



Opening Conversations

Developing a model for The Alzheimer Society of Ireland
of best-practice palliative care interventions for people
with dementia and their carers



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Acknowledgements

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“Too soon is never too soon”

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National Council for Palliative Care (2009)

It gives me great pleasure to introduce the research report ‘Opening Conversations – Developing a model for The Alzheimer Society of Ireland of best-practice palliative care interventions for people with dementia and their carers’. This small-scale piece of research uniquely presents the views of people with dementia and their carers in relation to the issues regarding planning their future and end-of-life care.

Good end-of-life care is a key part of providing quality person-centred dementia care. Having conversations with people with dementia very early in the condition and at appropriate times is essential in order to plan for the future and establish their wishes about their end-of-life care. But we all know how difficult having these conversations can be; indeed we know from this research report that having conversations about dementia is difficult without even attempting ones around end-of-life.

This research proposes a model of dementia palliative care based on the provision of good quality end of life care for people with dementia and their families. It begins at the time of diagnosis and is not confined to the end stage of the illness or to the period in which the person with dementia is actively dying. The illness characteristics of dementia, in particular cognitive impairment, make it imperative to engage with the process and practice of palliative care at the earliest stages of the illness as possible.

We need a palliative lens applied throughout the person's journey with dementia and across the whole dementia care pathway. Dementia provides many challenges but what we need is for the whole system to own those challenges.

I hope this report prompts new and many more conversations about the issues of living well with dementia and how we can make the dementia journey a better one for all.

A handwritten signature in cursive script that reads "Maurice O'Shannon".

Chief Executive Officer
December 2011

Executive summary

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Introduction

Palliative care and end-of-life issues for people with dementia are pertinent areas for research, policy and practice in dementia care. The Alzheimer Society of Ireland (ASI) is the national leader in understanding and providing dementia-specific supports and services, including the development of palliative care for people with dementia.

'Opening Conversations' was a small-scale qualitative research project aimed at developing a model of best-practice palliative care interventions for people with dementia in order to integrate palliative care interventions into ASI service planning. It also aimed to deepen an understanding of what palliative care means within the context of dementia care, as well as understanding the specific end-of-life issues for people with dementia, their carers and ASI and other service providers. This research proposes a model of dementia palliative care based on the understanding that the provision of good-quality end-of-life care for people with dementia and their families begins at the time of diagnosis and is not confined to the end stage of the illness or to the period in which the person with dementia is actively dying.

A number of research activities were developed on the basis of key issues identified by service managers and team members. Liaison meetings were ongoing throughout the research, incorporating ongoing reflective practice, evaluation and review. Research activities included conversations with people with dementia and family members and carers about end-of-life care; conversations with long-term service providers about the transition to long-term care; a review of ASI information provision, both current and future; and a survey of ASI staff regarding the end-of-life/palliative care issues.

Understanding dementia palliative care

The philosophy, principles and practice of palliative care were examined in order to reach an understanding of what palliative care means in the context of dementia care. Both models of care share a person-focused 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 the family. There are, however, considerable differences with regard to practice, which are shaped by the illness characteristics, resources and services.

In the context of current health service provision, specialist palliative care services provide an integrated comprehensive service for patients and their families across a range of settings. In contrast, dementia services are frequently fragmented and poorly resourced. People with dementia and their families and carers have similar needs to cancer patients and would benefit significantly from a palliative care approach on their journey of living and dying with dementia. The characteristics of the illness, in terms of cognitive impairment, gives a greater imperative to commence this level of care as early as possible in the illness trajectory.

Towards a model of dementia palliative care

In order to develop a model for dementia palliative care interventions for ASI services, two key areas were identified: end-of-life care needs and the transition from ASI services to long-term care. A number of activities were undertaken to gather information for potential interventions as well as a review of current ASI information products.

Conversations were conducted with people with dementia and family members. An Alzheimer's Society (UK) form 'This is me' was utilised and adapted to prompt conversations about illness progression and end-of-life care needs and decisions. It was found difficult to talk about this, as it was frequently difficult to talk about having dementia in the first place. Many people did not have a disclosed diagnosis of dementia, and as a result there is little financial, legal and future care planning.

The second activity of this research was to understand how best to provide a continuity of care from ASI services to the long-term care service provider. A number of interviews and a focus group were conducted with service providers in long-term settings. Key issues were identified – services and resources, preparation and education, managing relationships and forming partnerships, end-of-life care and decisions, and bereavement support.

A review of current ASI information products was conducted. The current and future information provision was grouped into three areas – pre-transition; transition; and end-stage dementia. Findings from the Opening Conversations project also identified a need to address specifically the early stage, diagnosis, illness progression and end-of-life care and decisions; these aspects will need to be incorporated into future information products.

An electronic survey was conducted to establish awareness of end-of-life/palliative care information needs and support for service users with staff working and coordinating ASI services such as home care, support groups, day care, drop-in centre and the helpline. The response rate was 38%; the respondents had a variety of roles (and also multiple roles) within ASI services.

Eighty-six per cent of respondents reported that end-of-life/palliative care has come up for discussion and as an area for support in home care, day care, carer support groups and with individual people with dementia, their carers and family members. All (100%) respondents expressed interest in receiving information on dementia palliative care and 96% would like training for themselves and their staff on end-of-life/palliative care. Ninety-one per cent of respondents expressed an interest in developing relationships with service providers in long-term care and specialist palliative care services, and 77% expressed interest in future developments of dementia palliative care within ASI services.

Understanding the journey and mapping the landscape

The Opening Conversations project has made more visible the current 'landscape' of dementia and the illness journey which people with dementia and their family members and carers undertake. This has highlighted the need for an integrated pathway through a variety of services and settings, and a need for involvement, support and interventions from an early stage of the illness, in order to facilitate a smoother, and supported, transition through the stages of the illness. Whilst recognising that a smooth integrated pathway may be challenging to achieve, the Opening Conversations project makes a number of recommendations to commence the building of solid foundations for this pathway.

Recommendations

The Opening Conversations research presents a total of fourteen recommendations in order to develop further a model of dementia palliative care. These are operational across a range of domains – policy advocacy, public advocacy and information and practice development – and address key issues such as raising awareness; removing barriers to a clear diagnosis; providing a continuity of care; active management of the transition of care; addressing end-of-life care needs; and supporting family members and carers. While these domains and recommendations are distinct and address specific issues, they are interwoven and all have the potential to strengthen and support the development of dementia palliative care.

1 Developing information, education and awareness strategies on dementia involving a range of key stakeholders and sites

An integrated information and education strategy needs to be developed, on both the macro- and the micro-level, about the illness and the implications for care.

An awareness of illness progression, specifically in relation to preparation, planning and end-of-life care needs and decisions, should form part of the information to be imparted. An information dissemination strategy needs to take account of multiple media formats appropriate for differing sectors of the population, and should identify routes for the distribution of information, such as GP surgeries and the ASI helpline.

There is a need to provide specific dementia awareness training for appropriate health care professionals who have contact with people with dementia. This will include frontline workers such as ambulance workers, the police and members of the legal professions and could take the form of developing a professional training educational module. In particular, the health care professionals in the acute hospital settings (especially A and E) should be targeted to lead ultimately to the creation of dementia-friendly hospitals.

Recommendations:

- 1 The Alzheimer Society of Ireland to identify specific target audiences and develop a range of multiple media information products and appropriate routes for dissemination, for example GP surgeries and the ASI helpline.
- 2 The Alzheimer Society of Ireland in collaboration with key stakeholder bodies including the HSE, An Garda Síochána and professional representatives from legal and financial bodies to develop specific dementia awareness training for appropriate frontline staff.
- 3 The Alzheimer Society of Ireland to explore, with key stakeholders, the potential for a dementia-friendly hospitals programme, along similar lines to the IHF Hospice Friendly Hospitals Programme.

2 Removing barriers to clear diagnosis and supporting the dementia journey in primary care

The role of primary care health care professionals is an important one for people with dementia and their family members. In particular, the GP plays a critical role on the whole journey of dementia as a constant and pivotal point of contact for diagnosis but also for palliative care needs. Many people with dementia do not receive a clear disclosed diagnosis of dementia, and this can lead to many difficulties and challenges when planning for the future. There is a need to develop protocols for diagnosis with the Irish College of General Practitioners.

Recommendation:

- 4 The Irish College of General Practitioners to build capacity for dementia care, with the development of protocols for diagnosis and the management of dementia within primary care settings and structures.

3 Develop an integrated dementia care pathway to provide joined up and continuity of services for people with dementia and their family members and carers

Current services are disjointed and there is an urgent need to join up existing services and resources in order to provide an integrated service for people with dementia and their family members and carers. The development of multidisciplinary teams within the community and the provision of a case management model with dementia specialist nurses in hospitals and primary care would further support a continuity of care. People with a diagnosis of dementia could be supported by the provision of a personal advocate. This would consolidate and further support other initiatives relating to a continuity of care.

Recommendations:

- 5 Priority needs to be given to the development of an integrated care pathway for people with dementia through the appropriate Health Service Executive structures.

The integrated care pathway for people with dementia needs to include a case management model, the provision of dementia specialist nurses in hospitals and primary care and community-based multidisciplinary teams to support a continuity of care for people with dementia and their families.

- 6 The Alzheimer Society of Ireland to develop a pilot dementia advisory service such as the model currently in place in the UK.
- 7 The Alzheimer Society of Ireland to work with Citizens Information Board to further refine and develop the existing advocacy services for people with disabilities, including dementia in line with developing integrated care pathways and community based services.

4 Develop procedures and practices to ensure a continuity of care to long term care settings.

The transition to long-term care or hospital can be a difficult time for people with dementia, their family members and carers. There may also be difficulties for service providers – existing as well as new. Active management of this transition could ease these difficulties, as would an established continuity of care programme within the community. Pre-planning of admissions and familiarisation strategies, such as respite care, can ease transition difficulties. Family members also need to be helped at this juncture, and active management would ensure transfer of information, clarify the roles and responsibilities within care settings and assist in providing a meaningful role for family members.

Recommendations:

In relation to the transition to long term care it is recommended that ASI and Nursing Homes Ireland collaborate to:

- 8 Develop procedures and practices to facilitate the exchange of information with, and between, the person with dementia, family members and service providers.
- 9 Develop procedures and practices to promote clarification of the roles and responsibilities of service providers and family members in the continuing care of the person with dementia.
- 10 Develop procedures and practices that provide for a meaningful role for family members in the care of their relative, as appropriate.

5 Address end-of-life care needs for people with dementia.

Awareness of the end-of-life needs of people with dementia and promotion of a palliative care approach in dementia to facilitate the provision of good end-of-life care, including specialist palliative care, as appropriate, needs to be established. This approach should extend beyond dementia-specific settings and be incorporated into all care environments.

Active development of partnerships between dementia and specialist palliative care health care professionals across a range of care settings would support an increased awareness of, and attention to, the end-of-life care needs of people with dementia. Good-quality end-of-life care requires additional resources in terms of time and training as well as support for staff. A broad range of issues – clinical expertise, artificial nutrition, hydration, burden/benefit considerations, advance directives, timely and considered decision-making – need to be addressed.

Recommendations:

- 11 ASI and Nursing Homes Ireland to work together to raise awareness of end-of-life care needs for people with dementia in long-term care settings through education and training in line with HIQA dementia-specific standards for end-of-life care.
- 12 ASI and IHF to facilitate the development of networks between specialist palliative care services and service providers in a range of health care settings, including primary care services.
- 13 ASI and IHF to facilitate the development of education and training to address pertinent end-of-life issues such as artificial nutrition, hydration, burden/benefit considerations, advance directives and ethical decision-making across a variety of care settings.

6 Support family members and carers

Care of family members, during a life-limiting illness and after death, forms a key part of the model of palliative care. Family members and carers of people with dementia generally care for their relative for a long time with limited support and can become socially isolated. Family members and carers need to be included as part of the remit of care within dementia palliative care. The implementation of previous recommendations, especially the strategies to provide a continuity of care over the duration of the illness, would support family members and carers in their role. Care of the family should incorporate bereavement support.

Recommendation:

- 14 Service providers to ensure the inclusion of family members and carers within the remit of dementia palliative care, as active partners in caring for people with dementia. Support for family members should include bereavement support that recognizes the uniqueness, and often lengthy, duration of the dementia journey.

Section 1: Introduction

Dementia is an umbrella term used to describe various conditions that damage brain cells and lead to a loss of brain function over time. Dementia causes a progressive decline in a person's mental functioning and is a broad term that describes a loss of memory, intellect, rationality, social skills and normal emotional reactions. Dementia usually has an insidious onset, with most people developing symptoms gradually over a period of years. The progression of these diseases is largely unpredictable for each individual. How and what symptoms develop depend on what parts of the brain are affected by which illness, and the unique characteristics of each individual.

Dementia has a life-changing physical, emotional and mental impact on the affected person and their primary carer and family. It affects almost 44,000 people and touches the lives of 50,000 carers and hundreds of thousands of family members in Ireland. Estimates suggest that within twenty years the number of people affected will double and that 104,000 people will be affected by 2036.

Dementia affects approximately one in twenty of people aged over 65 years. This rises to one in four in the 80-plus age group. While the risk of dementia increases with age, dementia is not a natural part of aging. Although it is comparatively rare, dementia can also affect younger people. There are approximately 4,000 people under the age of 65 with Younger Onset Dementia in Ireland.

A person with dementia will live for an average of four to eight years, depending on their age at diagnosis. Average lifespan will also be affected by gender, other medical conditions and the severity of dementia at the time of diagnosis. Dementia ranks as the fourth leading cause of death among the population aged 65 years and over.

Palliative care and end-of-life issues for people with dementia are pertinent areas for research, policy and practice in dementia care. Recent analysis of key issues for the extension of palliative care services, Palliative care for all (Irish Hospice Foundation & Health Service Executive 2008), offers a framework for the provision of palliative care to non-cancer patient groups, including people with dementia.

