

GUIDANCE DOCUMENT 1

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



This guidance document is a product of the Irish Hospice Foundation's Changing Minds Programme. Changing Minds is a three year project which is co-funded by the Irish Hospice Foundation and The Atlantic Philanthropies. This document entitled "Facilitating discussions on future and end-of-life care with a person with dementia" is the first in a series of guidance documents for healthcare staff in promoting and enabling excellence in end-of-life care for people with dementia.

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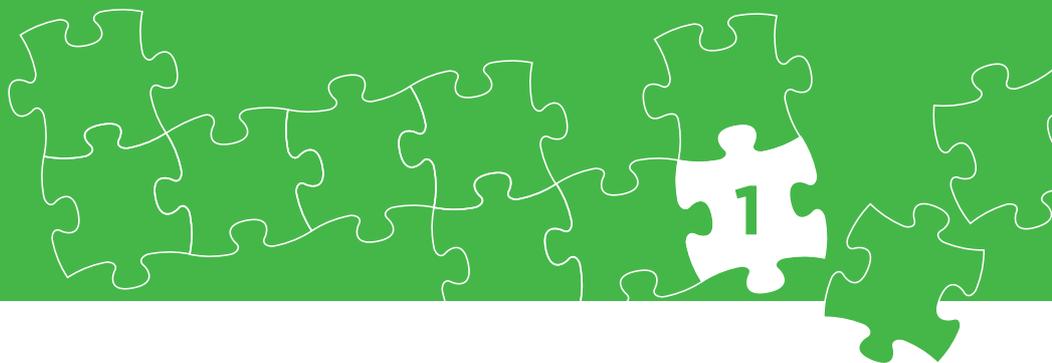
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BACKGROUND AND CONTEXT

Dementia is an umbrella term which is used to describe a condition which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function including; decline in memory, reasoning, communication skills and in the ability to carry out daily activities (1). The number of people living with dementia in Ireland today is estimated to be around 48,000 and this number is set to treble by 2045 (2). Dementia is a chronic, life limiting condition (3–5).

People with dementia have a unique set of care needs which include; a progressive cognitive impairment, diminishing capacity, communication difficulties, possible responsive behaviours and a prolonged illness trajectory leading to uncertainty in relation to prognosis (1,6). People dying with and or/from dementia are therefore a particularly vulnerable group who require staff to have knowledge, skills, competence and confidence in both dementia and palliative care (7). Palliative dementia care involves supporting the person with dementia and their family to address and relieve the pain, distress and discomfort associated with advancing dementia and inviting them to participate in making decisions about future care needs (8). Providing this care and comfort presents services with a significant challenge as each person's journey through dementia is unique with huge variability in the length of the final phase, difficulties in communication and a lack of awareness about the terminal nature of dementia (5,9). This is often compounded by staff lacking basic knowledge, awareness and skills in supporting people with dementia (1,4). It is recommended that palliative care principles are introduced in the person's care early on, ideally soon after diagnosis when the person can meaningfully engage in discussions about their future care (3,8,9).

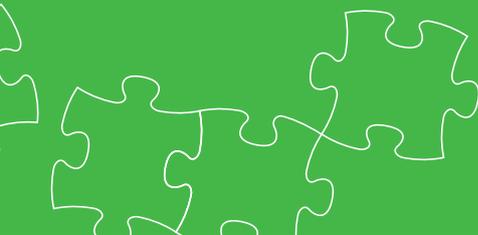
As illustrated, there has been growing recognition of the complexities involved in providing end-of-life care for people with dementia in the literature; however, there is a notable void of practice guidelines to support healthcare staff in delivering excellence in end-of-life care for people with dementia. In order to support staff in meeting the palliative care needs of people with dementia, there was a call for the development of practice guidelines for the Irish context (8,10–12).

In 2013, the Irish Hospice Foundation (IHF) embarked on a three year programme entitled *Changing Minds: Promoting excellence in end-of-life care for people with dementia*. The aim of this programme is to enable more people, particularly those living with dementia to live and die with dignity at home or in residential care settings.

The programme seeks to achieve the following:

- Ensure that palliative care for people with dementia is prioritised and developed in all care settings and more people are supported to be able to die well at home.
- Better end-of-life care in residential care settings for older people, with a particular focus on people with dementia.
- Increased public discourse on death and dying, with a focus on those with dementia engaging in early advance planning.

The programme has six projects, one of which has a dementia specific focus. The overall aim of this dementia specific project is to develop and adapt practice tools and service models for people with dementia. The project committed to develop a suite of guidance documents in order to support



healthcare staff working with people with dementia across all care settings in addressing specific aspects of dementia palliative care. This work was overseen by a Project Advisory Group (see Appendix 1 for membership). These documents aim to consider all stages of dementia and will include consideration of all people who have dementia (e.g. people with young onset dementia, people with intellectual disabilities etc.).

In order to determine the focus for the guidance documents, a desktop review of Irish literature on the topic of dementia and palliative care was completed and compared against an Irish review of the educational needs of staff working with dementia. Following a process of consultation and feedback with the Project Advisory Group, the following care domains were agreed upon as a focus for the suite of guidance documents:



1. Communication skills
2. Facilitating discussions on end of life care
3. Advance healthcare directives and advance care planning
4. Bereavement
5. Intellectual disability
6. Hydration and nutrition
7. Pain assessment and management
8. Ethical decision making
9. Medication.

At the time of this guidance document going to print (June 2015), these have been further condensed into the following guidance documents:

1. Facilitating discussions about end-of-life care with the person with dementia
2. Advance healthcare directives and advance care planning
3. Bereavement
4. Hydration and nutrition
5. Pain assessment and management
6. Ethical decision making
7. Medication.

When completed, it is envisaged that a final composite guidance document will be prepared based on key findings from those developed.

INTRODUCTION

“The lack of public understanding of dementia and the lack of willingness to discuss death and dying in society combine to create a double stigma around dementia and death. This means that it is rarely thought about and conversations that could achieve positive outcomes for personal choice at the end of life do not take place”

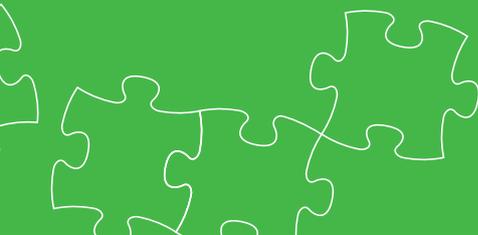
(13).

Creating early and repeated opportunities for discussions on future and end-of-life care with a person with dementia is recognised as best practice and should be considered as part of routine care planning (5,15–22). This allows the person’s will and preferences to be recorded and honoured throughout their condition in order to enable them to live well up to the time of their death (23,24). Furthermore, it supports the person to make informed decisions about their future care and helps to avoid potentially burdensome interventions as their condition progresses (23–29).

Dementia palliative care reflects the qualities of person-centred dementia care and the holistic focus of palliative care. Both models share a person centred 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 their family (8). Person centred care seeks to support and maintain personhood through relationships and recognises the need for attachment, comfort, identity, occupation and inclusion (30). This document is underpinned by these core values.

