

Facilitating discussions on future and end-of-life care with people 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

“The thing is once you’ve spoken about these things (as hard as it might be) you can put them away and focus on enjoying things” (NCPC 2011).

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

This is available to download on www.hospicefoundation.ie

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The Irish Hospice Foundation

Striving for the best care at end of life for all



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.



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 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.