The Alzheimer Society of Ireland (ASI) is the national leader in understanding and providing dementia-specific supports and services, comprising a national network of 115 specialist services, seventeen branches, 3,000 members, 700 staff and 300 volunteers. The ASI has specifically committed itself, in its strategic plan (2009–2013), to supporting work for the development of palliative care for people with dementia.

A number of initiatives have been established to begin the process of addressing the individual end-of-life needs in a holistic, person-centred and planned way. For example, the ASI chaired the Dementia Working Group of the Palliative Care for All Report (2008). In addition, the society is a funder/partner with the Irish Hospice Foundation-led exploratory research project 'Establishing a Framework for Palliative Interventions within Dementia Services', and is engaged in the Hospice Friendly Hospitals Community Hospital Network. It has also made a submission and presentation to the End of Life Forum and participated in a number of its workshops. Three ASI staff (services/day centre managers) have completed the University of Stirling module 'End of Life Care for People with Dementia'. The ASI has also begun to develop relationships with local palliative care specialists.

These initiatives have assisted the ASI in commencing a dialogue around end-of-life issues for people with dementia and enabling a deeper analysis of the factors that affect palliative care provision. These initiatives have also assisted in identifying potential areas for development in the organisation. The main focus of services provided by the ASI are day care services, home care/support services and carer supports, including information and family carer training. The ASI also plays a significant advocacy role, ensuring that the voice of the person with dementia and their carer is heard in Irish social, political and economic life. In the context of these levels of activities, the ASI has identified a need to develop a model of best-practice palliative care interventions for people with dementia and their carers, at home and in a variety of residential settings. This Opening Conversations project is intended to contribute significantly to the organisation's capacity to continue its programme for developing palliative care for people with dementia. The research project is in keeping with the ASI's research agenda, which focuses on niche pieces that can have an impact on policy and practice and provide an evidence base for action.

Aims and objectives of the Opening Conversations research project

This research aimed to develop a model for The Alzheimer Society of Ireland of best-practice palliative care interventions for people with dementia and their carers and family members in order to integrate palliative care interventions into ASI service planning.

The Opening Conversations project had a number of specific objectives:

- To develop a working model for integrating palliative care into The ASI dementia service planning that is focused on best practice and is person-centred.
- To pilot-test this model in three service sites – Sligo, Wicklow and North Dublin.
- To evaluate the results and share this information – internally and externally.
- To consolidate and further develop appropriate relationships with palliative care specialists.
- To integrate the results into the training and education elements of The ASI organisational work and other related areas.

Methodology and research activities

This was a small-scale, qualitative research project that aimed to deepen the understanding of what palliative care means within the context of dementia care, as well as gaining insights into the specific end-of-life issues for people with dementia and their carers and The ASI and other service providers.

The research team comprised Annie Dillon (ASI Practice and Innovation Manager), Aileen Doran (ASI Service Manager, Wicklow), Catherine Keogh (ASI Practice Development Officer and latterly Senior Occupational Therapist, Bloomfield Care, Dublin 16), Dr Una MacConville (Research and Project Coordinator), Grainne McGettrick (ASI Policy and Research Officer), Majella O'Donnell (ASI Service Manager, Sligo) and Sarah White (Day Care Manager, Raheny).

Team liaison meetings were held as part of the project, initially to develop an understanding of appropriate palliative care within the context of dementia care. A number of research activities were developed on the basis of key issues identified by service managers and team members. Liaison meetings continued throughout the research, incorporating ongoing reflective practice, evaluation and review (detailed below).

A number of research activities were undertaken for this project:

- Interviews with people with dementia (4) and family members (5)
- Interviews with long-term care service providers (4)
- Group discussions with long-term care providers (2)
- Development and implementation of process consent forms for research in ASI services
- Review of ASI information resources
- Survey of ASI service providers
- Development of a model of dementia palliative care

The detailed result of these research activities is presented in the following chapter. In addition, the project also undertook to disseminate the research findings, internally and externally.

Sample for interviews

Interviews with people with dementia and their carers as well as interviews with service providers were undertaken by service managers in three ASI service areas (North Dublin, Sligo and Wicklow), as it was considered that they were best placed to have intimate and site-specific knowledge of their client populations and external service providers. Recruitment for participation was drawn from staff, clients and carers associated with each of the centres, and inclusion was based on ability and willingness to participate. The selection criteria were established by the service managers in each of these locations, based on intimate knowledge of client/carer population and service contexts.

Ethical considerations

The research was guided by the principles that research with humans should produce some positive and identifiable benefit and should not be carried out simply for its own sake. Consideration, particularly with regard to the inclusion of clients, carers and staff in the pilot testing, was given to the duty toward participants and protection of the rights of participants.

The Alzheimer Society of Ireland established formal ethical guidelines for research in March 2010. These are under continual review (Appendix 1). As part of the research process, a consent document based on the work of Dr Jan Dewing was created for use in the pilot testing of the 'This is me' leaflet and the conversations between people with dementia, their carers and service providers (Appendix 2). A study information sheet was also provided for this intervention (Appendix 3).

An evaluation of the process of obtaining consent formed part of this research in order to understand more clearly the benefits and difficulties of obtaining process consent.

Process evaluation and review

The development of a model for palliative care interventions has involved a process of understanding what palliative care means in the context of dementia care and clarifying what the appropriate activities are in relation to palliative care interventions for people with dementia and their families, within ASI services and beyond.

This research has focused on 'opening conversations' – that is, beginning the process of understanding the end-of-life care needs of people with dementia and those of their family members and carers. To facilitate the development of the model and the appropriate interventions, a number of reflective practice meetings were held during the course of this research. In a sense these can also be viewed as another form of 'opening conversations' – a conversation between all involved in this project that provided the opportunity to deepen the understanding of palliative care and to clarify shared aspects of palliative care and dementia care philosophy and principles. This form of reflective practice can be seen as a form of cartography and, according to Gallo (2003, cited in Ryan et al. 2010), such a cartography, 'that is, a conversation – construed as a rhizome – can be accessed from an infinite number of points, and enables access to any other point in its territory. The rhizome as a map has always unsuspected regions, a rich geography framed in a logic of becoming, of exploration, of discovery of new facets' (Gallo 2003, 94).

Using this form of reflective practice framework it was possible to identify some key areas – the transition to long-term care settings and beginning conversations with people with dementia about illness progressions and what lies ahead – that would benefit from a palliative care approach.

Developing appropriate interventions involves a process of identifying key issues, clarifying the information needed, devising a way to gather this information, and reviewing action taken and the information gained in order to further develop and refine the process. A key aspect of palliative care is the responsiveness to individual needs on multidimensional levels. In dementia care, needs and issues can be identified in general terms – for example, preparation with regard to issues of wills and power of attorney, difficulties of decisions regarding artificial nutrition and hydration at end of life, insufficient support for family members. The impact of these issues and the responses to them will, however, vary amongst individuals, families, service providers and services, and will also change over time and the duration of the illness. As a result, any intervention developed to address core issues needs to be focused on the identified issue yet be flexible enough to respond to individual needs and how these may change over time. Therefore some core characteristics of any intervention need to be responsiveness, flexibility and a mechanism for adaptation to meet individual needs whilst still maintaining the focus on the overall aim.

The commitment to, and development of, process consent (see ethical considerations above), which involves regular monitoring of levels of understanding and agreement, mirrors the way in which the palliative care interventions developed also need regular monitoring and checking to ensure that they meet both overall aims and individual needs.

Summary

Dementia is an umbrella term used to describe various conditions that damage brain cells and lead to a loss of brain function over time. It has a life-changing physical, emotional and mental impact on the affected person and their primary carer and family, affecting directly almost 44,000 people and impacting on the lives of 50,000 carers and hundreds of thousands of family members in Ireland. A person with dementia will live for an average of four to eight years and dementia ranks as the fourth leading cause of death among the population aged 65 years and over.

Palliative care and end-of-life issues for people with dementia are pertinent areas for research, policy and practice in dementia care. The Alzheimer Society of Ireland (ASI) is the national leader in understanding and providing dementia-specific supports and services, including the development of palliative care for people with dementia.

The 'Opening Conversations' research project aimed to develop a model of best-practice palliative care interventions for people with dementia and their carers and family members in order to integrate palliative care interventions into ASI service planning. This was a small-scale qualitative research project that aimed to deepen an understanding of what palliative care means within the context of dementia care, as well as understanding the specific end-of-life issues for people with dementia and their carers and ASI and other service providers.

A number of research activities were developed on the basis of key issues identified by service managers and team members. Liaison meetings were ongoing throughout the research, incorporating ongoing reflective practice, evaluation and review. Research activities included conversations with people with dementia and their family members and carers about end-of-life care; conversations with long-term service providers about the transition to long-term care; a review of ASI information provision, both current and future; and a survey of ASI staff regarding the end-of-life/palliative issues.

Section 2: Towards an understanding of dementia palliative care

Introduction

The lack of palliative care for non-cancer patients is a serious issue of inequity in service provision (NACPC 2001) and has been considered 'the greatest inequity of all' by the Health Committee of the House of Commons (UK) (Hughes 2005). Currently palliative care services deal almost exclusively with cancer care, but the physical, emotional and spiritual needs of dying patients and their families are not exclusive to cancer patients and cancer does not have a monopoly on suffering (Wasson and George 2001, 240). The aims of palliative care, such as holistic care, maintaining quality of life and dignity, family and carer support, are equally applicable to patients who suffer from a large range of illnesses.

There are compelling arguments for the extension of palliative care to other patient groups (Addington Hall and Higginson 2001), and increasing attention is now being given to those with renal failure (Murtagh et al. 2006), Chronic Heart Failure (CHF) (Nordgren and Sörensen 2003) and COPD (Curtis 2007; Yohannes 2007). People with dementia have also been identified as an appropriate patient group for palliative care services (Addington-Hall and Higginson 2001), as they form a particularly vulnerable patient group and can suffer from medical complications arising from functional impairment. People with dementia may also suffer from conditions associated with old age such as osteoarthritis and cardiovascular problems (Hanrahan et al. 2001).

The 2002 WHO definition of palliative care clearly states that a palliative care approach is applicable across a broad range of illness trajectories and care pathways. In the Republic of Ireland, projects sponsored by the Irish Hospice Foundation, for example the extending access study Palliative care for all – integrating palliative care into disease management frameworks (2008) and the Forum on End of Life in Ireland, demonstrate commitment to an integrated, inclusive and responsive hospice and palliative care framework beyond the traditional cancer approach. In attempting, however, to address the issue of equity of service provision it is important to recognise that the needs of people vary according to the nature of the illness; thus the model currently applied to people with cancer cannot be uniformly applied to other individuals and groups, and there is a need to understand the specific end-of-life care needs of people with illnesses other than cancer.

Dementia is a progressive disease without cure and with known manifestations requiring specialised care from health care professionals. The final stage of the illness can be challenging and 'requires the incorporation of palliative approaches and training for health care workers and informal carers' (Palliative care for all, p. 103). The UK NICE guidelines (2007) state that dementia care should incorporate palliative care from the time of diagnosis until death, specifically aiming to support the quality of life for people with dementia, to enable them to die with dignity, and should also include support of carers during their bereavement, which may both anticipate and follow death.

Understanding palliative care

The Alzheimer Society of Ireland's commitment and involvement regarding the provision of palliative care for people with dementia have already been documented in this report. Nevertheless, Hughes et al. (2007) have stated that in addressing the particular issues that arise in palliative care in dementia there is a need to address two immediate questions – in the context of dementia, what is palliative care and is there a need for it (op. cit., 251).

The Opening Conversations research set out to interrogate these questions prior to the development of appropriate palliative care interventions for people with dementia within ASI services. A number of liaison meetings were held to more fully understand and clarify what palliative care means within the context of dementia that assisted in identifying similarities and differences between palliative care and person-focused dementia care.

Modern-day palliative care has developed from hospice care. Hospices, as places to care for the dying, have a long history and can be documented from the fourth century. Medieval hospices were dedicated to the sick and dying and the Christian burial of the dead. The Irish Sisters of Charity opened a hospice in Dublin in 1879 and in London in 1904. 'Hospice' is now a term that describes both a place and a philosophy of care that can take place in a wide range of care settings. 'Hospice care' and 'palliative care' are terms that are commonly regarded as being synonymous (Lawton 2000, 18), although 'palliative care' is more widely used than 'hospice care' since the development of the medical specialism of palliative medicine.

In the United Kingdom the current model of hospice care is one that has developed from the work of Dame Cicely Saunders. In the 1960s Saunders and other medical professionals became disillusioned with the care of dying patients in hospitals and established St Christopher's Hospice in London as a community 'inspired and informed by Christianity' (Small 1998, 170). The ideal of the hospice movement was to provide a form of extended family which sought to provide patients with a more personal form of care and which stressed the importance of including the family as well as the dying person within the remit of care (DuBois 1980).

Palliative care is the holistic care of people with a life-limiting illness that seeks to maintain quality of life and to relieve suffering for the person with the illness and their family. Palliative care is defined by the World Health Organisation (2001) as

'An approach to care that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (WHO 2001).

This definition was expanded by Ahmedzai et al (2004) to state:

'Palliative care is the person-centred attention to physical symptoms and to psychosocial, social and existential distress and cultural needs of patients with limited prognosis in order to optimise quality of life of patients and their families and friends'.

It was also further defined by Davies, E. and Higginson (2005) as

'the continuing active total care of patients and their families at a time when the medical expectation is no longer for a cure. Palliative care extends to support in bereavement and the goal is the highest possible quality of life for both patient and family, as defined by the patient, by maintaining dignity and controlling symptoms'.

Principles of palliative care

Lawton (2000) has argued that the modern hospice movement formed part of a broader cluster of social movements that shared a number of features. There is, according to Lawton, a distinct parallel between the hospice and alternative health movements, as both advocate that the patient should be seen as a 'whole person' (2000, 14). The holistic view of the patient and the emphasis on death as a natural event have shaped and informed the principles of palliative care, which are open awareness and communication and the concept of 'total pain'.