Having discussions about future and end-of-life care is a challenge which requires all staff supporting a person with dementia to be able to acknowledge and respond appropriately when that person gives a cue, asks a question, or talks about their wishes in relation to their end-of-life care (31). Research indicates that while healthcare staff recognise the need to have discussions on future and end-of-life care with people with dementia, they may feel unprepared and lack confidence in doing so. This may be due to a lack of training, a fear of upsetting the person, time constraints, lack of role clarity and death anxiety (1). These anxieties can be particularly heightened when speaking about these issues with a person who has dementia (15,32–36).

The aim of this guidance document is to inform and guide healthcare staff in initiating and facilitating discussions relating to future and end-of-life care with people who have dementia.



2.1 Scope of this guidance document

This guidance document will:

- List five key considerations to inform good practice in communicating with a person with dementia.
- Provide guidance on four areas which were identified during the development of this document (see Appendix 2 for methodology).

A separate guidance document will be developed later in 2015 on completion of advance care planning and advance healthcare directives and this will be guided by the forthcoming Assisted Decision Making (Capacity) Act (37).

2.2 Who is this document for?

This document has been written for all **health and social care staff** who work with and support people with dementia **across all settings** (e.g. in the home, in residential care settings, in hospitals, etc).

A whole person approach needs a whole team approach: all staff supporting people with dementia will interact and engage with the person with dementia and their families in different ways depending on their roles. Each of those roles are interconnected and are key to delivering good quality person-centred care. Therefore, all staff need to develop competence and confidence in supporting people to have these discussions within their own scope of practice.

2.3 How to use the document

End-of-life care reflects the whole continuum of care and the skills required to facilitate discussions on future and end-of-life care needs to complement existing practices within services. Therefore, this document needs to be used by healthcare staff within their own scope of practice, professional guidelines and standards.

This guidance document should be considered as an adjunct to: existing best practice guidelines in dementia care, best practice guidelines in end-of-life care, and national and local policies, standards and procedures which relate to working with people with dementia and older people.

It is recommended that if a person is not familiar with the document that they take the time to read it in its entirety as each section builds on the knowledge and information shared in the previous section. The factsheet which accompanies the document should serve as a visual reminder to people who have read the whole document. It is not recommended as a standalone item.

Changing attitudes, cultures and care practices takes time. How you choose to use this guidance document will depend on your setting. You may choose to adapt it into policies, deliver it as part of an education programme, hold information sessions on it or discuss it within individual teams to effect changes within services for people with dementia.

2.4 Structure of guidance document

This guidance document is based on key themes which emerged from three literature reviews and a process of consensus building by the Expert Advisory Group (see Appendix 2 for methodology).

The document is divided into 4 sections:

Section 1: Background and Context

Section 2: Introduction

Section 3: Five Key Considerations to Inform Good Practice

The five key considerations should be applied as foundation knowledge for staff supporting a person with dementia to ensure good practice in working with people with dementia.

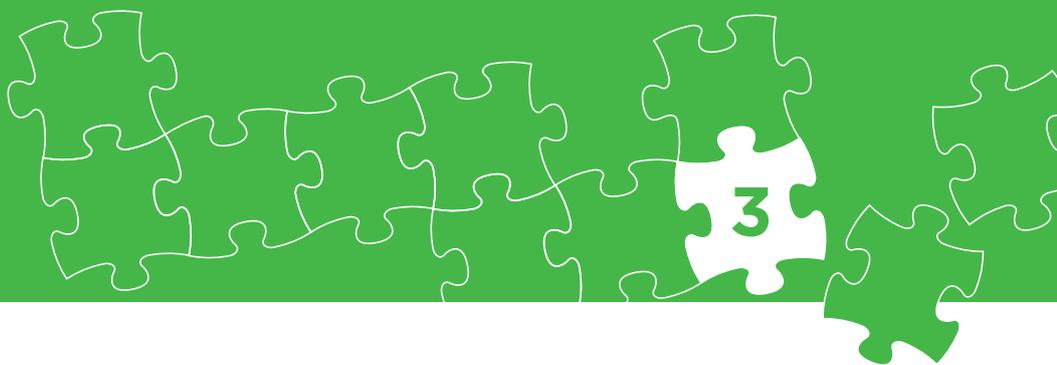
Section 4: Guidance and Resources

There are four areas where guidance is provided to the reader on aspects of communication relating to end-of-life care with a person with dementia and their families. Each guidance area is followed by resources and signposting to further information.

Section 5: Additional resources which can serve as supplementary information for staff.



Section 3



FIVE KEY CONSIDERATIONS TO INFORM GOOD PRACTICE

This section explores five key considerations which inform good practice in communicating with a person with dementia. They should be applied as foundation knowledge for all staff supporting the person with dementia. They are as follows:

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 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.



3.1 Recognise that communication is always possible with a person with dementia

“Relationships cannot develop without communication and quality care is impossible without relationships” (38)

As outlined in the statement above, communication is core to forming meaningful relationships and underpins all elements of quality care (39). A person centred approach to communication and to care involves taking the time to get to know each person, their fears and anxieties, listening to their wishes and dreams, and finding out about the things that bring them comfort and joy which enables staff to care for each person in a way that is right for them. This relationship will support staff to talk to people about their wishes for their future care, finding out how much they would like to know if their health begins to decline, or asking them what arrangements they would like to make for after their death (31).

Dementia is accompanied by a decline in the ability to communicate using speech. This reduced ability to talk is often misinterpreted as signifying that a person with dementia has nothing to say or, more significantly that they have lost the ability to communicate altogether. As dementia progresses and speech becomes less and less useful as a way of engaging or making contact, staff can easily give up because their attempts at communication are unsuccessful (40). It is **always** possible to communicate with a person with dementia but the manner in which the person can express themselves will change as their condition progresses, demanding increasingly sensitive communication from those supporting the person (17). Staff need to be creative and open to trying out different approaches to interact, connect with and support the person with dementia to communicate. This belief and willingness to be creative is key to delivering good person-centred end-of-life care. Further guidance on communication skills is provided in section 4.

3.2 Develop knowledge about the progression of dementia and key triggers for end-of-life care discussion

“One of the key challenges for managers and staff is knowing when and how to open a discussion with individuals about what they would wish for as they near the end of their life” (41)

Before healthcare staff enter into discussions relating to end-of-life care, it is important that they have a good understanding of the clinical progression of dementia as well as being informed of the events or transitions that can prompt or trigger end-of-life discussions (42). Having this knowledge will enable staff to anticipate and be prepared for end-of-life care discussions as part of their routine care planning and to manage informal discussions appropriately and sensitively. Sensitive communication is needed to guide the person and family carers through the potential scenarios which can arise as dementia progresses and where particular decisions may need to be made to ensure the optimum comfort for the person (17) (also see resources section 6.1 for information on the progression of dementia).

