Resource Guide*. 2009, ACH Group Australia: Melbourne, Australia. p. 82.
3. Irish Hospice Foundation, H., *Palliative Care for All, Integrating palliative care into disease management frameworks*. 2008: Dublin. p. 154.
4. World Health Organisation, *Dementia: A public health priority*. 2012: p. 112.
5. Department of Health UK, *End of Life Care Strategy Promoting High Quality care for all adults at end of life*, 2008. p. 171.
6. Department of Health UK, *Living well with dementia: A national dementia strategy*. 2009. p. 104.
7. Alzheimer Europe. *Alzheimer Europe's position and guidelines on end-of-life care*. 2008 [cited 2008; Available from: <http://www.alzheimer-europe.org/>].
8. European Association of Palliative Care. *White paper on dementia care*. 2010 [cited 2012 23 April 2012]; Available from: <http://www.eapcnet.eu/Themes/Clinicalcare/EAPCWhitepaperondementia.aspx>.
9. Cahill, S., O'Shea, E., Pierce, M., *Creating Excellence in Dementia Care* 2012, TCD & NUI Galway: Dublin p. 170.
10. Dept of an Taoiseach, *A programme for government*, 2011. p. 64.
11. Irish Hospice Foundation. *Palliative Care for All Programme*. 2009 [cited 2012 23 April 2012]; Available from: [http://www.hospice-foundation.ie/index.php?option=com\\_content&view=article&id=110&Itemid=42](http://www.hospice-foundation.ie/index.php?option=com_content&view=article&id=110&Itemid=42).
12. 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, The Alzheimer Society of Ireland: Dublin. p. 54.
13. Connolly M., Charnley, K., & Regan J., *A Review of Palliative Care Competence Frameworks*. 2012, AIHPC: Dublin. p. 53.



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