Communication and open awareness

The modern hospice movement formulated ways to understand the experiences and needs of dying people and how they could be addressed – through communication, listening and supporting both the patient and the family. There are several reasons why open awareness about death and dying became more common and why it is currently considered very important in palliative care. Improved health care, and in particular

improvements in the treatment of cancer, makes a prognosis clearer; it also means that many people spend a longer time living with incurable illness. As a result, it can be more difficult to hide the truth about a terminal illness, or at least more difficult to manage non-disclosure (Walter 1994, 32). McNamara et al. (1994) contend that while formalised hospice objectives do not state disclosure norms regarding impending death, open communication concerning death seems to be the 'preferred interaction between patients and nurse and a path toward a 'good death''. In spite of an ideological commitment to open awareness and a wish for full information, there is now recognition that while patients and family have a right to full information, and may wish to have this, they may not want to be continually reminded that they are dying (Field and Copp 1999, 466).

There are also considerable cultural differences with regard to the appropriateness of open awareness about death and dying. Seale (1998) argues that the Anglo-American culture of individualism is at the heart of the growth of the patient-centred approach to relationships between health professionals and patients. In other cultures, however, there is not necessarily the same individualism. A study conducted in Italy (Surbone 1992) argues that this idea of patient autonomy is, in an Italian context, considered as patient and social isolation. In this context, the protection of the patient by the family, considered negatively as collusion or denial in awareness contexts (Faulkner et al. 1994), is understood as protection and as shouldering the burden of knowledge for the patient (Seale 1998, 112).

The views expressed by some Irish people regarding communication around death and dying are varied and may reflect cultural differences. An analysis of a discussion about 'breaking bad news' to terminally ill people that took place over four days in November 2003 on the daily radio chat show *Liveline* documents the responses of nineteen callers who related their own experiences and their views on the appropriateness of telling people of a terminal prognosis. This describes the way health care professionals delivered this news (MacConville and McQuillan 2009) and concludes that while open awareness may be an ideal of palliative care, cultural differences may make it more difficult to implement.

The concept of 'total pain'

The palliative care model is the holistic care of the patient and the family and encompasses four dimensions: emotional, physical, social and spiritual. It operates to a holistic model of pain incorporating the idea of 'total pain' – pain is present on the physical, emotional, social and spiritual levels (Baines 1990, 26). This concept was developed from the work of Dame Cicely Saunders, who observed that, once the physical symptoms and pain were managed and controlled, patients often revealed their emotional, psychological or spiritual concerns about death and dying. The concept of 'total pain' is also a development of the Gestaltian idea that a dying person's physical, emotional, social and spiritual concerns are inextricably entwined and each contributes to a 'total pain experience' (Lawton 2000, 13). It is understood, however, that physical pain often masks pain on other levels, and that emotional or social pain can exacerbate physical pain (Baines 1990, 28).

Palliative care also provides support to the family as they experience bereavement and grief, and extends to preparing the patients and the family for the dying process and death, in addition to the management of that process. In order to address the multidimensional aspects of pain, palliative care draws on the expertise of different professionals. Abu-Saad (2001, 21) states that the goal of interdisciplinary palliative care is the provision of excellent care, taking into consideration the complexity of care provided, the utilisation of the appropriate skills provided by the team members and minimisation of fragmentation of care. Multidimensional and multilayered care is considered to be 'most effectively delivered by an interdisciplinary team which may complement and enhance disease-modifying therapy or alternatively become the total focus of care' (Higginson and Costantini 2008).

Understanding person-centred dementia care

The modern hospice movement developed as a response to the over-medicalisation of the experiences of death and dying and advocated an approach that considered the person with a terminal illness as a 'whole person', with multidimensional needs, in parallel with other social and health movements of the 1960s and '70s. From the early to mid-1980s a similar shift in focus developed in understandings of Alzheimer's disease and related dementias: a shift from a narrow medical model towards a greater understanding of the experience of dementia and a developing rationale for an approach to care that considers human rather than exclusively medical solutions (Kitwood 1997).

Developing a person-centred model of care for people with dementia has involved an engagement with long-standing issues of stigma associated with cognitive impairment, in addition to a western societal emphasis on individualism and rationality. Kitwood's seminal work *Dementia reconsidered: the person comes first* (1997) drills down to identify and find the 'person' with dementia and in so doing provides the foundation for understanding the philosophical basis of a person-centred dementia care model.

Kitwood examined the traditional perspective of considering people with Alzheimer's and related dementias, arguing that common descriptions such as 'Alzheimer victims' or 'elderly mentally infirm' (op. cit., 7) devalue the person and make 'a unique and sensitive human being into an instance devised for convenience or control'. Conventional thinking overemphasises the pathology and impairment and underemphasises the personal; this position does not have a logical base but is a reflection of the values that have prevailed and of priorities that were traditionally set in assessment, care practice and research. This is a similar view to that which led Saunders and others to develop a holistic approach to the care of dying people, as previously documented. Writing in the mid-1990s, Kitwood argues that the time has come to readdress this balance and to recognise 'men and women who have dementia in their full humanity' (op. cit., 7).

Understanding personhood

Kitwood enters into a deep examination of the whole notion of personhood – the centrality of relationship and the uniqueness of persons. Three main types of discourses surrounding personhood, those of transcendence, ethics and social psychology, are scrutinised to provide a core of meaning resulting in a basic conceptual unity (op. cit., 8).

Within a context of transcendence, the idea of personhood is one that holds that being is in itself sacred and that life is to be revered. This is a framework that exists within many religious traditions, including Buddhism and non-theistic spiritual paths that believe in an essential inner nature that is 'always present, always perfect' (op. cit., 8). Secular humanism also asserts that the 'ultimate is personal', although it makes no non-physical supposition about the essence of human nature.

Within the context of the ethical discourses of western philosophy, a dominant theme has been the idea that each person has absolute value. As a result, there is an obligation to treat each other with deep respect and, as Kitwood argues, this is the justification in which our lives as social beings make sense. A difficulty with this discourse, however, is that it is frequently framed within individual human rights and as such can fail to see human life as interdependent and interconnected. The discourse of social psychology considers personhood as more flexible and varied; its primary associations are with self-esteem and the place of the individual within a social group, with the performance of certain roles and with integrity, continuity and stability of the sense of self.

Kitwood also draws on the work of Martin Buber (1938) whose starting point differs from that of western individualism. Buber's central assertion is that relationship is primary – 'all real living is meeting' (1938, 11). In the form of meeting that Buber proposes, there is openness, tenderness, presence, awareness and full acceptance, with no attempt to manipulate. According to Buber, it is in these meeting that we can

begin to understand our ability to determine who we are and to choose the path that we will take. Buber's work provides Kitwood with a link between the three types of discourse in which the concept of personhood is found, transcendental, ethical and social psychological. Kitwood argues that Buber's account is transcendental in that he portrays human relationships as a way to what some would describe as an encounter with the divine. His account is ethical in that it emphasises the value of persons, while in relation to social psychology it provides a foundation for an empirical enquiry in which the human being is treated as a person rather than as an object. On this basis, Kitwood (1997, 11–12) argues, if we are to have an understanding of dementia, it is essential to see personhood as relational, as even when cognitive impairment is very severe the form of meeting and relating that Buber advocates is frequently possible.

Kitwood arrives at a definition of personhood which is informed by these discourses and perspectives and describes personhood as 'a standing or status bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust' (op. cit., 8).

The issue of inclusion

Kitwood's definition of personhood is clearly one that is established within the context of social relationships and is not simply an interchangeable term for 'person'. As such, critical questions arise, such as who is to be viewed and treated as a person, and what are the grounds for inclusion and exclusion (op. cit., 9). These are central questions that have been asked frequently and over time, particularly within Western philosophy. Quinton (1973) has suggested five criteria – consciousness; rationality; agency; morality; and the capacity to form and retain relationships. Kitwood (1997, 9), however, argues that the culture of extreme individualism that has dominated Western societies has prioritised two criteria: autonomy and rationality. This reduction provides a perfect justification for excluding people with severe disabilities from the 'personhood club' (op. cit., 9).

Post (1995) has considered this emphasis on autonomy and rationality as an imbalance within our cultural tradition and thinking and argues that personhood should be more strongly related to feelings, emotion and the ability to live in relationships, and it is here that people with dementia are frequently highly competent. Post also argues the point of moral solidarity – recognising the essential unity of all human beings, despite differences that may be present in their mental capabilities. As Kitwood (1997, 10) summarises, 'we are all in the same boat and there can be no empirically determined point at which it is justifiable to throw some people into the sea'.

Person-centred care

Kitwood also explores the detail of the cluster of needs that need to be addressed in a person-centred model of care. All human beings have needs such as comfort, attachment, inclusion, occupation and identity that cluster around a central need for love, although they are not all in evidence for most people all of the time. It is when a person is under great pressure or facing severe privation that these needs come into the open, however, and may be more obvious in people with dementia who are far more vulnerable and usually less able to take the initiatives that would lead to these needs being met (op. cit., 81). Kitwood argues that the primary task of dementia care is to maintain personhood in the face of the failing of mental powers, in addition to the sensitive meeting of this cluster of needs (op. cit., 84).

Kitwood presents a reconsidering of dementia as an invitation to a fresh understanding of what it means to be a person. The emphasis on individuality and autonomy is called into question and the reality of our interdependence becomes visible. 'Frailty, finitude, dying and death are rendered more acceptable ... reason is taken off the pedestal that it has occupied so unjustifiably and for so long; we reclaim our nature as sentient and social beings' (op. cit., 144).

Shared philosophy and principles

Although specialist palliative care services are currently largely available only for cancer patients and other patient groups such as those with motor neuron disease, the definitions and principles outlined above clearly indicate that palliative care is an approach to care that is appropriate for all people with a life-limiting illness and their families. The focus on the holistic care of people, maintaining quality of life and the relief of suffering on multidimensional levels is equally applicable to people with dementia and mirrors the focus of person-centred dementia care that Tom Kitwood (1997), and others, developed. As the Beyond Barriers Report (Alzheimer Scotland 2008) states, a person-focused philosophy in dementia care goes beyond physical care and sees the person first – involving all aspects of their lives, including emotional well-being, and preserving dignity; this philosophy has had considerable impact in shaping and influencing the care of people with dementia.

The holistic care of people, embodied in the palliative care model and focused on maintaining quality of life and the relief of suffering on multidimensional levels, is equally applicable to people with dementia and enhances person-focused dementia care. Addington-Hall (1998) has identified this shared philosophy and principles:

‘Both palliative care and person-focused dementia care share a philosophy of whole person care as well as shared basic principles that focus on quality of life, whole person care, a respect for autonomy and care of the person and the family’.

While it can be argued that a palliative care approach may only be applied in the later stages of the illness, the NICE UK guidelines state that in the early days of diagnosis the family and the person with dementia need support and help in planning and coming to terms with a life-limiting illness, and that a palliative care approach is necessary right the way through the illness until the eventual bereavement.

Differences in practice

Both models of care may share a philosophical perspective and fundamental principles but there are considerable differences at the level of practice. Practice differences are influenced by illness characteristics and also by the level of existing services and resources.

Table 1: Differences in services, resources and illness characteristics

	ILLNESS CHARACTERISTICS	RESOURCES	CARE SERVICES
PALLIATIVE CARE	<ul style="list-style-type: none"> Main focus of specialist palliative care provision is for people with cancer - duration of care is generally short - to medium-term. 	<ul style="list-style-type: none"> Specialist services across acute hospitals, hospices, home care, day care and respite care. Supports multidisciplinary team-working to address multidimensional needs. 	<ul style="list-style-type: none"> Expert pain and symptom management. Anticipating needs and providing information about illness progression. Close liaison with family members to provide support and information. Providing access to specialist services through telephone support. Bereavement support.
DEMENTIA CARE	<ul style="list-style-type: none"> Impaired cognitive ability and difficulties with communication - impact more deeply as the illness progresses. Establishing relationships and understanding needs should commence early in the process. Duration of care generally medium- to long-term. Family members may be carers for much longer, thus can experience greater stress. 	<ul style="list-style-type: none"> Care frequently fragmented across spectrum of health care services. 	<ul style="list-style-type: none"> Poorly resourced. Uncertain access to allied health care professionals.

Illness characteristics

Historically, palliative care has developed within cancer care, where there can be a need for complex pain and symptom control and management in addition to addressing social, emotional and spiritual needs, within a short timeframe. This can put considerable pressure on resources and the time to 'get things right'.

In contrast, dementia can vary in its course and rate of progression; the usual time from diagnosis to death is approximately ten years, with the end stage of the illness lasting from two to three years. Most elderly patients with dementia also have other illnesses, for example diabetes or heart disease, that can contribute to physical decline and eventual death (Shuster 2000, 374). Dementia patients also suffer from problems similar to those reported for cancer patients. A retrospective study of care for people in the last year of life that included 170 dementia patients (McCarthy et al. 1997) found that the most common symptoms reported for people with dementia were confusion (83%), urinary incontinence (72%), pain (64%), low mood (61%), constipation (59%) and loss of appetite (57%). Similar symptoms were reported for cancer patients, although dementia patients experience these symptoms for a longer period (*ibid.*, 405).

Dementia presents specific challenges regarding communication and treatment preferences as the illness progresses. In response to these difficulties, Shuster (2000) and Hughes et al. (2005) have argued for the application of a palliative care approach, in particular regarding meaningful discussions about treatment preferences, from the earliest possible point in the illness trajectory. The support of family members and carers should also commence as early as possible, as part of the overall support of the person with dementia. Some degree of advance care planning could enhance end-of-life care.