Some of the milestones which may act as triggers or prompts to facilitate discussions about future and end-of-life care with a person with dementia are as follows:

TRANSITION POINTS	HEALTHCARE EVENTS
<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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

(5,8,42,43)

3.3 Plan future care to optimise comfort

“People with early dementia are interested in participating in advance care planning discussions.....so we should not be scared of asking people with dementia their views” (44)

Having early and repeated discussions allows the person with dementia, their family and the team to plan their future care and to ensure that comfort is prioritised throughout the persons journey with dementia. Medical and clinical interventions can help manage many of the symptoms which commonly arise with dementia such as pain, agitation and swallowing difficulties. As the person's dementia progresses, it is important that the healthcare team discuss the changing needs of the person and explain to the person and their family that interventions should primarily focus on maximizing the person's comfort (17,42). Overly burdensome treatments such as transfer to hospital, the use of

some medications, use of restraints, artificial nutrition or hydration and attempting cardiopulmonary resuscitation need to be considered in light of each person's unique needs and set of circumstances (28,30). Such complex clinical decisions will be made by senior clinicians who should consider the will and preferences of the person when determining the most appropriate treatment and future care provided to the individual. It is important that the language used by senior clinicians does not transfer responsibility onto the person with dementia or their family member for the consequences of the decision that has been made. Pain management, advance care planning and advance healthcare directives, nutrition and hydration and ethical decision making will be covered in detail in separate guidance documents in this series.

3.4 Promote personhood throughout the person's journey

“We must never lose sight of the individual who must be afforded sufficient choice and the opportunity to live well with dementia and to be treated with dignity, kindness and respect” (10)

Being treated with compassion, kindness, care and respect is core to our humanity and the delivery of good end-of-life care (40). Good end-of-life care involves responding to and meeting a person's physical, social, spiritual and psychological needs. The person with dementia's values, will and preferences should be honoured and respected by staff throughout their journey with dementia. It is never too late to find out about a person's wishes in relation to their end-of-life care. People with advanced dementia can and do communicate their preferences about what is important to them (45). It is up to staff to recognise a person's communication attempts, validate and respond to them and share that information with the healthcare team. Relatives are often well placed to provide valuable information in aiding healthcare staff understand what is most important to their family member who has dementia. However, it is important to note that in terms of making medical or legal decisions, no adult has a legal right to give or withhold consent for another adult unless they have specific legal authority to do so (46). In conclusion, staff need to value people with dementia as people who have a unique history, values and preferences and support the person to maintain the essence of their personhood at all stages of their journey with dementia.

3.5 Record future wishes when they are expressed

“Discussions about end-of-life issues can be conceptualised as a process of ongoing conversations over time, rather than a single discussion.” (47)

In the instance that a person has clearly expressed their future wishes in any situation or context, it is important that there is a formal record of these wishes kept (42), and that relevant health care staff are made aware of this formal record. The person should receive regular prompts to review and update their record and it should be easily accessible to all staff who are involved in the person's care (48). While additional details may need to be recorded in the person's medical and nursing notes, it is beneficial for there to be a single document which can summarise what is important to the person when planning their future and end-of-life care. If this document relates to decisions regarding certain treatments (e.g. attempting cardiopulmonary resuscitation), this form should be signed and completed by a doctor and reviewed on a regular basis. Guidance on hosting formal family meetings and examples of documents used in Ireland for this purpose are given in section 4. Advance care planning and advance healthcare directives will be covered in a subsequent guidance document and this will be developed following publication of the Assisted Decision Making (Capacity) Bill (37).

▶ Section 4

GUIDANCE AND RESOURCES

The four areas which were identified as areas in which staff would benefit from guidance on facilitating discussions on future and end-of-life care are introduced below and are outlined in further detail in the subsequent four sections of this document. These are as follows:

1. **Communication skills.**
2. **Capitalising on informal opportunities.**
3. **Facilitating discussions.**
4. **Hosting formal family meetings.**

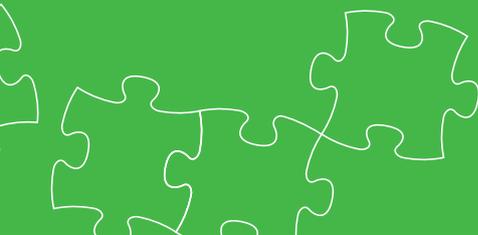


What follows in each section is guidance for staff on how best to approach each of these areas. Each guidance is followed by relevant resources to support learning, development and practice in that area.

4.1 Communication skills

Getting communication right is essential when discussing and delivering quality end-of-life care. Successful communication is dependent on two people sharing a common language or system of communication, an understanding and ability to interact using that system by both partners and a motivation, reason and opportunity to communicate. As illustrated in section 3, communication is about much more than words. People with dementia may communicate in lots of different ways using facial expression, eye contact, body language, vocalisations, responsive behaviours, writing and speech. The person with dementia may need additional time to process information and find the correct words to formulate a response. They may benefit from additional communication supports such as a pen and paper (writing down key words) / pictures and/or photographs. Some people with advanced dementia may communicate through responsive behaviours and subtle nonverbal cues. Staff should be attentive to the person's verbal and nonverbal communication in addition to the communication environment they are in in order to understand what the person is communicating and formulate an appropriate response.

Communication with people with dementia should take a person-centred approach. Knowing someone's life history is essential in helping staff to get to know a person, their family, their values and their wishes in order to build relationships with them. It is within this context that purposeful discussions about future and end-of-life care take place. Conversations about end of life often arise in informal everyday situations such as on the corridor, on the phone or by the bedside and are often directed at staff who have the most contact with the person with dementia and their family. All staff including healthcare assistants, catering and housekeeping staff need to be able to acknowledge and respond appropriately when a person makes a comment, asks a question or gives a cue to open a discussion relating to their wishes (8, 40, 48–50).



Staff should know when to refer to a more senior staff member if the conversation extends beyond the scope of their role or knowledge (21,22). Formal discussions on a person's future care are the responsibility of senior staff who have the expertise to answer the clinical questions which commonly arise in discussing end-of-life care for people with dementia. Hosting formal family meetings are discussed later in this section.

Finally, people with dementia may have a moment of clarity which are fleeting or 'special moments'. During these moments the person with dementia may spontaneously express their wishes, including their wishes and preferences relating to the end of their life. Information from an Irish study entitled 'Planning for the Future'(16) illustrated how people at an advanced stage of their dementia could express their wishes with clarity. The project illustrated how people with dementia often brought up issues regarding pain, their wish to stay in the centre and their readiness for death in these 'special moments'. This guidance document recommends that these spontaneous interactions from residents with dementia should be captured and documented as they happen. The figure below has been taken from this project and illustrates some of the key aspects of end-of-life care discussions.

Ask me what I want or what I would not want.

It's really important to us that you are happy here. We want to get to know you and want you to feel comfortable talking to us about your wishes or any worries you might have...

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?

We always want to know that we're doing what you want in relation to your care... We want you to be able to tell us what matters to you.

Is there anything that you'd like to tell us about looking after your future?

We have learned that communication with a person with dementia demands time, skill and creativity. It is essential that organisations place value on staff developing skills to allow them to create an atmosphere that enhances and supports communication. This requires a commitment to allocate time and resources to support staff in learning and developing skills in person-centred communication with persons with dementia.

