Developing approaches to end of life issues in dementia care

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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.

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Multiple conversations

Opening Conversations

- About ethical guidelines and process consent
- About the experiences and views of Alzheimer Society service providers
- About Alzheimer Society information resources
- About relationships with Specialist palliative care services
- About palliative care for people with dementia
- About communication and awareness about death and dying
- About the transition to long term care
About palliative care for people with dementia

Identifying similarities and differences between specialist palliative care and person focused dementia care.

World Health Organisation definition of palliative care

‘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’.
The focus on the holistic care of people is equally applicable to people with dementia.

Palliative care and person-focused dementia care share philosophy and principles.

‘Both palliative care and person-focused dementia care share a philosophy of whole person care as well as shared basic principle that focus on quality of life, whole person care, a respect for autonomy and care of the person and the family’. (Addington-Hall. 1998)
Differences in practice

Differences across services, resources and illness characteristics

Specialist Palliative Care
Services:  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  
Resources:  Specialist services across acute hospital, hospices, home care, day care and respite care.  
Supports multi-disciplinary team working to address multi-dimensional needs.  
Illness characteristics:  Main focus of specialist palliative care provision is for people with cancer-duration of care, is generally short to medium term.
Differences in practice

Dementia care services

Services: Care frequently fragmented across spectrum of health care services.

Resources: Poorly resourced. Uncertain access to allied health care professionals.

Illness characteristics: 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.
About communication and awareness

- Communication and open awareness of death and dying are key underlying principles of palliative care.
- Opening up a conversation about end of life care with people with dementia and family members.
- Adapted ‘this is me’ Alzheimer UK leaflet to prompt discussion with person with dementia and family members.
- Conversations with four people with dementia and five family members.
About communication and awareness

Key issues were identified.

For person with dementia

Uncertainty about diagnosis.

Very low level of awareness of change and illness progression.

Little or no preparation regarding legal and financial affairs.

Very difficult to have conversation about end-of-life care needs when it is already difficult to talk about having dementia.

Timing of information can be very important.

Person with dementia can be very isolated.
About communication and awareness

For family members/carers

Timing of information can be very important.

Family members can have limited understanding of illness progression and the planning that is required.

Family members can have difficulties with discussing the illness with person with dementia.

Family members/carers can be very isolated.

Caring for a person with dementia can put family members and their relationships with spouses/children under considerable strain.

Uncertain of role in long term care settings

No preparation for post caring role
About the transition to long term care

Four individual conversations and two group discussions with service providers in long term care settings about the transition to long term care.

Key issues identified

- Services and resources
- Preparation and education
- Managing relationships and forming partnerships
- End-of-life care and decisions
- Bereavement support
- Identified needs for the future
The transfer of trust

**Services and resources**

Differences between care settings/ uneven resources/ facilities/training. This has 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 LTC

Levels of multi-disciplinary input uneven
The transfer of trust

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

Poor information available from GP’s, 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.
The transfer of trust

Managing relationships and forming partnerships

Establishing trust can be difficult—especially in the first month.
- Families can find it difficult to let go of the care of their relative.

Staff need to be support during this initial period.
- Families can be very demanding.
- Need reassurance about care setting, level of expertise and specialist knowledge especially regarding pain relief.

Lack of shared understanding between service providers and family members.
- Managing these relationships can be difficult.
  - *walking a tightrope*: keeping family members on board but balancing with professional judgement.

There is a need to develop active partnerships.
The transfer of trust

End-of-life care and decisions
- Families generally prefer for their relative to remain in care setting rather be admitted to hospital.

Need for knowledge and expertise on end-of-life care in long term care setting

The duration of the end stage and dying can be uncertain and this can be difficult for families.

Need to anticipate needs and changes; best practice is not to bombard families with information.

Advance care planning issues need to be addressed
The transfer of trust

**End-of-life care and decisions**

Specialist level of expertise is needed.
- GP’s don’t have the same level of expertise as specialist palliative care professionals regarding medication.
- Access to telephone advice and support from a Palliative care Clinical Nurse Specialist would be beneficial.

Support for staff needed
- Different cultural practices around death and dying amongst staff which can be difficult to manage.

Nursing staff need support in dealing with difficult situations with relatives.
The transfer of trust

Bereavement support needed for

*Staff*

Sense of loss experienced by staff when a resident dies. Inexperienced staff can find deaths, and the dying process, particularly difficult.