Resources and services

The report of the National Advisory Committee on Palliative Care (NACPC 2001) for the Department of Health and Children recommended that palliative care services be structured in three levels of ascending specialisation. These levels refer to the expertise of the staff providing the service:

- Level 1 Palliative Care Approach: Palliative care principles should be appropriately applied by all health care professionals.
- Level 2 General Palliative Care: At an intermediate level, a proportion of patients and families will benefit from the expertise of health professionals who, although not engaged in full-time palliative care, have had some additional training and experience in palliative care.
- Level 3 Specialist Palliative Care: Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

Within the context of current health care provision, specialist palliative care services (level 3) are relatively well resourced, with a high patient/staff ratio and, in some service areas, a range of integrated services – day care, home care, in-patient care, respite care, and services within acute hospitals – although this is not uniform throughout the country.

The aim of level 3 specialisation is to provide holistic care for people with life-limiting illness and their families: the provision of multidisciplinary care to address needs on a physical level with optimum pain and symptom control and management, and the provision of support on multidimensional levels – emotional, spiritual and psychological – as well as the provision of family support, including support in bereavement.

Specialised palliative care at level 3 is provided through a number of health care services and locations, such as in-patient hospices, community (home care) service, day care, respite care in in-patient hospices, and by palliative care teams in acute hospitals. These services draw on the skills and expertise of multidisciplinary teams – consisting of doctors, nurses, social workers, chaplains, occupational therapists, physiotherapists and complementary therapists – to address multidimensional needs. Not all services at the level 3 grade of specialisation are resourced to provide this full range, however.

In contrast to specialist palliative care services, dementia care services are fragmented and poorly resourced (Cahill 2010; O’Shea 2007). The nature of the illness can mean that the relationship between the person with dementia and health care service/dementia services is generally medium to long term. This can be demanding on resources, although the longer duration does have the benefit of providing more time to understand fully the individual needs of people with dementia and their families, to develop these relationships and to facilitate the provision of formal and informal support.

The NACPC (2001) has recommended a level 2 approach for a proportion of people and families, but it stops short of specifically identifying how this approach is constituted and how it might be delivered. While accepting that a level 3 level of specialised palliative care is necessary for some patient groups that require complex pain and symptom control and management over the short to medium term, a level 2 approach would also need to encompass other aspects of the palliative care model, such as understanding and responding to individual needs and choices, anticipating needs and providing information about illness progression, a multidisciplinary approach to address multidimensional needs, access to respite facilities, close liaison with family members to provide support and information, facilitating a move to long-term care, bereavement support and liaison with external services to provide coordinated care. *See Table 2 Opposite.*

Summary

The philosophy, principles and practice of palliative care were examined in order to reach an understanding of what palliative care means in the context of dementia care. Both models of care share a person-focused 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 the family. Nevertheless, there are considerable differences with regard to practice, which are shaped by the illness characteristics, resources and services.

In the context of current health service provision, specialist palliative care services provide an integrated comprehensive service for patients and their families across a range of settings. In contrast, dementia services are frequently fragmented and poorly resourced. People with dementia and their families and carers have similar needs to cancer patients and would benefit from a palliative care approach, at a minimum of level 2. The characteristics of the illness, in terms of cognitive impairment, make it more imperative to commence this level of care as early as possible in the illness trajectory.

Table 2: level 2 palliative care activities and approaches appropriate for ASI dementia care services

ROLE OF ASI SERVICES		SPECIFIC EOL CARE, GENERALLY IN LTC
<p>Information</p> <p>Anticipating needs and providing information about illness progression</p> <ul style="list-style-type: none"> o Understanding level of awareness regarding illness and illness progression: need to identify a number of ways to do this <ul style="list-style-type: none"> • For person with dementia • For family members o Coordinating with primary care o Providing information (probably in stages), in multiple ways (for example, leaflets, one-to-one dialogue) on <ul style="list-style-type: none"> • Financial • Legal • Social • End-of-life care aspects 	<p>Transition</p> <ul style="list-style-type: none"> o Develop relationships with LTC to manage transition o Develop relationships with other care agencies (for example Home Instead) re provision of dementia palliative care at home o Clarify roles/relationships in developing partnerships of care o Facilitate/provide respite care o Develop and facilitate multidisciplinary networks and services in community <ul style="list-style-type: none"> o Primary care o Pastoral care o Develop multidisciplinary links into LTC settings o Primary care o Pastoral care 	<p>EOL care</p> <p>Availability/access to internal/external specialist expertise for EOL care</p> <ul style="list-style-type: none"> o Pain and symptom management o Adequate and appropriate education/training for staff o Knowledge of when spc is required o Requires established networks of expertise o Advance care planning o Preparation for decisions regarding feeding etc. o Requires clarity re artificial nutrition, antibiotic use etc. o Requires timely consultation with family <p>Understanding and responding to individual needs and choices</p> <ul style="list-style-type: none"> o Requires knowledge of preferences re treatment, place of care o Requires knowledge of the individual person o Requires adequate patient/ staff ratio <p>Multidimensional care of person with dementia and their family members</p> <ul style="list-style-type: none"> o Access to and availability of multidisciplinary team, medical, nursing, allied health professionals, social work, chaplaincy/pastoral care as appropriate <p>Family support in illness and bereavement</p> <ul style="list-style-type: none"> o Requires established relationship with family members o Requires an understanding of role of family in continuing care of person with dementia
<p>Preparation</p> <p>Understanding and responding to individual needs and choices</p> <ul style="list-style-type: none"> o Relationship with person with dementia and family members o Begin process of preparation for EOL o Choices regarding care, LTC and/or home care Information regarding levels of nursing care, social support and resources required o Financial issues o Difficult decisions regarding feeding etc. 	<p>After-death care of family ASI/LTC</p> <ul style="list-style-type: none"> o Support in bereavement for family members/carers o Acknowledging relationship between care setting and the deceased and family. o Activities may include remembrance services, counselling 	

Section 3: Towards a model of dementia palliative care

21

Introduction

In order to develop a model for dementia palliative care interventions for ASI services, two key issues were identified as needing specific attention: first, opening conversations with people with dementia and family members regarding the illness and what lies ahead in order to address the principle of communication and open awareness of death and dying; second, the transition from ASI services to long-term care in order to address issues of support for people with dementia and family members and carers, in and beyond ASI services.

A number of activities were undertaken to gather information for potential interventions in these areas and are detailed below. In addition, a review of current ASI activities in supporting the person with dementia and their family members was undertaken, as well as a review of currently available information products.

Activity 1: Having a conversation about end-of-life care

As previously identified, this is a key underlying principle of palliative care and it was considered important to begin opening up a conversation about end-of-life care with people with dementia and family members. It was decided to utilise and adapt a form designed by the Alzheimer's Society (UK) entitled 'This is me'; permission for use and adaptation was granted (Appendix 4). The original purpose of this form was to provide key elements of personal information about the person with dementia should an unscheduled admission to hospital or other health care setting become necessary. It is similar to the social profile form that is currently used in ASI services and completed by the service providers. The 'This is me' form, however, is primarily filled in by the person with dementia and was considered a way in which conversations about illness progression and end-of-life issues might be prompted over time. For the purpose of the research project, 'This is me' was used as a tool to facilitate a conversation about end-of-life issues.

A process consent form was devised for use in this intervention.

Profile of participants

Conversations were held between four people with dementia and five family members/carers and service managers in the ASI service areas. Participants with dementia – three women and one man, aged between the late sixties and mid-seventies – were at the early and early to middle stage of the illness. Five family members/carers – not all of whom were connected to the participants with dementia – took part in a conversation with ASI service providers. Key issues for the person with dementia and family members/carers. A number of key, and interwoven, issues emerged from these conversations.

Table 3: key issues for people with dementia and family members/carers

Key issues for person with dementia	Key issues for family members/carers
Uncertainty about diagnosis.	
Very low level of awareness of change and illness progression.	Family members can have limited understanding of illness progression and the planning that is required.
Little or no preparation regarding legal and financial affairs.	
Timing of information can be very important.	Timing of information can be very important.
Person with dementia can be very isolated.	Caring for a person with dementia can put family members and their relationships with spouses/children under considerable strain.
Very difficult to have conversation about end-of-life care needs when it is already difficult to talk about having dementia.	Family members can have difficulties with discussing the illness with the person with dementia.
	Uncertain of role in long-term care settings.

For the person with dementia there was an uncertainty about diagnosis; while there may be an awareness of memory problems, there may not be a formal disclosed diagnosis of dementia. All participants had very low levels of awareness of change and illness progression, and as a result they had made little or no preparation regarding their legal and financial affairs.

While the intention of this intervention was to open up a conversation about end-of-life needs and care issues, it was found to be very difficult to talk about this because it is already difficult to talk about having dementia. Some participants did not want a lot of information in one go and did not want to know too much about the later stages of the illness, so the timing of information can be very important.

Unsurprisingly, it was clear that the person with dementia can be very isolated; this may be as a result of the illness but also because of family and neighbourhood demographics. For example, Catherine, a 72-year-old lady with dementia, lives alone with no immediate family. Her next of kin is her first cousin. She likes meeting people, looks forward to attending the day centre once a week and 'has a lovely girl that goes into her house, for an hour every morning'. Other than that she does not see anyone except for a few neighbours, who are also getting older – she said that she often feels lonely, particularly in the evenings and at night-time. This lady does not have any concept of change; she thinks that things will stay as they are. She said that if she was unwell for a while she would not mind if help came to her house but will not consider leaving it and does not see the need to go to a solicitor to write a will or to give her cousin power of attorney.

Margaret is in her late sixties with early to mid-stage dementia, and she did not think about her future either. While she is aware that she has a memory problem and that it is getting worse, the service manager reported that, after a lot of discussion, it was apparent that she had no concept of future needs or changes. Margaret said that her sons organised everything for her, such as setting up direct debits for all her bills. She did not know whether she has made a will or whether anyone has power of attorney over her affairs, but feels that her sons will make sure that everything will be okay for her and she will do anything they want.

Mary is in her mid-seventies and said that she had a lot of support from her family, particularly her daughters. She feels that she can do everything for herself and is very independent, does not have any home help and does not want any. She showed no insight into her illness, no awareness that she is forgetting things and no concept of future changes or needs. Interestingly, after this conversation her daughter, Susan, asked to speak to the service manager on her own, relating that her mother had no idea that she has dementia and does not think that there is anything wrong. Susan said that she feels that she does not understand the illness very well herself; she finds it difficult to talk to the consultant in front of her mother and he will not give her time alone. Susan also thought that it would be a good idea to have a specialist dementia nurse to advise both the person with dementia and the family on best treatments and care needs on an ongoing basis. Ideally this person would be on the end of a phone if required, or would be able to change medication when necessary. She said that her mother only sees the consultant every six months and that her last appointment was with a registrar who did not know anything about her mother.

Susan also feels that family carers should be assessed – for their ability to understand the illness and to understand changing needs, and their ability to care at a later stage of the illness. While she has no difficulty caring for her mother at present, as she is quite independent, she feels that if her mother becomes incontinent she will be unable to deal with that, and her sisters have said the same. Susan also said that support groups are good initially but feels that they should be professionally driven by people who can answer questions and who have a thorough knowledge about the illness, including talking about and preparing family carers for late-stage dementia. Susan also suggested that the subject of death, dying and old age should be discussed more generally in society as people get older. GPs, consultants, public health nurses and people working with older people in general should be having those discussions, irrespective of their diagnosis, to advise people of the importance of getting their affairs in order and documenting their wishes, both medical and social, for future reference.

When asked about palliative care needs, she said that she had never thought about it. She thinks that the needs at earlier stages are completely different than at a later stage. She would like to get more information and be able to talk to someone about end-of-life needs and care when her mother is a lot worse than she is now. She is not sure whether she should be told too much too early.

Conversations with other family members/carers reflected similar issues to those raised by Susan and those that arose for people with dementia. There was a limited understanding of the illness progression and the planning that is required amongst family members/carers, but there was also a similar resistance to a lot of information at one time. Family members were also very isolated

Some carers expressed concerns about their other relationships, as they felt that these were under strain as a result of caring for their relative with dementia. For example, one carer who cared for her mother with dementia in her own family home reported difficulties between her mother, her husband and her teenage son, causing considerable family tension. This carer felt that the 'impact on family is more frustrating than the dementia itself'. The ASI service manager reported the conversation as follows:

'The biggest impact is on her teenage son as his grandmother says hurtful things, i.e. what are you doing here, and ordering him out of the room. This has resulted in avoidance of her and he doesn't have friends over. He stays away until she has gone to bed. He feels hurt and doesn't appear to understand that this can be part of dementia. They don't have family meals as Mum primarily stays in the kitchen area and doesn't like many people in there. Mum "refuses to recognise her husband", he receives similar treatment to son ... [and] feels neglected as so much time is taken up with caring for his mother-in-law. He feels guilty that he cannot help his wife as Mum won't allow him in the kitchen to cook etc. Huge impact on all relationships and social isolation, not being able to go out together and no friends visit.'

For some carers, however, looking after their relative with dementia was an enjoyable experience; for example, one daughter caring for her mother with dementia, who is in her 90s, finds caring enjoyable as her mother is very appreciative of what she does for her and is easily distracted with humorous comments – 'they have a good laugh together'.

Some carers expressed concerns about their role once their relative went into long-term care. One carer, for example, looked after her father, who also had Parkinson's disease. She had cared for her mother, who also had Alzheimer's disease, since 1999. Her mother died in 2009 and she moved directly to care for her father. Unsurprisingly, she reported that she felt isolated from society and abandoned. She was also concerned about her own role once her father passed away and is uncertain what she will do.

Addressing issues about illness progression

Following the conversations with people with dementia and family members and carers, it was clear that any intervention developed would need to address the central issues that arose.

It is very difficult to have an open discussion about death and dying with a person with dementia, as it is not easy to have an open discussion about the diagnosis of Alzheimer's disease and related dementias. There appears to be a lack of disclosure about the diagnosis, although health care practitioners in primary care, such as GPs, are ideally positioned to begin a discussion about the diagnosis and its implications. Many people in the early stages of their illness do not feel that it is appropriate to have those discussions at this time, but when the person goes into the later stages their ability to communicate effectively or make decisions for themselves is very limited, so at this later stage family members have to be consulted.