Below are four recommendations or guidance in the area of communication skills. This is followed by a resources section which goes into more detail on these areas and signposts the reader to additional related resources.

GUIDANCE – COMMUNICATION SKILLS

- 1. Communicating with a person with dementia requires time, skill, creativity and an openness to trying out new approaches. Service providers and staff need to factor in additional time and resources when organising and managing services in order to facilitate good communication with the person with dementia.**
- 2. It is strongly recommended that all staff develop skills in:**
 - person-centred communication with a person with dementia**
 - using a range of communication tools to facilitate effective communication**
 - responding to and facilitating end-of-life care discussions with people with dementia.**
- 3. When talking to the person with dementia it is recommended that staff use short sentences, familiar language and a calm tone of voice. They should be aware of their own nonverbal communication.**
- 4. The use of active listening techniques can facilitate discussions and conversations with the person with dementia.**



Resources

TIPS FOR COMMUNICATION

These are based on themes arising from the literature review and views of the Expert Advisory Group.

1. Adopt a person centred approach to communication

Staff should adopt a person centred approach which values people as individuals with unique histories, values, likes, beliefs and strengths. A total communication approach is one such approach which values all forms of communication and respects individuals' right to choose the mode or modes in which they communicate. Staff should:

- Find out about how best to support a person to understand information and how to facilitate interactions with them. Understand that the person may interact best at certain times of day. This will have a big impact on the success of your interactions.
- The use of communication aids that support the person could include objects, visual supports, communication passports, life story books, story boards, maps, photos, picture boards (16,50), pen and paper, Talking Mats (50) and sign such as Irish Sign Language or Lámh (51) which is commonly used by people with intellectual disabilities.
- Be creative! Communicating and interacting with people with dementia requires staff to be creative and open in their approach.
- People with advanced dementia can communicate their views and preferences in a way that is subtle and often not obvious to people who do not know them well. This means that you need to document communication behaviours that you have noticed and build up a picture about the person's preferences and wishes around their care including their end-of-life care. This demands a collaborative approach using key 'nuggets' of information from staff observations, family and friends. Life story work could form the basis for this work. This is explained in point two below.

2. Connect with the person

In section 3, emphasis was placed on the need to promote personhood throughout the person's journey with dementia. Good quality interactions have a big impact on how a person with dementia feels; there is a strong link between positive, friendly communication and improved mood in people with dementia (52).

- Staff should prioritise connecting with a person and try not to get overly focused on exchanging information and facts. Enjoy the contact and the connection and promote success in the interaction.
- Life story work can be a very effective way of developing meaningful relationships with the person with dementia (53). This involves taking time to get to know a person and their life history in order to understand and connect with them on a personal level. By knowing who the person is and what is important to them, you can build a meaningful relationship and foster successful interactions.
- It can often be useful to focus on the feelings or the intent behind the words instead of facts in order to foster successful interactions.

- Talking a lot about the past can foster success. Everything has potential to lead to a conversation about the past. Using this can be a way of engaging the person about their own wishes and preferences.
- Be cautious of correcting a person with dementia – this can have a negative effect on a person's self-esteem and be counterproductive. Do not argue over facts which the person presents to you which may be inaccurate. Accept this as their reality.

3. Consider the communication environment

The communication environment in which an interaction takes place can have a positive or negative impact on the person with dementia's ability to engage (54).

Consider the following aspects of the communication environments you support people in:

- **Lighting:** Good lighting in buildings can help people to see what is around them, to navigate, identify signs and spaces, see others' faces and participate in activities. However, strong lighting can have a negative effect on people with dementia's energy levels (55,56).
- **Noise:** It is important to be aware of the level of noise in the environment. Background noises such as TV, music, people moving around, activities in the unit, chatting etc can make it very difficult for a person with dementia to concentrate. Try to reduce noise levels or move away from noise during an interaction as much as possible.
- **Seating:** Ensure that where the person is seated maximizes their ability to engage in interactions (e.g. can they see and hear well in that position? Are they comfortable? Do they have a pen and paper/ photos or other supports they need for communication within reach?).
- **Resources:** Ensure that there are resources to support communication available in the environment such as pens and paper/photos of relevant items for choice making etc. You could set up communication stations within units to have communication supports readily available as they are needed.

4. Be aware of your own communication style and approach

The importance placed upon nonverbal communication increases for people with dementia as they lose their ability to follow conversations. The person with dementia may struggle to find meaning in your words but take meaning from your tone of voice, your body language and your eye contact. Body language, posture, facial expression and eye contact are powerful in supporting a person to engage/disengage.

The following tips should help you to engage with the person with dementia:

- Approach the person from the front and make eye contact.
 - ✓ Sit at the person's level – eye level is best.
 - ✓ Introduce yourself by name – do not expect the person to remember your name: asking them if they remember may be distressing.
 - ✓ Call the person by name and tell them what you are there for.
- Be attentive to the person's non-verbal communication. Use your observations of the person's nonverbal signals to open up a conversation– if a person's facial expression displays a particular emotion, label it (e.g. say " I see you look a bit happy/sad today").

- Responsive behaviours may be the person's only way of communicating – it is important that you always view behaviour as a form of communication.
- Be aware of your own non-verbal communication. Think about your body language, your eye contact, your tone of voice etc and how this may affect the person's ability to engage with you.
- Speak slowly and clearly using a calm tone.
- Avoid extremes, by not talking too loudly or too slowly and avoiding childish vocabulary (40, 46,48,49).

5. Active Listening

The use of active listening is particularly important when talking to a person with dementia. It involves fully attending to the person and allowing them to lead the conversation without disruptions. Active listening also involves the use of silence, and although this can be unnerving for staff, sensitive discussions often require these silences to allow the person to assemble their thoughts and questions. These tips might help:

- Show you are listening by employing conversational cues such as “mmm”, “I see”, and “really” (15,59) along with an open posture, eye contact and nodding.
- Try not to jump in and fill silences with more language.
- The person with dementia may struggle to make meaning of what they are hearing and finding the words they wish to say. Give the person extra time to process information and find the words they want. Don't continue to speak as this may overwhelm the person with dementia.
- How long a person with dementia needs to allow them to process information will vary from person to person so find out what works best for the person you are supporting (33,58,60,61).

6. Use simple language

Supporting a person with dementia in conversation means that you may need to think in advance about the words you are going to use. Keep it simple and easy to understand. These tips should help:

- Use the person's name in conversation.
- Keep your language clear and concise.
- Focus on one topic at a time.
- Avoid medical jargon and terminology.
- Point or demonstrate to help a person understand what you are saying.
- Use visual supports such as photos and/or write down key words.
- Use different words to get the same point across if the person does not understand the first time.
- Provide support and affirmation when a person gets stuck in a story/idea e.g. “you were telling me all about your family and how you felt about your day today” (5,22,44,46,47,49–51).

7. Focus on one question at a time.

Be aware that reasoning, logic and time requires complex thought processes that a person with dementia may struggle with (33,58,60,61,64). Open ended questions (e.g. what do you feel about?) or choice based questions (would you like tea or coffee?) can be very difficult to retain and to process for some people with dementia.

