People with dementia in hospital: addressing their palliative and end-of-life care needs

Acute hospitals network meeting
12th November 2015

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Outline of Workshop

- IHF Programmes
- Dementia in Ireland
- Dementia in Hospitals
- Palliative Care and dementia
- Communication with the person with dementia
- Update on IHF resources relating to dementia palliative care
What are the challenges that arise in your workplace in providing palliative and end-of-life care for a person with dementia?
Irish Hospice Foundation Programmes

- Bereavement
- Education & Research
- Healthcare
- Public Engagement

- Final Journeys, What Matters to Me
  Supporting Families
  Communicating with a person with dementia
IHF Healthcare Programmes

- 43% die in Hospitals
- 70% die with diseases other than cancer
- 25% die in Residential care
- 25% die at home

- HFH programme
- Journey of Change programme
- Palliative care for all programme
- Primary palliative care programme

Dementia

Residential

Community
Context

Living and dying well with dementia in Ireland:

2001

2008

2011

2012

2013

2014
Dementia is an umbrella term used to describe a range of conditions which cause changes and damage to the brain.
Setting the Scene: Dementia in Ireland

47,744 people are currently living with dementia in Ireland.

30,359 women
17,385 men


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Striving for the best care at end of life for all
The number of people with the condition will double in the next 20 years and treble in the next 35 years.

The prevalence of dementia increases with age:

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Cases of Dementia</th>
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<tbody>
<tr>
<td>Under 60</td>
<td>2,866</td>
</tr>
<tr>
<td>60-64</td>
<td>1,200</td>
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<tr>
<td>65-69</td>
<td>2,776</td>
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<tr>
<td>70-74</td>
<td>4,604</td>
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<tr>
<td>75-79</td>
<td>7,475</td>
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<tr>
<td>80-84</td>
<td>10,958</td>
</tr>
<tr>
<td>85+</td>
<td>17,867</td>
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</table>

25% of people aged over 65 admitted to a general hospital have dementia.

PEOPLE WITH DEMENTIA ON AVERAGE SPEND 22.7 DAYS IN ACUTE HOSPITAL WHILE THOSE WITHOUT DEMENTIA SPEND 9.17 DAYS

Barbara’s Story...
So, how might people with dementia feel?

- Lost, confused, bewildered...
  - Where am I? • What is this place? • Why am I not at home? • What is happening to me?

- Anxious, fearful...
  - Why are these people asking me questions? • Why do I have to follow their rules? • Why are they taking me away? • What do they want from me?

- Sad, lonely, depressed...
  - When can I go back to live with my people again? • Where are my family? • Am I dying?

- Angry, frustrated...
  - Why can’t I have/do what I want? • Why can’t I remember? • Why can’t I find the words I need? • Why can’t they understand?

- Embarrassed, ashamed...
  - Why are they looking at me like that? • I can’t remember who that is... • I don’t know what they mean... • What’s wrong with me?

As well as happy, content, amused, excited and all the other ‘good’ emotions...
Experience of acute hospital environment

• For the person with dementia

• For family /carers

• For hospital staff caring for people with dementia

• What could be done differently?
People with dementia – what the research tells us...

- Dementia is not recognised as a progressive/life-limiting illness
- Progression varies significantly from person to person
- People with dementia less likely to be referred to Specialist Palliative care
- Less likely to be given pain relief
- Palliative care needs poorly recognised and prioritised in healthcare settings
- Can be more likely to undergo burdensome treatments
- Training, knowledge and education of staff working in care settings with people with dementia requires an integrated an interdisciplinary approach (Cahill et al, 2012 :ASI and IHF, 2012)
End-of-life care needs of people with dementia

Communication
Loss and bereavement
Pain & other Symptoms

Multidisciplinary team involvement
Care Transitions
Good end of life care for people with dementia

Requires additional emphasis

1. Communication skills with people with dementia and families
   due to cognition, capacity, lack of diagnosis

2. Assessment of end of life symptoms
   due to diminishing ability to communicate and co-morbidities

3. Wider MDT involvement
   due to complex symptoms & range of specialist involvement

4. Increase in acute events/transitions
   for continuity of care transitions

5. Bereavement interventions
   Anticipatory and ambiguous grief and longer trajectory
What does it involve?

“Palliative dementia care is that which actively treats distressing symptoms (physical and/or psychological/emotional) to optimise Quality of Life of the person with dementia and their family knowing that the underlying cause cannot be cured”

(ACH, Australia, 2009).