The illness and/or dying trajectory of dementia can be unpredictable – it can be sudden and unexpected or it can last months or even years. More preparation is required by families to deal with major changes, such as understanding the different stages of the illness or dealing with their loved one going into long-term care.

The importance of open and transparent dialogue between all parties involved from early on in the illness cannot be emphasised enough with families.

In the earlier stages the person with the illness should be given as much information as they request or can handle. Family carers should also be given information at all stages as the illness progresses.

Care teams – community-based or nursing home care teams – need to be kept informed and consulted, where appropriate, as changes occur. Supports can be put in place for both client and family if all contributing professionals are aware of the illness progression in each individual case.

Methodological review: using the ‘This is me’ form

The research group reviewed the use of the ‘This is me’ form after a number of interviews had taken place. A number of benefits were identified; the form was found easy to use and very useful in raising pertinent issues, providing an understanding of the levels of awareness of the illness and illness progression, and in particular for providing insight into family member/carer needs and concerns. Nevertheless, there were some difficulties experienced in introducing the form, and in particular the issue of consent, as this caused a degree of anxiety and was felt to be an ‘elephant in the room’. It may be that this difficulty is primarily about gaining consent, as this shifts the intervention from a conversational exchange to a more formal interaction.

Some feedback was also received from participants regarding the form. Most carers were quite receptive to the form, saying that it was ‘easy to fill in’ and would have been very useful for families when their loved ones had been going into respite for the first time, and would be useful if the time came for long-term care. Carers suggested two additions – the name of their GP and the public health nurse.

One carer who looks after her father with dementia and Parkinson’s disease found it a good exercise to think through the wishes of her father. She is considering completing another form with additional details (she felt that there was not enough room to fill everything in on this form) to have in case of emergency so that others will know as much about him as possible. Currently she is the only person who knows everything about her father and she would like to impart this to other professionals/carers so that they will be considerate of his wishes and needs.

Following this review of both the ‘This is me’ form and the process consent, it was agreed that an adapted version of the form (Appendix 4) would be of benefit for continued use and that the difficulties experienced regarding consent would need to be managed and continually reviewed for future work, without compromising the requirements of ethical research behaviour in future research.

Activity 2: The transfer of trust – the transition to long-term care

The transition to long-term care can be a particularly difficult time for people with dementia and their family members, but also for ASI staff members and long-term care service providers. Moving to long-term care can be a recognition, and acknowledgment, that the person with dementia is moving into a more advanced stage of their dementia. Recent ASI research findings (Argyle et al. 2010) regarding the impact of moving to long-term care on family members provided information from that perspective. There was an interest in finding out more about the perspective of service providers and what could be done to ensure a continuity of care in addition to addressing end-of-life care issues.

The aim of this intervention was to understand how best to provide a continuity of care from ASI services to the long-term care service provider. The focus was on understanding how to help the person with dementia 'settle in' to a new environment, as well as providing support that addresses the practical, social and emotional difficulties which family members and carers may experience during this transition. Service managers also identified the need to develop ways of linking with service providers in long-term care settings that support the person with dementia, family members and service providers.

Key issues identified

The recent Argyle et al. (2010) report has documented some of the difficulties experienced by the person with dementia and family members regarding a move to long-term care. For the person with dementia there is a loss of familiar carers, familiar surroundings and routines, and these changes may happen suddenly or with little preparation. Family members and carers can experience relief that their caring role is eased while also experiencing painful emotions such as guilt, bereavement and loneliness.

Family members and carers were helped by having some continuity in caring for their relative in the new setting. Adjustment to the new role was also helped by knowledge of the quality of care in the new setting, familiarity with the setting, and emotional and spiritual support. These are generalised findings; it was also clear from the report that responses and reactions can be very individualistic – for example, some family members/carers did not welcome group support.

In this Opening Conversations project, ASI service managers identified a number of key issues from the perspective of ASI and long-term care service providers, such as lack of planning and preparation, the loss of familiar and established relationships, and difficulties in establishing new relationships for, and with, long-term care service providers.

– Planning and preparation

The move to long-term care is best done in a planned and considered way. The current level of resources for people with dementia frequently means that this move happens suddenly when beds become available, or when the physical condition of the person with dementia changes rapidly. A lack of preparation and a sudden move can increase difficulties for the person with dementia, family members and carers and service providers.

– Need for continued support

For existing (ASI) service providers there is the loss of the relationship with the person with dementia and their families. There can also be frustration and uncertainty about the quality of care in long-term care settings. There can be a need to provide ongoing and increased support for family members and carers.

– Establishing new relationships

In long-term care there is a loss of information about the person with dementia and the family, and there can be difficulty in establishing new relationships in long-term settings. For new service providers there can be difficulties in managing the care of a new person and the interactions with family members, especially when they may have limited knowledge about the person with dementia. A further difficulty may be a lack of commitment to and/or resources and procedures for ensuring a smooth transition.

A continuity of care

There was also interest in drilling down to an understanding of what a continuity of care actually means; for example, what are the characteristics of this level of care, how can it best be provided and supported, and what are the challenges to its provision?

Continuity of care is very difficult to define, although ASI service managers were able to identify the aspects that family members and carers talk about in relation to a continuity of care:

- Routines like time to get up/go to bed, bath or shower, diet etc. are not changed too much.
- Family members being able to visit as much as possible (some families complain that they are advised not to visit in the beginning at all until the person settles).
- Care plans drawn up, and all decisions to be made in consultation with main family carer.
- Family GPs and consultants to remain the same where possible, as they are familiar with the person with dementia.

Family members also spoke about the importance of staff understanding the person as an individual – understanding that they are of an older generation with psychological and social needs as well as care needs. There may be staff with cultural differences or significant age differences, however, and as a result many people feel that they are not treated with the respect and dignity they deserve or are not understood. This is particularly noticeable with very vulnerable, highly dependent dementia patients who have very limited communication abilities.

ASI service managers were also able to identify elements that, in their experience, assisted in a continuity of care for both the person with dementia and family members and carers. These include the following points.

Assisting the person with dementia in becoming familiar with small changes

If, for example, the person is still aware of family members and their environment, some preparations for change need to be made; these can include assisting the person with dementia to get more comfortable with different people in their present environment, such as by having home carers and attending day services.

Introducing overnight respite care

Introducing overnight respite care over a period, in the nursing home where they will be residing.

Using a carer's diary

Over the years a profile could be built up about the person, to include desires and wishes, likes and dislikes, opinions about religion and spirituality, medical interventions and long-term care.

Having a transfer plan in place

Having a transfer plan in place and organising a visiting roster to include family members, carers and any other significant person in their lives at present would also be helpful in managing the transition and would assist in settling the person with dementia into their new environment.

Advocacy in the long-term care setting

An implementation of an overlapping phase at the initial stages of a transfer to long-term care services. A continuation of contact with ASI service providers in the long-term care setting in order to enhance the transition to other services and to act as an advocate for the person with dementia and family members.

Supporting family members

Many families say that the transition is more difficult for them if their loved one is in the very late stages of their illness and they need the most help with adjusting and dealing with change. Helpful interventions can include having someone from the present service to talk to about the changes and getting to know and build up a relationship with two or three key people in the new environment. For family members it is reassuring to know that they will be included in all planning and changes that may occur for their loved ones.

Conversations with long-term care service providers

Further information was needed from long-term care service providers before any intervention could be developed to address the key issues already identified. As a first step in addressing the transition to long-term care, it was decided to identify the challenges for long-term care service providers and a number of questions were devised to address these issues with service providers in these settings.

1. What measures or interventions would be beneficial from their perspective on admission to their long-term care setting of an individual with Alzheimer's disease or a related dementia?
2. What difficulties could they identify that might arise when a person with Alzheimer's disease enters long-term care?
3. Are any measures currently in place that are specific for admission of individuals with Alzheimer's disease or related dementias?
4. Who are the key people that service providers feel would be beneficial in facilitating the transition into long-term care?
5. Is there a practical role for families in the transition into long-term care?
6. At present is there any expertise in the end-of-life care for individuals with Alzheimer's disease or related dementias in their long-term care facility (e.g. pain relief, artificial hydration/nutrition, spiritual care etc.)?

Four interviews were held with service providers in long-term care settings. A number of key issues were identified. It was felt, however, that there was a high level of guardedness on the part of service providers. One group discussion with care assistants and nurses was more successful. As a result, a further focus group with management, nursing and allied health care professionals was held in a long-term setting. This group discussion allowed some of the issues to be explored in greater depth.

Variations in service provision

Following interviews and group discussions it was clear that there is an unevenness of service provision, with considerable variation between long-term care facilities regarding the range of services they are able to provide and the available resources. There were also considerable differences regarding the level of multidisciplinary approaches to care, an understanding of family perspectives and needs, and the level of dementia-specific education and training of staff.

According to one service provider, the needs of people going into long-term care have changed quite significantly over the years and patients are now far more dependent. Twenty years ago, 75% of patients going into long-term care were fully mobile and aware; now 75% of patients are fully dependent in respect of all their personal and emotional needs when they are going into care.

Some service providers felt that family carers can be very focused on the environment of the nursing home rather than the quality of care it provides and the type of service it offers. For example, some families may not accept a place in a nursing home if they are not offered a private room, as they feel that their loved one was always a very private person, but they may not take into account that, owing to their deteriorating health, their needs have now changed. The person with dementia may be far better off in a shared room if they are very highly dependent, as staff will spend more time in a shared room because there are more people requiring assistance; family visitors from other patients may also provide interaction.

Some service providers remarked that family carers, particularly spouses, are often very critical of how staff in the nursing home carry out tasks. Some of this may be constructive criticism but may be perceived by staff in long-term care settings as resulting from family members transferring their guilt feelings about not being able to continue care at home onto staff.

Service providers also found that most families have a limited understanding of Alzheimer's disease or any form of dementia, with little understanding of the way the illness progresses and knowledge of their loved one's prognosis. Although they have seen changes over the years while they lived at home, family members often cannot understand that their relative is deteriorating when in long-term care.

Some service providers felt that GPs, consultants and voluntary organisations should give more education, support and advice to families through all the different stages of the illness. While this can be general information, it also needs to be specific to each individual and family. It was recognised that families may go through a grieving process a lot earlier when their loved one has dementia. At present this is not addressed and this can result in considerable denial, anger and frustration.

The provision of services in the long-term care settings encompassed a spectrum of resources and services. On one end of this spectrum, some services had comprehensive assessment procedures and access to multidisciplinary services, with high levels of staff training and awareness of dementia-specific care. Other services, however, offered only physical assessments and showed a lack of staff training, and staffing, to meet the needs of people with Alzheimer's and related dementias.

A group discussion in one care setting provided the opportunity to drill down into some of the issues which arose and provided greater detail about aspects such as the implications of differences in cultural practices and expectations and the impact of death and dying on long-term care staff.

Key issues for service providers

The long-term care settings differed considerably in their standards and resources, but it is possible to identify key issues such as services and resources, preparation and education, managing relationships and forming partnerships, end-of-life care and decisions, bereavement support and identified needs for the future (see Table 4).

Table 4a	Services and resources
	Differences between care settings, uneven resources, facilities and training have implications for managing transition and quality of end-of-life care.
	Lack of appropriate care settings for people with dementia.
	Lack of dementia-specific training and education for staff in long-term care.
	Levels of multidisciplinary input uneven.

Table 4b	Preparation and education
	Admissions are largely crisis-driven; little preparation for person with dementia, families or service providers.
	Need for information about the person with dementia on admission.
	Hospitals provide very little information to patients and families regarding services; just really provide a list of care homes.
	Poor information is available from GPs; this is generally better from Old Age Psychiatry.
	Lack of awareness on the part of families about illness progression and quality-of-care issues.
	Lack of awareness and knowledge on the part of families regarding artificial nutrition and Peg feeding and other difficult end-of-life decisions.

Table 4c	Managing relationships and forming partnerships
	The first month can be very difficult as trust is not yet established and families can find it difficult to let go of the care of their relative. Staff need a lot of support during this time as families can be very demanding.
	Family members have a need to know that the person is comfortable and that the care setting has specialist knowledge; also need reassurance that there is a high level of expertise, especially regarding pain-relief.
	Lack of shared understanding between service providers and family members. Managing these relationships can be difficult. It can be like 'walking a tightrope', keeping family members on board but balancing with professional judgement—need to develop active partnerships.

Table 4d	End-of-life care and decisions
	Best practice is not to bombard families with information. Important to notice changes that may be occurring and stay one step ahead.
	Families generally prefer for their relative to remain in care setting rather be admitted to hospital, probably based on poor experience of hospital admissions in the past.
	Specialist level of expertise is needed. GPs don't have the same level of expertise regarding medication and dosages. Access to telephone advice and support from a Clinical Nurse Specialist (PC) would be good.
	Advance care planning issues need to be addressed.

Table 4d	End-of-life care and decisions contd.
	Need to have an awareness of specific religious requirements for all residents.
	There can be different cultural practices around death and dying amongst staff and this can be difficult to manage.
	The duration of the end stage and dying can be uncertain and this can be difficult for families. Nursing staff felt that they need support in dealing with difficult situations with relatives. They are in the frontline and receive most of the complaints and demands.

Table 4e	Bereavement support
	There can be a significant sense of loss experienced by staff when a resident dies. There is no formal bereavement support. Inexperienced staff can find deaths, and the dying process, particularly difficult.
	Residents may also find it difficult and may miss the person who died.
	For some families it can be difficult when the relationship with the care home ends, especially if there have been daily visits, as there is a major gap created in their lives.
	Family Family members need bereavement support.

Table 4f	Identified needs for the future
	Education: specifically regarding appropriate cultural and religious practices around death and dying; this also has implications across the spectrum of practice, not just at death.
	Access Access to specialist palliative care expertise, perhaps at the level of access access to a CNS for advice and telephone support.