These tips may help:

- Reframe open-ended questions. If the person is struggling to answer a question, it may be beneficial to rephrase it as a closed question which involves a yes/no answer (e.g. would you like a cup of tea?).
- Asking a series of short closed questions which focus on one key idea at a time can be of benefit.
- Try not to ask the person to give you lots of facts as this information is difficult for a person with dementia to access and can make conversations feel like a test rather than a two way interaction. It can be useful to ask questions related to feelings rather than facts (e.g. say “Do you like children?” or “Tell me about your children” rather than “How many children do you have?”)
- If the person does not appear to understand what you have said, repeating and/or rephrasing the question can help.

8. Clarify information and check for understanding

- If you have difficulty understanding what the person is saying, ask some questions to help clarify what the person wishes to communicate.
- Do not pretend to understand if you do not. Share responsibility (e.g. say “I’m sorry we are getting a bit stuck” or “I didn’t get that”).
- Check the person has understood what you are saying. The person may demonstrate this through nonverbal means.
- Ensure you have heard and understood the person correctly by repeating back the information to them to allow them to clarify their meaning (e.g. “you’ve told me that you wish to get more help with getting dressed, is that right”).

Additional Resources

1. The National Dementia Training Programme (65) has a session on communicating with the person with dementia which enables staff to develop skills and knowledge in this area.
2. The Social Care Institute for Excellence has a module on positive communication as part of its e-learning “Dementia Gateway” (66). This is available free of charge to the public.
3. The Alzheimers Society of Ireland have produced two factsheets relating to communication. These are as follows:
 - Communication: Understanding changes in behaviour (67)
 - Understanding and respecting the person with dementia (68).

4.2 Capitalising on informal opportunities

Throughout the course of the person's journey with dementia relationships develop between staff members, the person with dementia and their families as a natural component of care. As discussed in section 4.1, it is within the context of these relationships that discussions regarding a person's feelings, wishes and preferences for future will take place. Opportunities to address concerns and queries relating to a person's health and future care will often arise as part of an informal chat or during casual conversations with health care staff (42). At such moments it is vital that staff recognise this as an opportunity to give clear information, explore people's wishes, thoughts and fears and respond to this in an appropriate way. In order to do this, staff need to ensure they are informed and prepared for the changes that come about during the course of a person's dementia (9,15,17). See section 5.1 for additional information on understanding the progression of dementia.

Informal conversations can be guided by the **AFIRM** approach (69). AFIRM is an acronym which gives staff a suggested framework to deal with informal conversations. AFIRM has been devised to support staff to be ready to use these occasions as opportunities to pick up on underlying apprehensions or queries that the person with dementia or their family has. The AFIRM acronym is described below and the subsequent case studies (adapted from (69)) illustrate how the AFIRM approach can be used to structure spontaneous and informal conversations.

ACKNOWLEDGE the person's concern or questions.

FIND out what the person knows about the condition.

IMMEDIATE concern addressed by providing adequate information within the scope of your work.

RESPOND to subsequent questions by providing accurate information within the scope of your work role.

MEETING suggested to discuss their concerns with a senior clinician.

When casual or unplanned conversations about end-of-life care occur, it is important that staff are aware of the steps to take and who they can inform, so that the information shared can inform formal care planning process (69).

GUIDANCE ON CAPITALISING ON INFORMAL OPPORTUNITIES

1. Staff can use the AFIRM approach as a process to help them to manage informal conversations effectively.
2. Staff need to be clear about the scope of their role when unexpected conversations about future planning and end-of-life care present themselves, so the opportunity for discussion can be optimised.
3. Staff need to ensure that information shared in informal conversations that address matters relating to future and end-of-life care preferences are shared with all people involved in the person's care and documented.
4. Staff should familiarise themselves with case studies presented below to learn how to capitalise on casual conversations in order to address underlying concerns expressed by the person with dementia or their families.





CASE STUDY 1 | TOM

Tom has been a resident in a nursing home 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 regularly visits and has become anxious about her husband's deteriorating health. His wife, who is distressed, approaches a healthcare assistant asking "Could my husband die from not eating enough?". As a healthcare assistant, you know that his wife visits regularly but you aren't sure what she knows about her husband's diagnosis and care plan.

Possible responses using the AFIRM response may include:

Acknowledge concerns

"Your husband is certainly eating less now."

Find out what is known

"How do you feel your husband is doing?"

"What's your biggest concern right now?"

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."

Respond to further questions

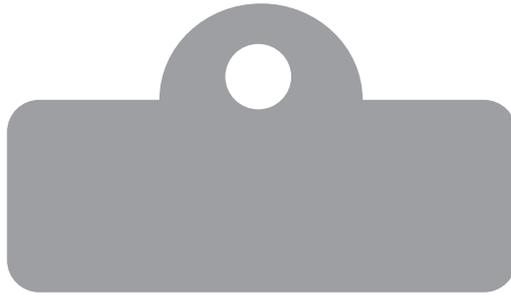
"Yes, your husband is walking much less and that has gradually reduced over the past year which can be another sign that his dementia is progressing."

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 | KATHLEEN

Two years ago, Kathleen was diagnosed with dementia and remains living alone in her own home. Over the last year, she has needed a lot more help from her daughter and needs help with most personal and domestic activities. One day when Kathleen was attending a day care centre, she became quite tearful when speaking to the nurse and said “I am so frightened of having to move from my home and the thoughts of being cared for and dying in a strange place”.

Possible responses using the AFIRM response may include:

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?”

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 there particular concerns you have about your future care?”

“What is frightening you the most?”

ImmEDIATE concern addressed

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

Respond to further questions

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

Meeting suggested

“As you have been 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?”



CASE STUDY 3 | MICHAEL

Michael is 43-year-old man who has Down Syndrome and a mild Intellectual Disability.

He lives in supported accommodation. Michael had until lately travelled either by bus or train to visit his family or to attend matches as he is a passionate supporter of his local and county GAA teams. Monday to Friday he 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. Reports from the staff in his home have concurred that Michael has lost interest in doing everyday things for himself. 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 staff and other residents, 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 family members, key staff from his home setting and his workplace 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. The psychiatrist has told Michael that he is presenting with memory problems and has explored with him what that means for him.

Prior to engaging with a person with an Intellectual Disability and using the AFIRM response, it is important to acknowledge that the person may find it hard to express how they are feeling. Consequently, it is important that staff who know the person very well, and who understand the person's usual methods of communication are involved when a diagnosis is being explored – particularly where the person involved does not use words to communicate.

Continued Overleaf ►



CASE STUDY 3 | MICHAEL (continued)

Possible responses using the AFIRM response may include:

Acknowledge concerns

“Michael you are having trouble remembering things?”

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?”

ImmEDIATE concern addressed

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

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.”

Meeting suggested

“Would you like me to arrange a care plan meeting, who would you like with you to support you at the meeting?”

Additional resources

The National Clinical Programme in Palliative Care have developed two resources that will support understanding and development of roles and competencies in the delivery of palliative care:

- The Palliative Care Competence Framework (70)
- Role Delineation Framework (71).