• Supporting the person with dementia and family to:
  • Address and relieve pain, distress and discomfort associated with advancing dementia
  • Inviting them to participate in making decisions about future care needs and where it is best delivered.

“The aspirational aim will always be to maintain personhood and to enable the person to live well. When, then, it comes to dying, the aim should be for death to occur with dignity, without suffering or distress; it having never been hastened or postponed in-keeping with the principles of palliative care”

(Hughes, 2013)
What is palliative care for people with dementia?

PHILOSOPHY OF CARE
- Recognition of anticipatory and ambiguous loss and grief – people with dementia and families
- Planning for the future
- Recognition of support that staff need to deliver quality end of life care
- Ascending level of specialisation – approach, generalist, specialist

SERVICE INTERVENTION
- Assessment and treatment of pain & symptoms (under-detected in people with dementia)
- Advice re hydration & nutrition
- Support decision making re potentially burdensome interventions
Components of Dementia Palliative Care (ASI & IHF, 2012)

Responsive Services

- Shared expertise
- Life cycle approach
- Integrated care pathways
- Person centred services
- Timely Information needs
- Building capacity

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Challenges of providing a Palliative Care Approach

PALLIATIVE CARE APPROACH
All stages
All settings
Person with dementia, their family, service providers
EOLC for people with dementia in hospital

- 8% of people with dementia died while in hospital
- 6% were receiving EOLC or were being managed according to an EOLC pathway
- 1 in 12 people with dementia admitted will die during that admission

Need for a coordinated PC approach
Advance care planning
Continuity of care
Dying with Dementia in Hospital

• Think about some of the pros/ benefits of dying in a hospital from a patient and family perspective?

• Think about some of the cons?

• How can staff help to provide support for families of dying patients on wards?

Competence
Compassion
Conversations
Summary

✓ Palliative care is part of dementia care and should begin at the time of diagnosis
✓ Requires collaboration across teams and settings
✓ Timing of intervention paced/guided by people with dementia

✓ KEY ISSUES
  ✓ Planning and preparation
  ✓ Need for continued support
  ✓ Recognition of protracted losses
  ✓ Catering for cultural and spiritual needs
  ✓ Continuity of care
  ✓ Staff training
SUPPORTING PEOPLE WITH DEMENTIA
Communication in practice

• In reality, communication in any circumstance can easily go wrong.
• One of the biggest challenges in any interpersonal communication is making wrong or unchecked assumptions...
• Common assumptions that have been made in the past about people with dementia include:
  • “That’s not my mother in there...”
  • They’re beyond reach, ‘just an empty shell’
  • Their dependence makes them children again
  • ‘Once they’re gone, they’re gone’
  • All people with dementia are pretty much the same
  • They don’t or can’t know what they want
  • Their dementia is the single source of all their problems and behaviours
Seeing the person
Key Considerations to Inform Good Practice

1. Recognise that communication is ALWAYS possible with a person with dementia
2. Develop knowledge about the progression of dementia and key triggers for end-of-life care discussions
3. Plan future care to optimise comfort
4. Promote personhood throughout the person’s journey
5. Record future wishes when they are expressed
Dementia and emotional memory
8 Tips for Effective Communication

- Adopt a person centred approach to communication
- Connect with the person
- Consider the communication environment
- Be aware of your own communication style and approach
- Use active listening
- Use simple language
- Focus on one question at a time
- Clarify information and check for understanding
Information leaflets for people with dementia

Understanding late stage dementia

How does dementia progress?

Dementia is a progressive condition and currently it cannot be cured. Each person's experience with dementia is unique, and that means it is not possible to know exactly how a person's dementia will progress, or how long they will live with dementia.

How dementia progresses is influenced by a number of things:

- The type or cause of dementia, e.g. Alzheimer's, vascular or unspecified.
- Age when dementia develops.
- General health and well-being.
- Other illness or health issues that may emerge.

Grieving following the death of someone with dementia

The grief process

Grief is both a universal experience and a unique experience. Grief does not happen in any set way, or have any defined stages. Grief is a natural process of reaction and adjustment to loss and change. When we lose someone or something that is important to us, we grieve.

The feelings and thoughts of grief come and go in waves. Sometimes you may feel you are coping quite well and then experience a burst of grief as you are reminded of your loss.

The truth is we don’t “get over” grief. It is not like having the flu, where you feel very ill and then begin to feel a bit better until you finally return to being your old self again.