Activity 3: A review of ASI current information provision

The emerging information from the Opening Conversations project, such as the need for incremental information addressing key issues for people with dementia and their family members and carers, prompted a review of the current ASI information provision. Following this review, the current and future information provision was grouped into three areas – pre-transition; transition; and end-stage dementia. As later findings from the Opening Conversations project also identified a need to address specifically the early stage, diagnosis and illness progression, these aspects will need to be incorporated into future information products.

Current information provision

The Alzheimer Society of Ireland currently provides a range of information for people with dementia, and in particular for family members and carers. A number of information leaflets are available on the website and include information on diagnosis, practical tips for daily living, planning for the future and, specifically for carers, information on carer self-care (see Appendix 5 for content details).

The Alzheimer Society also provides a number of booklets and guides, including Understanding Alzheimer's disease and other dementias, which provides a brief explanation of dementia and an outline of the early signs and symptoms of Alzheimer's disease and the stages of the condition. The booklet contains a memory checklist and a diary section that can help people to prepare for a visit to their doctor about their concerns.

The ASI provides information about nursing homes and residential care. Guidelines to choosing a nursing home provides practical tips on choosing a nursing home for a person with dementia; it also contains information about meeting the cost of private nursing homes and an appendix about the Nursing Home Subvention Scheme or Fair Deal.

The ASI also provides resources such as a Caregiver's Diary. This helps to ensure a person-centred approach to care by providing a practical resource to record a person's personal details (date of birth, contact details, etc.), their history (family members, past occupation, etc.), likes and dislikes (foods, music, etc.) and routine. The aim of the diary is to provide a full and rounded picture of the person with dementia which can then be used by staff in any service which the person with dementia may avail of in the future – day care, home care or residential care.

'The life story book' is a further resource provided by the ASI. This is a well-established method of communication with people with dementia and offers family, friends and professionals a greater insight into the person, their life and history. This publication offers space to collect photographs and other memorabilia for the person with dementia to look through and reminisce with. It covers areas such as home, schooldays, working life and special memories.

Considerations for future developments in information provision

For future provision there is a need to clarify the audience(s) for information. While the primary target audience is the person with dementia and their family members and carers, 10% of calls to the Helpline are from secondary users. There are a number of considerations to be taken into account in the development of future information products, such as the staged provision of information; identifying gaps in information provision; practice development; training and resources; and legal and financial planning.

Staged provision of information

Information from the Opening Conversations project suggests the need for staged or incremental information about the illness and its progression. In addition, the conversations with people with dementia and family members have highlighted that while people did need information, there was a level of resistance to what is perceived as too much information too early and/or all at the same time.

Identifying gaps in information provision

The current information resources are based on the anticipatory needs of people with dementia and their carers. It is recognised, however, that there are a number of gaps in current ASI information provision, especially in relation to the transition to long-term care. For example, the ASI provides very practical information on how to choose a nursing home, the 'Fair Deal' and so on, but there is a gap in the area of support for the emotional impact of decision-making and the effect on the person with dementia of going into long-term care. Support could also be provided for family members, addressing issues such as respite care, visiting and meaningful activities, and taking into account the different needs of spouses and adult children. In addition, there is a need for practical information regarding hydration, artificial nutrition, pain management and other end-of-life issues.

Practice development

The main focus of the current information development plan is on the person with dementia and carers/families and does not include care staff, although 10% of calls to the helpline are from secondary users – health care staff and other professionals who also use ASI information products. The current HSE Dementia Education Project has been provided with ASI information such as leaflets and carer's booklet for the pilot course. The practice development aspect of the information resources needs to be acknowledged and developed and this requires resources. In addition, ASI staff can frequently be the first point of contact after the receipt of a diagnosis.

There may often be a gap between the time of diagnosis and a conversation with anyone, including health care professionals. The stage of dementia also needs to be considered: for example, at what stage are the ASI meeting people with dementia?

Training and resources

Providing information for people with dementia and their family members and carers regarding end-of-life care needs and decisions could trigger a conversation about such aspects as advance care planning. This can be considered a ‘therapeutic conversation’ and as such will require training and support for staff, including strategies for opening and exiting conversations.

Legal and financial planning

Legal and financial planning information and advice may be best located within a conversation at primary care level and after the diagnosis. This may involve some level of education and information for health care providers at primary care level. The information can be phrased positively – for example, the benefits of enduring power of attorney. The information could also contain pointers about what may need to be discussed with legal advisers. It may also be appropriate to direct information products to legal and financial advisers.

Activity 4: A survey of The Alzheimer Society of Ireland service providers

An electronic survey was conducted with ASI staff to establish awareness of end-of-life/palliative care information needs and support for service users. This was a short questionnaire to ascertain whether end-of-life/palliative care has come up for discussion with service users and whether it has been discussed in connection with support or interventions for people with dementia, their carers and family within ASI services. Respondents were also asked for their views on the needs of people who use ASI services in relation to end-of-life care/dementia palliative care and whether they would be interested in information and training on end-of-life/palliative care, developing relationships with other service providers, such as long-term care service providers and specialist palliative care services. Respondents were also asked whether they had an interest in being involved in any future developments on dementia palliative care within the Alzheimer Society.

The questionnaire was administered to staff working and coordinating a range of The Alzheimer Society of Ireland services such as home care, support groups, day care, drop-in centre and the helpline. Twenty-two completed questionnaires were returned, giving a response rate of 38%; the respondents had a variety of roles (and also multiple roles) within ASI services.

Table 5: Roles within ASI services of respondents to questionnaire (staff may have multiple roles).

ROLES WITHIN ASI	NUMBER OF RESPONDENTS	RESPONSE RATE
Services manager	6	27%
Day care manager	7	32%
Home care coordinator	11	50%
Support group coordinator	4	18%
Other roles: home care services manager, helpline coordinator, home support supervisor and drop-in centre	5	23%

Eighty-six per cent of respondents reported that end-of-life/palliative care has come up for discussion and as an area for support in home care, day care, carer support groups and with individual people with dementia, their carers and family members.

All (100%) respondents expressed interest in receiving information on dementia palliative care and 96% would like training for themselves and their staff on end-of-life/palliative care. Ninety-one per cent of respondents expressed an interest in developing relationships with service providers in long-term care and specialist palliative care services, and 77% expressed interest in future developments of dementia palliative care within ASI services.

End-of-life/palliative care as an issue for discussion

It was clear from the responses that end-of-life/palliative care has come up for discussion with service users and did so across the whole spectrum of service provision. One respondent involved in support group services commented:

‘Yes, it is often discussed at support group meetings. Families like to know what help will be out there towards their loved one’s end-of-life, can they nurse them at home etc.’

Respondents from the helpline service commented that, while this issue came up infrequently within this service, when it did ‘the caller usually wished to talk through the pro’s and con’s of peg feeding or signs and symptoms that may indicate end-stage dementia’.

Other service respondents also commented that ‘families are just concerned as to how they can manage the progression’, while others remarked that family members raised concerns about their ability to look after their relative towards the end of life. Many families felt that the only option was long-term care, as private sector home care agencies are not trained or equipped to deal with this kind of care at present.

Nevertheless, respondents from the ASI home care services stated that they deal with many people up to the time of death.

‘We deal with many people at home up to the time of their death. The care we give has to adapt accordingly. These changes are discussed with all parties.’

While home care workers did continue to care for people with dementia up to the time of death, one home care worker remarked on the difficulty of accessing appropriate training. This respondent wished to engage in palliative care education but found that this was difficult to access at a local level.

Respondents also remarked that carers felt that palliative care should be available for people with dementia. One respondent remarked on the experience of a family member whose relative was unable to access palliative care services within their long-term care setting, causing considerable distress: ‘this family found it terrible that their mother had to suffer more as they felt she should die with dignity and respect’.

End-of-life/palliative care support or interventions for people using ASI services

It was also clear that end-of-life/palliative care comes up as an area for support or interventions for people with dementia, their carers and family members in the service.

‘[Family] Carers feel very strongly that palliative care should be available to our clients.’

Other respondents stated that families feel that their loved ones do not get the dignity they deserve in long-term care settings and would prefer to keep their relative at home; there are concerns, however, about providing the high level of care that is needed for

their relative at the end stage of the illness, and consequently many families feel very alone at this stage.

Respondents from the helpline service stated that, as the service is non-directive, they do not provide advice but are there to provide emotional support and a listening ear for people to talk about the decisions they are facing and to facilitate them in their decision-making.

Nevertheless, the home care service does continue to support people with dementia and their families through all stages of the illness. One respondent from home care stated that they continued to support the family even when their relative has entered long-term care. Other respondents from the home care service stated that

'A number of clients have been cared for at home during the end stages of their condition. Whilst we have not always been in a position to offer additional hours at this time due to lack of funding, home care workers often worked over and above their hours on a voluntary basis.'

End-of-life/palliative care needs of people using ASI services

When asked about the needs of people who use ASI services in relation to end-of-life/palliative care, all respondents considered this a particularly important aspect. Respondents felt that it was important to be able to provide support and information for families even when their relative was no longer availing of ASI services.

'Very important as a service to be able to support the client and their family through all stages of the illness regardless of whether they can still attend or avail of the service. In other words, be there for them towards the end-of-life stage, and offer support to their families after death.'

Respondents strongly stated the need for information and support for families, to support them in caring for their relative.

'Many people have difficulty accepting that their loved one is dying. They need time and patience but they also need as much information as possible about caring for a person who is dying.'

One respondent suggested specific support groups, or individual support sessions to talk through end-of-life decisions, and that it also needs to incorporate support in bereavement.

'I think it would be helpful for people to have specific support groups or individual support sessions where people have the time and opportunity to talk about end-of-life care and can assess information and support in relation to making the difficult decisions they face. I also think it would be important to have a follow-up support service for people when there is a death.'

Many respondents felt that palliative care should be available for people with dementia, while recognising that this may involve additional training for staff and that this would involve specific funding.

'I think there needs to be more training and support for both family carers and home care workers in this area. Palliative care still seems to be associated with cancer. Funding needs to be made available to offer additional supports at this time.'

'The service is poorly coordinated and difficult to instigate but when it is up and running it works well. It is imperative that GPs buy into the service, otherwise access is denied to the family.'

One respondent felt that palliative care was important for people with dementia because of the illness characteristics:

'as dementia progresses the client is unable to express verbally if they have pain and pain scales may not show correctly if they have. Because of this I feel palliative care is a necessity.'

It was also clear from this survey that many of the ASI service providers provide ongoing support for family members even when the person with dementia is no longer availing of ASI services. ASI services are an important point of contact and support for family members.

'Our clients and their families need support from us at this important time. I am often contacted by families for support when their loved one is dying. Their loved one may be in long-term care and may not have used our service for a number of months or even years. They are always very upset and feel unsupported at this time, as some people may assume that [the carers] are glad that the end is near. We need to offer more support at this time.'

While this was a short questionnaire survey to ASI service providers, it was clear that information and support for end-of-life care is an important issue for service providers. ASI service providers supported families whilst their relative was in receipt of ASI services, and in some cases this continued when their relative was no longer availing of services. Bereavement support was also an identified need.

Activity 5: Reflecting on the implications for policy and practice within ASI services

As part of the project's objective to identify appropriate palliative care interventions, team members reflected on current ASI practice in order to identify existing and potential appropriate interventions and activities. This involved identifying the range of activities across a range of service domains within specialist palliative care and identifying those that are appropriate for dementia palliative care. In this context, maintaining the relationship with the person with dementia and family members beyond direct service provision is considered appropriate, as this constitutes ongoing support for the family. In order to maintain this relationship, especially in terms of supporting the person with dementia and family members, appropriate activities for ASI service provision include facilitating the transition to long-term care; providing support for long-term care service providers; and establishing and facilitating relationships with specialist palliative care services.

An initial projection of appropriate activities for dementia palliative care can be considered as follows.

Appropriate activities for dementia palliative care within ASI services

Support

- Working closely with the family, advising and supporting at each stage, and preparing them for the time of transition so that it is planned in a timely manner and not done in haste.
- Supporting through service interventions across the continuum of dementia care, i.e. day/home care, respite, support meetings and one-to-one meetings with client and family carer, and phone support.
- Maintaining the relationship with the carer when the person with dementia has moved to a long-term care setting. The relationship with the family/carers is possibly one that has been built up over a number of years.
- Respecting the spiritual beliefs of client and family, i.e. birthday remembrance/Mass or sending a card – this currently forms part of the service manager's role.

Facilitating adjustment to long-term care setting

- Establish a good relationship with the new service provider, finding out how they will help with the transition.
- Information evenings for carers, organising training in dementia care and facilitating carers to continue attending support meetings/clubs.
- Maintaining a good relationship/partnership with all parties, communicating care needs between new provider, family and ASI to optimise care.
- Education and support regarding new role in long-term care setting and managing the long-term care relationship.

Summary

In order to develop a model for dementia palliative care interventions for ASI services, two key areas were identified: end-of-life care needs and the transition from ASI services to long-term care. A number of activities were undertaken to gather information for potential interventions, as well as a review of current ASI information products. Conversations were conducted with people with dementia and family members. An Alzheimer UK form, 'This is me', was utilised and adapted to prompt conversations about illness progression and end-of-life care needs and decisions. It was found difficult to talk about this, as it was frequently difficult to talk about having dementia in the first place. Many people did not have a disclosed diagnosis of dementia and as a result there is little financial, legal and future care planning.

The second activity of this research was to understand how best to provide a continuity of care from ASI services to the long-term care service provider. A number of interviews and a focus group were conducted with service providers in long-term settings. Key issues were identified – services and resources, preparation and education, managing relationships and forming partnerships, end-of-life care and decisions, and bereavement support.

A review of current ASI information products was conducted. The current and future information provision was grouped into three areas – pre-transition; transition; and end-stage dementia. Findings from the Opening Conversations project also identified a need to address specifically the early stage, diagnosis, illness progression and end-of-life care and decisions; these aspects will need to be incorporated into future information products. An electronic survey was conducted with ASI staff to establish awareness of end-of-life/palliative care information needs and support for service users. The questionnaire was administered to staff working and coordinating a range of ASI services, such as home care, support groups, day care, drop-in centre and the helpline. Twenty-two completed questionnaires were returned, giving a response rate of 38%. The respondents had a variety of roles (and also multiple roles) within ASI services.

