FACILITATING DISCUSSIONS ON FUTURE AND END-OF-LIFE CARE WITH PEOPLE WHO HAVE DEMENTIA

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Palliative Care Needs of People With Dementia: Building Capacity
Mullingar, November, 2015
What would you like from today's session?
Today...

• Background & Context

• Group Work

• Discussion

• Going Forward
### Dementia Population:

<table>
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<tr>
<th>Age group</th>
<th>2011</th>
<th>2016</th>
<th>2021</th>
<th>2026</th>
<th>2031</th>
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Policy:

- 2001: [Image of document 1]
- 2008: [Image of document 2]
- 2011: [Image of document 3]
- 2012: [Image of document 4]
- 2013: [Image of document 5]
- 2014: [Image of document 6]
Context:

• People with dementia have unique care needs
  • Long illness trajectory
  • May be complicated with responsive behaviours and communication difficulties

(Bayer, 2006 & Tilly et al, 2008)

• Staff should be knowledgeable, confident and competent

(Bayer, 2006 & VanDerSteen et al, 2013)
I’m not ready to die yet...

Am I dying?

Please don’t send me away to die

I’m not afraid to die. But I don’t want to be in pain
In Groups:

- Discuss the case study presented
- Identify possible responses
Case Study 1:

- Tom, who has dementia has been in your care for the past six months and has become increasingly frail. He is currently unable to walk and has a very poor appetite which has caused him to lose a noticeable amount of weight in recent months. His wife has become anxious about her husband's deteriorating health. His wife, who is distressed approaches you asking "could my husband die from not eating enough?". As a healthcare worker you know that Tom's wife is heavily involved in his care but you aren't sure what she knows about her husband's diagnosis and care plan.
Case Study 2:

- Two years ago, Kathleen was diagnosed with dementia. Over the last year, she has needed a lot more help with most personal and domestic activities. One day Kathleen became quite tearful when speaking to you and said “I am so frightened of having to move from here and the thoughts of being cared for and dying in a strange place”.

Case Study 3:

- Michael is a 43-year-old man who has Down Syndrome and a mild Intellectual Disability. He had until lately travelled either by bus or train to attend matches as he is a passionate supporter of his local and county GAA teams. Michael attends a day service where staff have observed that he was “not himself” and that he was not engaging with either them or his colleagues. He has appeared to be withdrawn at times. He has also become more reliant on others and less likely to initiate activities. Michael recognises that he is struggling more now, his coping skills are diminishing, and he is finding it increasingly difficult to make sense of the world around him. There is evidence of reduced emotional control, irritability and loss of self direction. He is less tolerant of his peers, and with decline in social behaviours becoming more evident, he has begun shouting at others, for no obvious reason. Michael attended the memory clinic. A full physical work-up was carried out to rule out pseudo dementia and to inform differential diagnosis. He had a full cognitive work up and following comprehensive interviews with key people in his life a consensus diagnosis agreed that he met ICD-10 criteria for Alzheimer’s type dementia. It was agreed that Michael is presenting with a very compressed decline and that the level of support that he will require in the future will be significant.
5 Key Considerations to Inform Good Practice

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

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8 Tips for Effective Communication

1. Adopt a person centred approach to communication
2. Connect with the person
3. Consider the communication environment
4. Be aware of your own communication style and approach
5. Use active listening
6. Use simple language
7. Focus on one question at a time
8. Clarify Information and check understanding
It's really important to us that you are cared for as you want. We want to make sure that any decisions about your end of life care or treatment now and in future are based on your wishes and preferences.

We always want to know that we're doing what you want in relation to your care. We will discuss this every 3 months or sooner if your condition changes.

Ask me what I want

Do you have any worries or wishes about your future care?

Have you ever thought about what you might want if you became very unwell...

What do you think is most important to you as you near the end of life... Who? Where?

The Irish Hospice Foundation

Striving for the best care at end of life for all
AFIRM Approach to Active Listening

Acknowledge the person’s concerns and fears.
Find out what the person knows about their condition.
Immediate concerns addressed.
Respond to subsequent questions.
Meet again or with senior staff to address concerns.

(Stirling et al, 2011)
Case study 1: Possible responses

A. Acknowledge concerns
   “Your husband is certainly eating less now.”

F. Find out what is known
   “How do you feel your husband is doing?”
   “What’s your biggest concern right now?”

I. Immediate concern addressed
   “We know that your husband has dementia and reduced appetite is a common problem as dementia progresses.”
   “There are many ways to help people in this situation to eat, but we know that it may be more comfortable for your husband to eat only when he feels like it.”