Grief is a process that changes us and challenges us. Most people find that over time and with the help of supportive family and friends they find their way through grief, and while they may have low days or difficult days, their grief resolves and they can pick up the parts of their life that have been put on hold.

- Grief is a process and it takes time.
- Everyone’s grief is different and unique.
- There is no right or wrong way to grieve.
- Stages an emotion, and those are part of grief.

The changes that dementia brings

Dementia is progressive and means that over time, the person with dementia will experience changes in how they communicate, remember, think and manage day-to-day tasks. It is not possible to say exactly how long a person will live with dementia or how their dementia will progress.

Many people changes happen gradually and there is time to adjust. These changes also impact families and you will need time to adjust both practically and emotionally. Some of the changes caused by dementia involve loss of independence and dementia, are a part of grief, but there are no right feelings and emotions come and go.

Physical

You may feel more tired than usual, yet find it hard to sleep. It is not unusual to have very vivid dreams. Your appetite may change and energy levels may be low. Your concentration may be low so that you are absent-minded or have difficulty absolving new information. These are grief and stress reactions which are often experienced.

Loss and grief when a family member has dementia

Looking after yourself

Grief - the process of adjusting

Adjusting to the changes that dementia brings is a process. It can affect us in many different ways - emotionally, mentally, physically, and spiritually. Sometimes we can feel that we are managing well and at other times we can be surprised by strong feelings. These can include anger, guilt, frustration and resentful. This process of adjustment is similar to that of grieving - except that the person is still with you.

Such feelings are a normal part of the process of grieving. It is important to realize that you may be under a great deal of stress and to seek emotional support for yourself.

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I have dementia...

How do I plan for the future?
Education

Seminars

National Conference

Training days
Education and Training
2: Advance care Planning

3: Loss and grief

Draft 1.2016

Consultation extended to 23 Nov 2015
Series of Fact Sheets accompanying guidance documents

**FACT SHEET 1**
Facilitating discussions on end-of-life care with dementia

**Why this is important?**
- Dementia is a progressive, life-limiting condition.
- People with dementia should have opportunities for future care at an early stage and have their needs met.
- Planning future care can optimize comfort care and have a long-term impact on the person's well-being.

**When should these discussions take place?**
Discussions on future end-of-life care should start as early as possible. There are some key prompts for staff to facilitate discussions about future end-of-life care for a person with dementia. Below is a list of some of the key points:

- Time of diagnosis
- When the person is doing their enduring power of attorney
- Change of care setting: transfer to an acute hospital/residential care setting etc
- Care plan review or referral for homecare package

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**FACT SHEET 8**
Ethical decision making in end-of-life care for the person with dementia

**Principles for optimal hydration and nutrition**

**Four overarching principles are recommended for optimal hydration and nutrition for people with dementia.**

**Core ethical principles to underpin decision making**

- Respecting autonomy
- Assessing capacity to consent to treatment
- Truth-telling
- Converting administration of medication
- Ensuring the overall well-being of individuals as well as their family/careers
- Making decisions about pain management
- Withholding and withdrawing treatment

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**Dementia is a life-limiting condition, communicating and collaborating on matters relating to future end-of-life care requires a considered approach. This FACT SHEET is a visual aid to accompany the IFH guidance document 'Facilitating discussions on future end-of-life care with a person with dementia.'**

This is available for download on [www.hospitalfoundation.ie](http://www.hospitalfoundation.ie)

June 2015
Going Forward……

• What one thing are you already doing well?

• What one thing can you do differently within your workplace in order to meet the palliative care needs of people with dementia?
“Professional carers will never fully understand the light and shade, the hope and despair and the frustration and joy of each family members relationship with a person who has dementia. The best they can do is develop in partnership with families a mutually agreed plan that includes the very best physical care, thoughtful and sensitive social support and emotional and spiritual space for each unique passing”

(Hudson, 2003)
Contact Information

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References

- ACH (2009). Planning for Dementia Palliative Care. ACH Group Australia: Melbourne
References

Resources

The Irish National Audit of Dementia in Hospitals

Alzheimer’s UK funded a 3 year study on dementia in acute hospitals in the UK and from that have developed 2 excellent free online modules for staff training and development sessions. The links are:

- Dying in Hospital http://sonet.nottingham.ac.uk/rlos/placs/dih/story.html
- Every Death is Different http://sonet.nottingham.ac.uk/rlos/placs/edd/story.html