*Residents*

Residents can miss the person who died.

*Family members*

In addition to personal bereavement the ending of the relationship with the care home can create a major gap in their lives.
The transfer of trust

Identified needs for the future

Education: About end of life care
Appropriate cultural/religious practices around death and dying—has implications across the spectrum of practice not just at death.

Support from other services
Access to specialist palliative care expertise, perhaps CNS for advice and telephone support.
About the experiences and views of Alzheimer Society service providers on end of life issues

Finding out from ASI service providers whether end of life issues arise in interactions with clients and families

Questionnaire administered to ASI service providers.
22 questionnaires returned—response rate of 38%.

Respondents had a variety of roles (and also multiple roles) within ASI services
★ Service managers ★ Day care managers ★ Home care coordinators
★ Support group coordinators ★ Home care services manager
★ Help line coordinator ★ Home care supervisor ★ Drop in centre manager
86% of respondents reported that end-of-life/palliative care is an issue that has come up for discussion with service users across the spectrum of service provision.

‘Yes, it is often discussed at support group meeting. 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.’

‘Families feel their only option for end-of-life care for their loved one is in long term care. Home care agencies are not trained or equipped to deliver this care at present’.
Support about end of life issues

86% of respondents reported that end-of-life/palliative care is an issue that has come up for support or intervention with service users across the spectrum of service provision.

‘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’.
100% of respondents identified palliative care needs for people who use Alzheimer Society services.

- Information about recognizing end stage dementia
- Information about caring for a person who is dying
- Anticipating needs for people with dementia and family members
- Support and information about difficult end of life decisions
- Education and support for family carers and ASI home workers
- Training in palliative care needed for ASI staff
- Support from GP to access services
- Funding for additional supports that are needed at this time
- Support needed for families after the death
Developing an integrated model of dementia palliative care for ASI services

The ‘opening conversation’ project has made visible some key characteristics of the illness journey for people with dementia and their family members and carers.

Not a road that people wish or choose to travel.

The ‘landscape’ of dementia care is one of limited visibility for the person with dementia and their family members and carers.

A terrain that is often uneven and unmarked thus making it even more difficult to traverse and to connect with the frequently fragmented and isolated services.

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

The journey of dementia is not a neat linear progression from one stage and service to another, it is frequently a circular and overlapping journey.

People with dementia and their families visit various locations along the way—Primary care ★ Day care ★ Respite care ★ Hospitals ★ Long term care settings.

Visits are of varying durations, frequently these are unplanned and crisis driven—such as sudden admissions to hospitals or long term care settings.
Understanding dementia palliative care

The aim of palliative care is to facilitate a ‘good death’ — a death in which there is a level of acceptance and peace, for the dying person and also their families.

Attention needs to be paid to the multi-dimensional needs—physical, emotional, social and spiritual—of the dying person and their families.

Need for considerable preparation by way of integrated interventions prior to the active dying phase.

The illness characteristics of dementia, in particular cognitive impairment, gives a greater imperative to engage with the process and practice of palliative care at an early stage in the illness.
Creating a smoother path with greater visibility

Opening conversations has

🌟 Identified 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.

🌟 Identified some of the main obstacles for people with dementia and their families and carers.

🌟 Identified some key interventions for the provision of a smoother path and greater visibility have been identified—within and beyond ASI services.

🌟 Identified arenas for interventions—policy advocacy, public advocacy and information and practice development.

🌟 Interventions involve ASI and partnerships with key stakeholders in a number of sectors.
Interventions for Dementia Palliative Care

Alzheimer Society of Ireland and partners from other sectors

Policy advocacy
- Universal entitlement to community care
- Equity of access to Palliative Care

Practice development
- Provide dementia training for appropriate Health Care professions
- Remove barriers to clear diagnosis. Develop protocols for diagnosis/ICGP
- Facilitate continuity of care for people with dementia and their family members
- Shape and influence best practice dementia care in LTC settings
Interventions for Dementia Palliative Care

Alzheimer Society Interventions

Public advocacy and information
  Public awareness campaigning
  Review ASI information products

Practice development
  Personal advocacy service

  Facilitate appropriate end of life care, at home by providing information, making the necessary resources available and supporting staff