4.3 Facilitating discussions

Future care should be planned with a view to enabling the person with dementia to live as well as possible right up until they die. As outlined in section 3, conversations on future and end-of-life care should be a natural extension of the regular care planning discussions healthcare staff have with the person (9,21). These discussions may relate to what is important to the person with dementia in the forthcoming days or could specifically relate to the care they would like to receive if they became unwell. There will be some people who do not wish to or are reluctant to discuss any aspect of end-of-life care (9) and this should be respected, but the option to revisit this subject should always remain open. Similarly, it is important not to assume that a person does not want to plan for their future care because they have not initiated a discussion (15,72).

As discussed in section 3, healthcare staff may feel ill equipped and reluctant to approach this sensitive topic (15,19,24,25). The barriers experienced by staff in discussing end-of-life care with people were explored in an Irish study (16). This study highlighted staff's concerns about their use of language, how to sensitively introduce the topic and how to respond to questions that challenge them. These fears/anxieties can be explored through the use of reflective practice which allows for personal and professional development thus enabling practitioners to provide high standards of care (74). St Vincent's Hospital in Athy developed prompts for assisting staff in holding discussions which address future and end-of-life care planning (16). This can be seen in more detail overleaf.

GUIDANCE – FACILITATING DISCUSSIONS

1. **Use team meetings and case reviews to reflect with other staff on situations where opportunities to discuss end-of-life care can be optimised.**
2. **Develop 'end-of-life care' domain questions as part of care planning documentation, and prepare sentence prompts to facilitate discussions on end-of-life and future care planning.**
3. **Review documentation to determine the extent that end-of-life discussions are discussed, recorded and followed through.**
4. **Access communication and training opportunities to support discussions on end-of-life care for the person with dementia.**



'Planning for the Future Project' St Vincent's Hospital, Athy, Co. Kildare (16)

This project commenced in 2010 and aimed to develop a framework to support staff with initiating discussions around end-of-life care issues with residents and families in Le Cheile (dementia specific unit) and was funded by the IHF. The interim report on this project was published in Sept 2013. One aspect of the project was the development of an end-of-life care form with accompanying guidance, which is available on the IHF website. See below for adapted content.

End-of-life care form (Adapted from St. Vincent's Athy)

Planning for End-of-life Care Form

Before completing this form, please refer to page 2.

It is really important to us that we care for you in the way that you want to be cared for. We want to make sure that any decisions about your end-of-life care and treatment both now and in the future are based on your values, wishes and preferences.

1) We want you to remain as well as possible for as long as possible but have you ever thought about what would be most important to you if you became seriously ill while you are in St Vincent's?

If the doctor and staff felt that acute treatment in a general hospital would not be of benefit to you at that particular time, what would you prefer to do?

2) Remain in St Vincent's hospital for treatment and symptom management

Yes No

3) Transfer for more advanced acute medical treatment to Accident and Emergency department.

Yes No

ALL DECISIONS ABOUT YOUR ONGOING MEDICAL CARE WILL BE MADE IN CONSULTATION WITH YOU AND YOUR DOCTOR, AND IN YOUR BEST INTEREST.

4) You might find discussing end of life care difficult, in which case could I ask you to think about your wishes and preferences around future end of life care and I will back to you again on

Nurse's Signature _____
Date _____

5) Are there any documents we should be aware of in relation to your end of life care e.g. Enduring Power of Attorney (EPA)/Ward of court?

Ensure relevant information is documented and updated in residents medical notes

6) Can you tell me what you understand about your illness and this particular stage of it?

7) What do you think would be most important to you when you are nearing end of life? E.g; Have you ever thought of where you would like to be? Who would you like to have with you?

8) Would you like to talk about worries or fears that you may have about death and/or dying?

9) Any preferences/wishes for after death?

10) Wish to be Cremated: Yes No

11) Have you shared any of this information with your family, friend or any other person?

Yes No

With _____

Relationship _____

12) Would you like to share this information with your other relatives or friends?

Yes No

We will give you the opportunity every three months (or sooner if there is any change in your condition), to revisit these discussions. This will allow you to add to, or change any preferences and wishes already discussed.
Information obtained from _____

Relationship: _____

Care Plan Commenced: Yes No Date _____

Palliative care Plan: Yes No Date _____

Nurse's Signature _____ Date _____

End-of-life care form continued (Adapted from St. Vincent's Athy)

Identifying what is most important to the person when they become unwell can be a very broad topic. The person might want to talk about and focus on what is meaningful to them in their daily life before they can specifically focus on what would be most important to them if they became seriously ill. People may want time to consider this question and revisit the conversation in order to allow the healthcare team develop a deeper understanding of what is most important to the person.

"How do you see things going from here?", "What are you hoping for?" "How do you see the future?" "Let me reassure you that we speak to all residents about their future care and this conversation has not been triggered by any bad news about your health" "you said you don't want to be a hero, what do you mean by that". "Could you explain what you mean you said you don't mind if you slip away and die alone"

Explore if they would prefer to remain at home or be transferred to hospital for more aggressive/ burdensome treatment. It is important that the person understands that their care needs will continue to be met and their comfort will be prioritised at all times, regardless of whether they wish to have active treatment or not. In discussing these questions, it can be helpful to ask the person if they ever cared for someone who was sick and what their feelings were about this experience. This may help the person identify what was 'good' or 'bad' about that situation and what they would want for themselves. The issue of capacity should be considered when discussing future care. This should be done by the team and guided by upcoming legislation (Assisted Decision Making (2013) Bill) and the HSE Consent Policy (2013).

"Even when we are not providing aggressive treatment, we will always take a very active approach to making sure you're very comfortable and that any pain or other symptoms are well managed."

When enquiring about what is most important to the person when nearing the end of their life, it can be helpful to think about their final days and hours, as they may wish for different things at different stages of the journey.

Environment "where would you like to be, and if home is not possible, how could we create a comfortable place. e.g. separate room, items from home, beside altar, candles, music, smells, devotional pictures?"

People "Who would you like to be with you if you were at the end of life/dying. Is there other family and friends you would like to come when you could still tolerate short visit? Are there people you don't want around?"

Actions "Are there any spiritual or religious practices that you would like to be carried out before or at the time of death i.e religious leader visits, spiritual rituals, meditation?"

Exploring the person's worries and fears about death provides an opportunity to discuss any concerns they may have about the person's last few days or final minutes. There may also be specific disagreements or regrets that they may wish to resolve to allow a sense of closure to their life (via. Letter, telephone or person).

"Is there anything you are concerned about when you think about dying...big or small worries?"

Asking someone about what their wishes are in relation to after their death can help the person feel in control right to the end of their journey. Some people may have very clear preferences about their burial and related rituals.

"What arrangements would you like to be made...appearance and clothes... location of removal...type of burial...type of spiritual service...readings, poems and songs?"