R. Respond to further questions
   “Yes, your husband is walking much less and that has gradually reduced over the past year which can be another sign that his dementia is progressing.”

M. Meeting suggested
   “Given that your husband’s condition is changing, this could be a good time to arrange to meet the nurse manager to discuss his current health and future care needs.”
   “This meeting would also be a good time to answer any other questions you may have.”
   “Would you like a meeting to be organised?”
Case study 2: Possible responses

Possible responses using the AFIRM response may include:

A. Acknowledge concerns
   “Let’s talk a little bit more about this.”
   “Would you like to go somewhere quieter so we can have a chat about this?”

F. Find out what is known
   “Are you worried about not being able to remain at home?”
   “Is this something that is on your mind a lot?”
   “Can you tell me more about your fear of dying?”
   “What worries you about being in a strange place?”
   “Are their particular concerns you have about your future care?”
   “What is frightening you the most?”

I. Immediate concern addressed
   “Yes many people are frightened of what will happen as their health deteriorates.”

R. Respond to further questions
   “Yes, most people prefer to remain in their homes for as long as possible but as they become increasing frail, some people need to move into more supportive accommodation such as a nursing home.”

M. Meeting suggested
   “As you have being thinking about your future needs, this could be a good time to arrange a meeting with the doctor and/or PHN so we can explain your options if you become increasingly unwell. Would you like a meeting to be organised?”

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Striving for the best care at end of life for all
Case study 3: Possible responses:

CASE STUDY 3 | MICHAEL (continued)

Possible responses using the AFIRM response may include:

A. Acknowledge concerns
   “Michael you are having trouble remembering things?”

F. Find out what is known
   “How do you think you are managing at home?”
   “How do you feel about getting the bus to work?”
   “Do you think you need more help from staff?”

I. Immediate concern addressed
   “Michael, people worry when there are changes in how they are. What change worries you the most?”

R. Respond to further questions
   “You have said that you are worried about having to leave your home. Lots of people stay in their homes and some people might need to move to somewhere where they can get the care they need.”

M. Meeting suggested
   “Would you like me to arrange a care plan meeting, who would you like with you to support you at the meeting?”
FACT SHEET 1

Facilitating discussion on future and end-of-life care with a person with dementia

Why this is important?
- Dementia is a progressive life-limiting condition.
- People with dementia should have opportunities to make informed decisions about their future care at an early stage and have their palliative care needs addressed.
- Planning future care can optimise comfort care at end of life, enabling a person to live well until they die.

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

TRANSITION 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

HEALTHCARE EVENTS
- Deterioration or decline in a person’s condition
- Person presenting with complex symptoms
- Person presenting with difficulty with nutrition and hydration
- Decreasing response to antibiotics
- Consideration of the need for further medical investigations or treatments
- Discussion about attempting cardiopulmonary resuscitation

8 Tips for Effective Communication
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3. Consider the communication environment.
4. Be aware of your own communication style and approach.
5. Use active listening.
6. Use simple language.
7. Focus on one question at a time.
8. Clarify information and check for understanding.

AFIRM Approach to Active Listening
- Acknowledge the person’s concerns and fears.
- Find out what the person knows about their condition.
- Immediate concerns addressed.
- Respond to subsequent questions.
- Meet again or with senior staff to address concerns.

8 Steps for Family Meetings
1. Prepare discussion.
2. Introductions.
3. Determine the family’s knowledge of dementia.
4. Explain about dementia.
5. Allow space for emotions.
6. Discuss care options.
7. Clarify understanding.
8. Reflect and self-care.

“Dementia does not equate to a loss of communication but to a different system of communication” (Bush 2003).
Going Forward……

• What one thing can you do differently within your practice or organisation with regard to discussions on future and end of life with a person with dementia?
# List of Guidance Documents Being Developed:

1. Facilitating discussions on future and end-of-life care with a person with dementia

2. Advance care planning and advance healthcare directives

3. Loss & Grief

4. Hydration and Nutrition

5. Pain assessment & management

6. Ethical decision making

7. Medication
Useful Resources:
Acknowledgements

✓ People with dementia and carers who have contributed and advised IHF
✓ IHF Changing Minds Team
✓ Project and Expert Advisory and Governance Groups
✓ Atlantic Philanthropies

Thank you and Questions

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