Eighty-six per cent of respondents reported that end-of-life/palliative care has come up for discussion and as an area for support in home care, day care, carer support groups and with individual people with dementia, their carers and family members. All (100%) respondents expressed interest in receiving information on dementia palliative care and 96% would like training for themselves and their staff on end-of-life/palliative care. Ninety-one per cent of respondents expressed an interest in developing relationships with service providers in long-term care and specialist palliative care services, and 77% expressed interest in future developments of dementia palliative care within ASI services.

A fifth activity involved identifying the range of activities across a range of service domains within specialist palliative care and identifying those that are appropriate for dementia palliative care and ASI services. In this context, maintaining the relationship with the person with dementia and family members beyond direct service provision is considered appropriate, as this constitutes ongoing support for the family. In order to maintain this relationship, especially in terms of supporting the person with dementia and family members, appropriate activities for ASI service provision include facilitating the transition to long-term care; providing support for long-term care service providers; and establishing and facilitating relationships with specialist palliative care services.

Section 4: Developing dementia palliative care

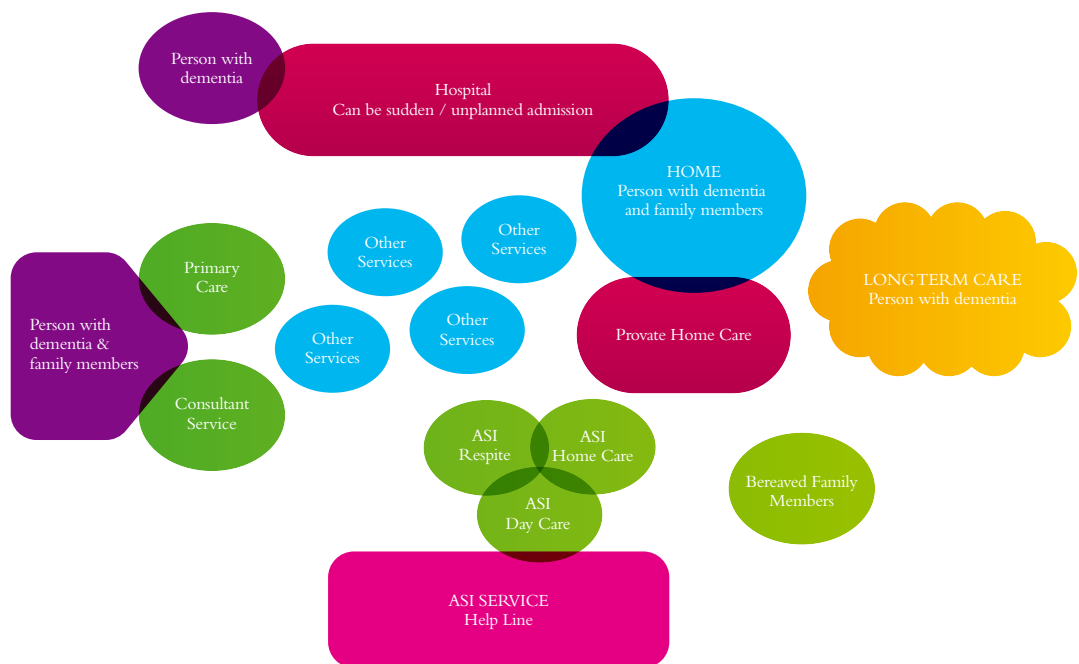
37

Understanding the journey and mapping the landscape

The Opening Conversations project set out to develop a model of best-practice palliative care interventions for people with dementia and their carers and family members with the intention of integrating palliative care interventions into ASI service planning. While this was a small-scale qualitative project, the ongoing reflective work that formed part of the research served to deepen understanding of palliative care within the context of dementia. In addition, a number of 'conversations' or activities were undertaken that served to make some of the key characteristics of the illness journey for people with dementia and their family members and carers through the 'dementia landscape' more visible.

The ongoing process of reflective practice in which team members engaged became a form of cartography or mapping that Gallo (2003) suggests offers the opportunity to access unsuspected regions as well as providing access to any other point of its territory. As a result of these conversations or reflections it became clear that the 'landscape' of dementia is one of limited visibility for the person with dementia and their family members and carers. A major feature is a frequently uneven and unmarked terrain, which makes it even more difficult to negotiate and to connect with the often fragmented and isolated services.

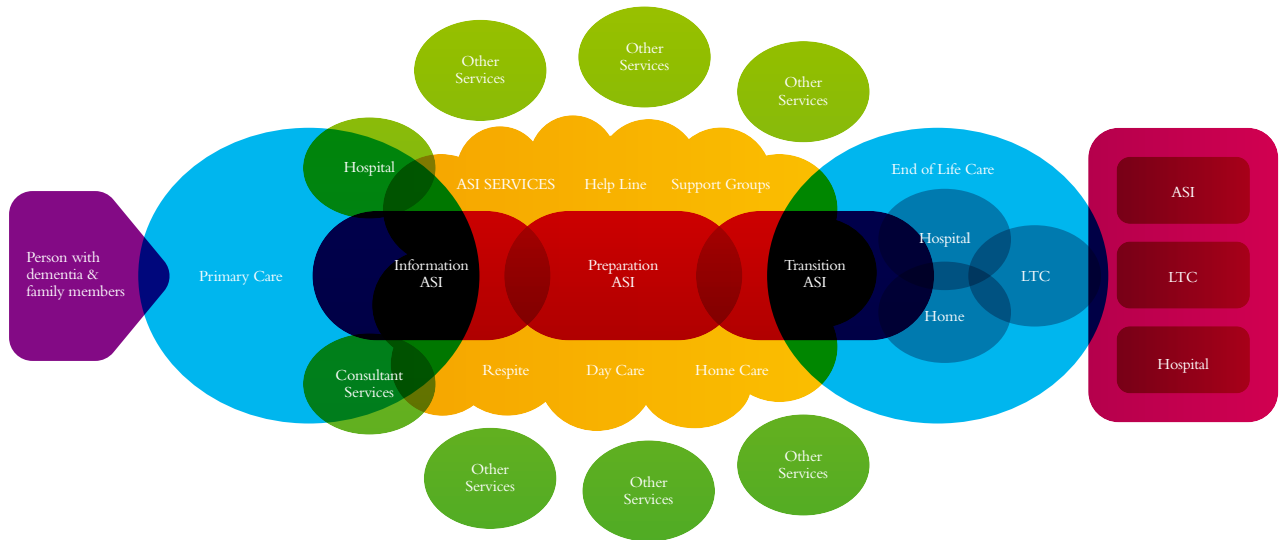
Current dementia landscape



These features can increase the sense of isolation experienced by people with dementia and their family members and carers.

Identifying the current landscape of dementia has highlighted the need for an integrated pathway through a variety of services and settings for people with dementia and their family members and carers, and a need for involvement from an early stage of the illness, in order to facilitate a smoother, and supported, transition through the stages of the illness. This is presented as an idealised landscape of dementia care.

Dementia Palliative Care
A clear pathway for good quality end of life care



Whilst recognising that a smooth, integrated pathway for people with dementia and their family members may be challenging to achieve, the Opening Conversations project has identified a number of interventions to commence the building of solid foundations for this pathway.

Dementia Palliative Care

This research proposes a model of dementia palliative care based on the understanding that the provision of good-quality end-of-life care for people with dementia and their families begins at the time of diagnosis and is not confined to the end stage of the illness or to the period in which the person with dementia is actively dying.

The project identified a number of interventions, within public advocacy and information and practice development domains, to form an integrated pathway for the provision of a palliative care approach from diagnosis to end-of-life care across the spectrum of services in the sector. We have termed this ‘dementia palliative care’, as it focuses on the specific needs of this patient population as well as recognising the particular challenges of resources and services.

The aim of palliative care is to facilitate a ‘good death’; this can be considered as a death in which there is a level of acceptance and peace on the part of the dying person and also of their families. In order for a death to be peaceful, attention needs to be paid to the multidimensional needs – physical, emotional, social and spiritual – of the dying person and their families, as appropriate. Meeting these needs calls for considerable preparation by way of integrated interventions prior to the actively dying phase. This is true for the provision of palliative care for all patient groups, but the illness characteristics of dementia, in particular cognitive impairment, make it even more imperative to engage with the process and practice of palliative care at an early stage in the illness.

An underlying principle of palliative care is open awareness and communication about death and dying. Being able to talk openly about, or having an awareness of, illness progression is a key part of the preparation for death and dying.

The results of the Opening Conversations project have revealed a number of obstacles to the provision of palliative care within dementia care. A key obstacle is the low level of awareness regarding the diagnosis and illness progression; as a result, it can be difficult to make adequate and timely preparation. Therefore information about and preparation for end-of-life decisions and care need to commence at an early stage and continue throughout the illness trajectory. This process can involve a variety of service providers and services in which there may be differing levels of awareness, resources and commitment to the provision of dementia palliative care.

There is a broad range of stakeholders involved with the provision of dementia support and services. The Alzheimer Society of Ireland (ASI) currently occupies a key position and has a high level of commitment to the provision of palliative care for people with dementia. The journey of dementia is not a neat linear progression from one stage and service to another. Frequently, people with dementia and their families visit various locations along the way – for example, primary care, day care, respite, hospitals and long-term care settings. These visits are of varying durations; some are planned but more frequently they are unplanned and crisis-driven, such as sudden admissions to hospitals or long-term care settings.

While recognising the often circular and overlapping nature of the dementia journey, for the purposes of clarity in terms of interventions this research has identified a number of key stages on the journey: pre-diagnosis, primary care, hospital and consultant services, ASI services, home and long-term care settings, end-of-life care and post-death care of the family. Some of the main obstacles for people with dementia and their families and carers have been identified. A number of interventions for the provision of a smoother path and greater visibility have been identified, within and beyond ASI services.

These interventions are relevant in three areas – policy advocacy, public advocacy and information and practice development – and involve the ASI and partnerships with key stakeholders in a number of sectors. These interventions are presented as key recommendations arising from this research and are presented in greater detail in the following pages.

Recommendations

The Opening Conversations research presents a total of fourteen recommendations in order to develop further a model of dementia palliative care. These are operational across a range of domains – policy advocacy, public advocacy and information and practice development – and address key issues such as raising awareness; removing barriers to a clear diagnosis; providing a continuity of care; active management of the transition of care; addressing end-of-life care needs; and supporting family members and carers. While these domains and recommendations are distinct and address specific issues, they are interwoven and all have the potential to strengthen and support the development of dementia palliative care.

1 Developing information, education and awareness strategies on dementia involving a range of key stakeholders and sites

An integrated information and education strategy needs to be developed, on both the macro and the micro level, about the illness and the implications for care.

An awareness of illness progression, specifically in relation to preparation, planning and end-of-life care needs and decisions, should form part of the information to be imparted. An information dissemination strategy needs to take account of multiple media formats appropriate for differing sectors of the population, and should identify routes for the distribution of information, such as GP surgeries and the ASI Helpline.

There is a need to provide specific dementia awareness training for appropriate health care professionals who have contact with people with dementia. This will include frontline workers such as ambulance workers, the police and members of the legal professions and could take the form of developing a professional training educational module. In particular, the health care professionals in the acute hospital settings (especially A and E) should be targeted to lead ultimately to the creation of dementia-friendly hospitals.

Recommendations:

- 1 The Alzheimer Society of Ireland to identify specific target audiences and develop a range of multiple media information products and appropriate routes for dissemination, for example GP surgeries and the ASI helpline.
- 2 The Alzheimer Society of Ireland in collaboration with key stakeholder bodies including the HSE, An Garda Síochána and professional representatives from legal and financial bodies to develop specific dementia awareness training for appropriate frontline staff.
- 3 The Alzheimer Society of Ireland to explore, with key stakeholders, the potential for a dementia-friendly hospitals programme, along similar lines to the IHF Hospice Friendly Hospitals Programme.

2 Removing barriers to clear diagnosis and supporting the dementia journey in primary care

The role of primary care health care professionals is an important one for people with dementia and their family members. In particular, the GP plays a critical role on the whole journey of dementia as a constant and pivotal point of contact for diagnosis but also for palliative care needs. Many people with dementia do not receive a clear disclosed diagnosis of dementia, and this can lead to many difficulties and challenges when planning for the future. There is a need to develop protocols for diagnosis with the Irish College of General Practitioners.

Recommendation:

- 4 The Irish College of General Practitioners to build capacity for dementia care, with the development of protocols for diagnosis and the management of dementia within primary care settings and structures.

3 Develop an integrated dementia care pathway to provide joined up and continuity of services for people with dementia and their family members and carers

Current services are disjointed and there is an urgent need to join up existing services and resources in order to provide an integrated service for people with dementia and their family members and carers. The development of multidisciplinary teams within the community and the provision of a case management model with dementia specialist nurses in hospitals and primary care would further support a continuity of care. People with a diagnosis of dementia could be supported by the provision of a personal advocate. This would consolidate and further support other initiatives relating to a continuity of care.

Recommendations:

- 5 Priority needs to be given to the development of an integrated care pathway for people with dementia through the appropriate Health Service Executive structures.

The integrated care pathway for people with dementia needs to include a case management model, the provision of dementia specialist nurses in hospitals and primary care and community-based multidisciplinary teams to support a continuity of care for people with dementia and their families.

- 6 The Alzheimer Society of Ireland to develop a pilot dementia advisory service such as the model currently in place in the UK.
- 7 The Alzheimer Society of Ireland to work with Citizens Information Board to further refine and develop the existing advocacy services for people with disabilities, including dementia in line with developing integrated care pathways and community based services.