Additional resources

Resources to support end-of-life reviews

1. The IHF have developed guidance for residential care centres to support Compassionate End-of-Life review (CEOL) meetings. These meetings are designed to give staff the opportunity to review and reflect on care provided to a resident who has died. The guidance provides the steps to take to host a review meeting, optimising learning opportunities for staff. The guidance has been developed as part of the IHF Journey of Change programme, email journeyofchange@hospicefoundation.ie for more information.
2. The End-of-life Care Toolkit (31) has a useful section on communicating around end of life issues and breaking bad news.
3. The DML Integrated Minimum Dataset (75) contains relevant sections and documentation in relation to discussing and documenting palliative care needs, psychosocial and spiritual needs and end-of-life care decisions.
4. The National Clinical Programme for Palliative Care have developed a number of key resources to aid documentation and planning in palliative care such as:
 - The rapid discharge guidance for people who wish to die at home (76)
 - Palliative care needs assessment guidance (77).
5. The quality and patient safety directorate in the HSE have prepared a Practical Guide to Clinical Audit (78). Clinical audit is a tool which can be used to discover how well clinical care is being provided and to learn if there are opportunities for improvement. This method can be used to support the review of documentation relating to end-of-life care.
6. The IHF have developed a series of end-of-life care training workshops which have been adapted for different care settings (Final Journeys, What Matters to Me and Dealing with Bad News). The What Matters to Me workshop is geared towards staff in residential care settings and addresses communication with the person with dementia (79).
7. The series of Prompts for Good Practice in end-of-life care were developed by the IHF for general information and to provide 'Just-in-Time Guidance' for health professionals facing challenges in providing good end-of-life care in acute hospitals and residential care settings (80).

4.4 Hosting formal family meetings

Formal meetings which address future and end-of-life care can be prompted in a number of different ways, including a request from the person or their family, a change in a person's health status, or where a person has survived a critical healthcare episode(15). It is important to get the person's consent before hosting a family meeting. The following is a list of possible prompts or triggers for formal meetings to discuss end-of-life care.

TRANSITION POINTS	HEALTHCARE EVENTS
<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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
	(5,8,42,43)

The meetings would generally involve the person with dementia and/or representatives of their family, and would be led by a senior staff member who has the clinical expertise to answer the medical questions which commonly arise when discussing end-of-life care with people who have dementia (15,72). It may be of benefit to have an advocate present for this discussion where they have been involved with the person.

The purpose of formal family meetings is:

- To provide an opportunity to explore the person's goals of care and preferences for their future and end-of-life care.
- To give clear and consistent information to the person on their current and future health care.
- To clarify how the person's care preferences will inform future medical and clinical decisions.
- To clarify the decision making responsibility of the medical team, particularly in instances where the person is not in a position to communicate their wishes or preferences or may lack capacity.

In summary, formal meetings are designed to enable clear and open conversations about future and end-of-life care and are a means of identifying and recording concerns, wishes, preferences and responsibilities so that everybody may be aware of these if/when it is necessary. Whilst these discussions can be beneficial, they can very be daunting for the person with dementia and their families, and staff are also likely to be apprehensive (36). Consequently good preparation for these meetings is vital. It must be remembered that the extent that a person wishes to participate must be respected, and family participation is at the behest of the person with dementia (15,72).

The eight step approach devised by Derksen et al (81) can help facilitate clear and open conversations between healthcare staff and the person, their relatives or friends, and this has been adapted with prompts to facilitate formal discussion on future and end of life – this is shown in detail overleaf. The steps they recommend are as follows:

1. Prepare for the discussion
2. Introductions
3. Determine their knowledge
4. Explain about dementia
5. Allow space for emotions
6. Discuss care options
7. Clarify understanding
8. Self-care.

GUIDANCE ON HOSTING FORMAL FAMILY MEETINGS

1. **Staff need to recognise prompts which signal the need for a formal family meeting that address matters relating to end-of-life care.**
2. **Services would benefit from having step by step guide for staff to prepare for formal family meetings.**
3. **Services should prepare an information leaflet for persons with dementia and their family on the purpose of family meetings. It may be of benefit if this was in an easy to read format and included visual aids in order to support the person with dementia to understand it.**



The resources section which follows will demonstrate the eight step approach with prompts and show an example of a form used in Marymount University Hospice and Hospital and Milford Care Centre to record family meetings.

EIGHT STAGE APPROACH TO FACILITATE A FORMAL DISCUSSION ON FUTURE & END-OF-LIFE CARE

Adapted from Derksen et al (2006) (81).

1. Prepare for discussion (meeting)

- Introduce the need for the meeting with the person.
- Explain the aim.
- Ask the person with dementia what relatives and staff they would like to attend.
- Invite relatives and other staff members as appropriate.
- Ask family to write down their questions for the meeting.
- Allocate adequate and suitable time for the discussion.
- Arrange suitable private space with no interruptions.
- Read medical records to learn their history and liaise with staff to familiarise yourself with the person's situation.
- Decide who should chair the meeting (taking account of familiarity with the person and experience in conducting formal discussions of this nature (10,15,33,35,44,69,82–84).

As part of our normal care planning, we would like to invite you to meet with us to discuss your mother's condition and care plans. The doctor and your mother will also be attending the meeting.

If you have any questions that you would like to discuss, you may want to write them down as this meeting will be an ideal opportunity to discuss them.

Thanks for coming in today. From my point of view, for the next 20 minutes or so we want to talk about how you are doing and what we think might happen in the next 12 months, so that we can plan together to ensure you receive the best care possible.

2. Introductions

- Introduce yourself and everyone present.
- Put people at ease.
- Outline the purpose of the meeting.
- Ask the person/relative what they would like from the meeting.
- Ask the person/relatives what questions they have (69).

Did you have any things that you wanted to talk about at this meeting? I will jot them down and make sure that we answer them before we finish.

3. Determine their knowledge of dementia

Establish the person's:

- knowledge of dementia.
- understanding of their symptoms.
- understanding of the prognosis and treatment options (33,82,85).

Tell us about how the last few months have been?
What symptoms are you experiencing?
Do you have any queries about the treatment available or how the disease will progress?

4. Explain about dementia

Remember to refer back to what the person/relative has already said and **clarify the level of detail the person wants**. The information shared should be related to the persons wish for information and associated co-morbidities.

- Stress the uncertainty and individual nature of presentation of symptoms.
- Explain the cognitive decline and the functional decline associated with dementia.
- Describe the indicators to influence it's progression.
- Discuss the prognosis and average life span after diagnosis.
- Pause regularly to allow the information to be processed (11,15,19,23,72).

I understand that you would like to know more about the progression of your condition. Dementia will affect each person in a different way but we know their abilities will decline. As dementia progresses, many body functions are affected and people can lose the ability to walk, talk and swallow normally. This means they are more at risk of problems like pneumonia.

We have noticed that lately your mother is not eating and drinking as much and is losing weight. She also dislikes getting out of bed and sleeps most of the day... and unfortunately these are signs that the dementia is advancing.

5. Allow space for emotions

- The person with dementia and their relatives may be upset, shocked and angry by the content of the conversation.
- Allow space for emotions and acknowledge strong reactions.
- Help the family to give a name to their emotions.

I can see that you are very upset.

I wish the situation was different.