4 Develop procedures and practices to ensure a continuity of care to long term care settings.

The transition to long-term care or hospital can be a difficult time for people with dementia, their family members and carers. There may also be difficulties for service providers – existing as well as new. Active management of this transition could ease these difficulties, as would an established continuity of care programme within the community. Pre-planning of admissions and familiarisation strategies, such as respite care, can ease transition difficulties. Family members also need to be helped at this juncture, and active management would ensure transfer of information, clarify the roles and responsibilities within care settings and assist in providing a meaningful role for family members.

Recommendations:

In relation to the transition to long term care it is recommended that ASI and Nursing Homes Ireland collaborate to:

- 8 develop procedures and practices to facilitate the exchange of information with, and between, the person with dementia, family members and service providers.
- 9 develop procedures and practices to promote clarification of the roles and responsibilities of service providers and family members in the continuing care of the person with dementia.
- 10 Develop procedures and practices that provide for a meaningful role for family members in the care of their relative, as appropriate.

5 Address end-of-life care needs for people with dementia.

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Awareness of the end-of-life needs of people with dementia and promotion of a palliative care approach in dementia to facilitate the provision of good end-of-life care, including specialist palliative care, as appropriate, needs to be established. This approach should extend beyond dementia-specific settings and be incorporated into all care environments.

Active development of partnerships between dementia and specialist palliative care health care professionals across a range of care settings would support an increased awareness of, and attention to, the end-of-life care needs of people with dementia. Good-quality end-of-life care requires additional resources in terms of time and training as well as support for staff. A broad range of issues – clinical expertise, artificial nutrition, hydration, burden/benefit considerations, advance directives, timely and considered decision-making – need to be addressed.

Recommendations:

- 11 ASI and Nursing Homes Ireland to work together to raise awareness of end-of-life care needs for people with dementia in long-term care settings through education and training in line with HIQA dementia-specific standards for end-of-life care.
- 12 ASI and IHF to facilitate the development of networks between specialist palliative care services and service providers in a range of health care settings, including primary care services.
- 13 ASI and IHF to facilitate the development of education and training to address pertinent end-of-life issues such as artificial nutrition, hydration, burden/benefit considerations, advance directives and ethical decision-making across a variety of care settings.

6 Support family members and carers

Care of family members, during a life-limiting illness and after death, forms a key part of the model of palliative care. Family members and carers of people with dementia generally care for their relative for a long time with limited support and can become socially isolated. Family members and carers need to be included as part of the remit of care within dementia palliative care. The implementation of previous recommendations, especially the strategies to provide a continuity of care over the duration of the illness, would support family members and carers in their role. Care of the family should incorporate bereavement support.

Recommendation:

- 14 Service providers to ensure the inclusion of family members and carers within the remit of dementia palliative care, as active partners in caring for people with dementia. Support for family members should include bereavement support that recognizes the uniqueness, and often lengthy, duration of the dementia journey.

The 'Opening Conversations' project was a small-scale qualitative study that aimed to develop a model for palliative care interventions for The Alzheimer Society of Ireland. In the process of the research numerous 'conversations' were conducted which have made more visible the illness journey for people with dementia and their family members and carers as well as service providers. In addition, the landscape through which people with dementia must travel has been revealed as frequently uneven and difficult to negotiate.

The 'Opening Conversations' project has highlighted ways in which this landscape could be more easily traversed and has made a number of recommendations that would provide greater integration and support.

The project engaged in numerous conversations in pursuit of its research aims. An integral part of this was dissemination of the research. Since the research was completed, five oral presentations on aspects of the project were undertaken including at the Dun Loaghaire Rathdown County Council Social Inclusion Week 2010, the Irish Association for Palliative Care conference in February 2011, the School of Social Gerontology NUIG in June 2011, the Dementia Palliative Care conference in Limerick in September 2011 and the Alzheimer Europe conference in Warsaw in October 2011.

Further development of a model of dementia palliative care, with an initial development of a network of specialists in dementia and palliative care, and the development of information and education products specifically in line with the Opening Conversations recommendations are scheduled.

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Ethical guidelines for The Alzheimer Society of Ireland research programme, March 2010

Introduction

The Alzheimer Society of Ireland is engaged in a range of social and health research activities, including:

- Commissioning external researchers to complete research on our behalf on topics prioritised by the organisation.
- Partnering with other like-minded organisations as either the lead or secondary partner in research projects.
- Completing internal research/evaluations in the organisation, conducted either by staff or employing an external third party.
- Supporting external researchers in a variety of ways, including brokering access to key informants.
- Engaging in health research looking at medical and scientific elements of AD/dementia.
- Funding doctoral and fellowship students registered in recognised academic institutions in the state.
- Engaging in research networks that generate ideas and contribute to the wider aging research agenda.

The Alzheimer Society wishes to adhere to the highest standards of ethics in its approach to research. It will maintain the highest professional, legal and ethical standards and competencies. The organisation will adhere to the most up-to-date best practices regarding the engagement of people who are cognitively impaired. It will continuously strive to ensure that their participation in research is actively promoted and supported using creative evidence-based techniques that adhere to the ethical principles outlined below. In relation to research that is contracted out externally, funded or supported by the Alzheimer Society, ethical approval must be granted by the relevant institution's ethics committee before the research progresses.

Ethical principles

Regardless of the nature, type or level of research, the Alzheimer Society will adhere to the following ethical principles:

- The research results should benefit the population in which it is carried out (beneficence).
- The research must not cause any harm to the participants or population in general (non-maleficence).
- The research must respect and protect the rights and dignity of the participants (autonomy).
- The benefits and risks of research should be fairly distributed (justice).
- The research participants clearly understand that participation is entirely voluntary and that their decision to consent or not in no way alters their overall relationship with the organisation.

Consent

All research participants must give consent to their engagement in the research prior to the commencement of the research. There are a number of ways in which consent will be sought, depending on capacity.

Informed consent

A person consents if he/she agrees by choice, and has the freedom and capacity to make that choice. (Giving informed consent assumes that the person can make their own decisions.)

Process consent

Where there is diminished capacity as a result of cognitive impairment, process consent will be used. Process consent uses a profile of the usual ways in which the person communicates 'yes' and 'no', and builds into the profile information from those who know the person well. Written information is provided to the family to involve them in the process. Simplified written information and photos/other visual cues are also used to support the person to appreciate the information.

In this method consent is revisited on each occasion or even within the same occasion to ensure that it is still valid (McCormack and Dewing 2009).

Proxy consent

When an individual has been judged not to have capacity and a guardian has been appointed, the guardian must give consent, i.e. when there is an enduring power of attorney in place. There should also, however, be an opportunity for the person to express assent. Where assent is documented as not given, the guardian must be informed and given the opportunity to re-examine the decision to consent.

Responsibilities of the researcher in gaining consent

The researcher must ensure that consent in whatever form is obtained from each individual participant prior to their involvement in the research. The researcher must maximise the person's capacity to consent, using a range of techniques including simple language, use of illustrations, non-verbal demonstrations and repeating information several times if necessary.

The researcher is responsible for:

- Describing the study.
- Ensuring that the consent is genuinely voluntary.
- Explaining confidentiality and anonymity and the right to refuse to participate at any stage, and that it will not impact on their relationship with the organisation.
- Explaining that consent is an ongoing process.
- Explaining how the information will be collected and the findings disseminated.
- Ensuring that the process of consent is implemented and reviewed at all stages, where necessary.
- Having a contact person identified and named to provide help and support at any stage of the research process.

Organisational structures to support the ethics agenda

The Research and Policy Officer will take day-to-day responsibility for communicating with all stakeholders regarding the ethical guidelines and ensuring that they are implemented throughout all of the research programme.

In order to support the understanding, build capacity and develop the knowledge/expertise base in the organisation of research ethical issues, an internal Ethics Committee is to be established.

External expertise will be sought using a virtual ethics group. Dr Brendan McCormack (University of Ulster) and Dr Jan Dewing (Visiting Fellow, University of Ulster) have agreed to join this virtual group. Other members will be identified and invited accordingly.

Review and ongoing development of the ethical principles

This document will be under continuous review. It forms part of the wider organisational debate that needs to take place on a range of ethical issues that impact on how it works.

Material used in completing the document

The following documents were utilised:

- National Federation of Voluntary Bodies Consent in Research, Research Factsheet No. 3.
- National Federation of Voluntary Bodies Basic Ethical Principles in Conducting Research, Research Factsheet No. 2.
- McCormack, B. and Dewing, J. (2009) Developing person-centred practice in residential care, with a particular focus on people with dementia. (Dementia PD project ethics protocol v5.)

Opening Conversations – Developing a model for The Alzheimer Society of Ireland of best-practice palliative care interventions for people with dementia and their carers

Method and documentation of consent process for individuals with impaired/absent capacity to consent to take part in the research project

Client's name _____

Interviewer's name _____

Assessing capacity to consent:

Guidance:

- Begin by assuming that the individual has capacity to consent to take part, and look for evidence that may prove this in their day-to-day life and care.
- Make every effort to communicate with the person to explain what is happening.
- Make every effort to try to help the person to make the decision or to communicate choice using communication aids.
- See whether there is a way to explain or present information about the decision in a way that makes it easier to understand. If the person has a choice, ask whether they have information about the options.
- Find out whether the person understands what decision/choice they need to make and why they need to make it.
- See whether the person understands information about the decision and whether they can retain it, use it and weigh it to make the decision or choice.
- Where capacity fluctuates, see whether the decision can be delayed to take time to help the person make the decision, or to give them time to regain the capacity to make the decision for themselves.

Initial consent

- Outline the approach to seeking consent from the client.
(Make notes on the location, time, information given, props or equipment used, questions and answers.)
- In what ways did the client indicate their consent?
(Identify verbal, non-verbal and behavioural signs. Does it match up with their usual way of indicating consent?)
- Who else was consulted (usually a family member involved in the person's care and interested in their welfare)?

Name _____

Relationship to resident _____

Family member may advise on whether the person who lacks capacity should take part in the project, and what they think the person's feelings and wishes would be, if they had the capacity to decide whether to take part:

Ongoing consent monitoring

Date and time notes made:

- If you involve the client in more than one episode of conversation you may need to treat each episode as a new interaction and make additional notes.
- Was ongoing consent provided in a way that was consistent to the initial consent? (If not, then consent must be revisited in full. Any decision to continue must be justified.)
- At the end of the conversation/interview the person's level of well-being was: (Provide a description of behaviour, verbal and non-verbal signs and relative well-being level.)
- Has anyone independently tracked this person's well-being during any of the consent process? (If so, make a note of their observations in relation to the person's level of well-being/ill-being.)

Feedback given to carers:

- (Specify whether this was verbal or written.)
- State why you gave this feedback: (Your key responsibility is to ensure that anything the person would wish to be kept confidential remains so.)
- Describe any interactions or interventions you made with the client in order to achieve a transition/return back into another social relationship or their environment of care.

Signature of the researcher _____

Date _____

Appendix 3

Information sheet for participants:

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Opening Conversations – developing a model for The Alzheimer Society of Ireland of best-practice palliative care interventions for people with dementia and their carers

You have been invited to participate in a small-scale research project. This research is being conducted internally in The Alzheimer Society of Ireland. The research wishes to work with carers and people with dementia. You have been chosen as you are accessing the ASI day care service. It will not require any additional time or effort on your part. It will in no way affect or impact on the services you are accessing from The Alzheimer Society of Ireland.

Who is involved?

We are planning to involve people with dementia, the family carers and staff in three ASI sites – Sligo, Wicklow and Dublin.

The aims of the research project are:

To develop a model of best-practice interventions for end-of-life/palliative care provision for people with dementia and their carers who access the society's services.

To integrate appropriate palliative care interventions in the Alzheimer Society service planning.

Participation:

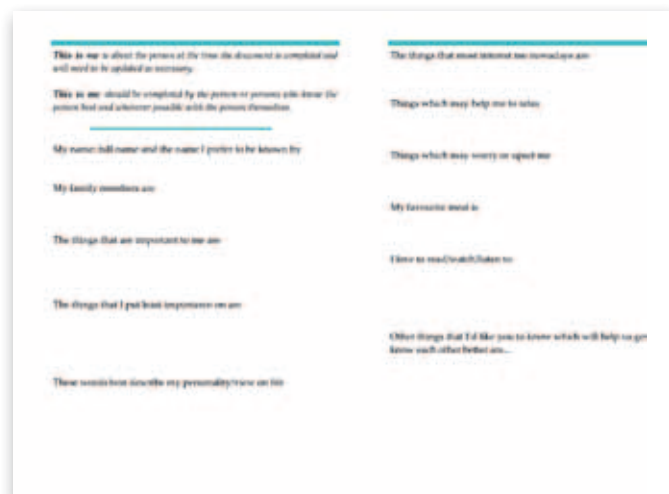
Your participation is entirely voluntary and you have a right to withdraw at any time.

Contact details:

Each service manager to fill in their own details here:

Appendix 4

Adapted 'This is me' form



Appendix 5

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Contents of ASI carer's information pack

The ASI carer's information pack is available in leaflet form and also available in pdf format from the website.

The information pack contains separate leaflets on the following:

Diagnosis – what is Alzheimer's disease/dementia:

- Alzheimer's disease – early symptoms and diagnosis
- Who's who in dementia care
- Understanding and respecting the person with dementia

Practical tips for daily living:

- Coping with memory loss
- Communication
- Maintaining skills
- Unusual behaviour
- Aggressive behaviour
- Wandering
- Activities
- Sleeping
- Eating
- Dressing
- Bathing & washing
- Sexual difficulties
- Continence management
- Pressure sores
- Hallucinations and delusions

Planning for the future

- Legal and financial arrangements
- Driving and dementia
- Safety in the home
- When a person with dementia lives alone

Looking after you

- Carers – looking after yourself
- Staying healthy
- Feelings of guilt
- Explaining to children
- Grief and bereavement



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National Office, Temple Road,
Blackrock, Co. Dublin.

T: 01 207 3800 F: 01 210 3772
Helpline: 1800 341 341

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Charity registered number:
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