6. Discuss care options (also see section 4)

(This step may require a second meeting depending on how the person and their relatives respond to the initial discussion about dementia).

- Clarify the person's hopes, wishes and fears for their future care.
- Explain that care should focus on the person's comfort, drawing distinctions between benefit versus burden and explain comfort care.
- Explain the limitations of some treatments with advanced dementia.
- Outline a future plan of care for the person.
- Discuss scenarios/complications which are likely to arise considering their health and specific situations (i.e. tube feeding, cardiopulmonary resuscitation, antibiotics and admission into hospital).
- Clarify that their wishes will inform their care but stress that one cannot guarantee that all of their requests are followed as this may be dependent on available resources/capability of family/carers and other variables.

It would help me if I could hear what you are worried about and what you would like or what you don't want to see happen?

Let's write down some of those things so that we can make sure they are an important focus of your care

While dementia can't be cured, we will do everything possible to make sure that your relative has the best quality of life and that their comfort and dignity are supported and maintained.

It is very helpful that we understand what is important to you and your wishes will certainly inform all decisions that we will make about your care, and we will do our best to make sure these are fulfilled. It is useful to clarify at this point that the medical team have ultimate responsibility for your care.

7. Clarify understanding and follow up

- Check whether information shared has been understood by the person and their family.
- Address any questions the person/relatives may still have.
- Plan next meeting to review the situation.
- Identify and delegate follow-up tasks.
- Make a formal note of the meeting (see form overleaf) (15,33,85,86).

This is a summary of what we have decided.

Are you clear about the information we have discussed or would you like me to go through any part of it again?

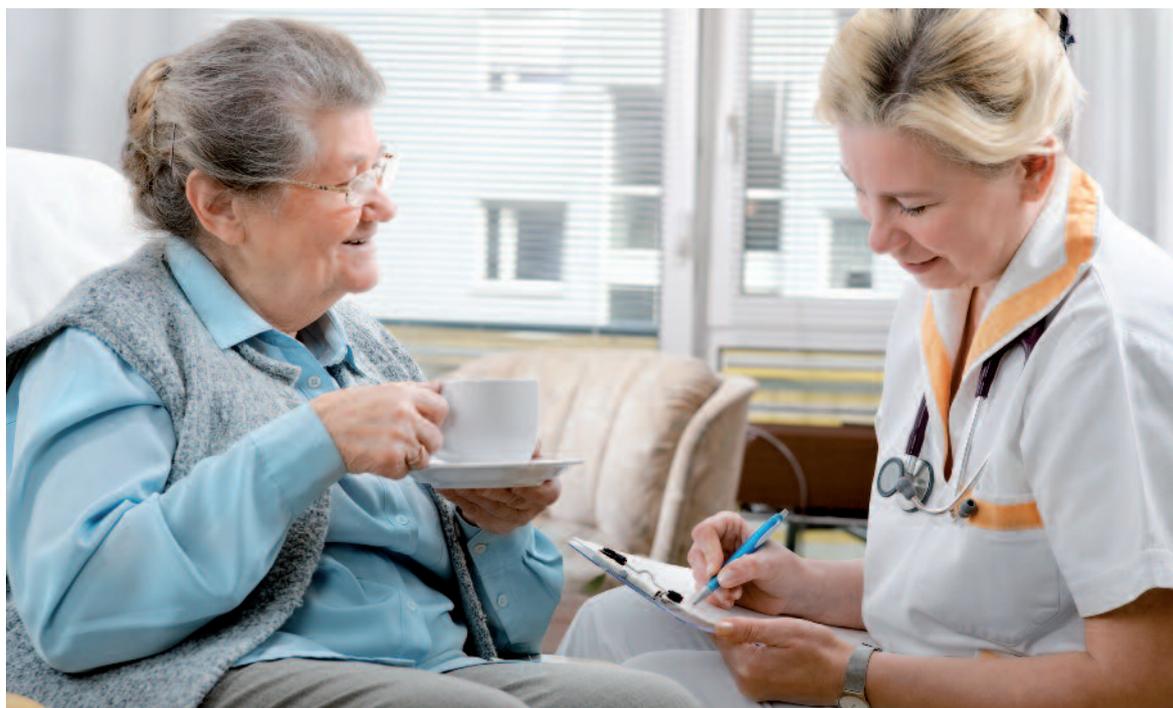
Do you have any further questions at the moment?

We can have a further meeting in X months to review the situation.

8. Self-care

- Be aware of your own personal experiences towards death and dying (i.e. fear & guilt) as they can unintentionally influence your behavior.
- Seek support if you have been upset by the meeting.
- Debrief with the staff members after the meeting and discuss how it went, provide support for each other (15).

It was really upsetting to speak to the person and her family; there was so much anger and grief in the room.

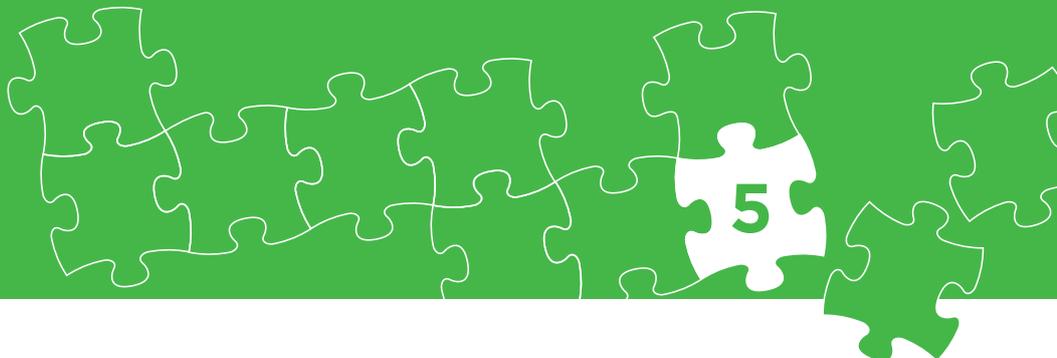


Additional resources

Marymount University Hospice and Hospital and Milford Care Centre have prepared an eLearning programme addressing communication issues in Palliative Care. This online programme, which has a blended component, is aimed at guiding participants in all aspects of communicating with patients and families with particular emphasis on communicating in family meetings.

Sample of Family Meeting Record Sheet used by Milford Care Centre and Marymount University Hospital and Hospice

<p>Family Meeting Record Sheet</p> <p>Date & time of meeting: _____</p> <p>Venue: _____</p> <p>Duration: _____</p>	<div style="border: 1px solid black; width: 100%; height: 100%; display: flex; align-items: center; justify-content: center;"> <p>Patient Information Label</p> </div>
<hr/> <p>PRE-MEETING PLANNING</p> <p>Family Meeting discussed with patient Yes <input type="checkbox"/> No <input type="checkbox"/> Reasons if not discussed _____</p> <p>Verbal consent obtained from the patient Yes <input type="checkbox"/> No <input type="checkbox"/> If not, why? _____</p> <p>Patient attending: Yes <input type="checkbox"/> No <input type="checkbox"/> If not, why? _____</p> <p>Family members to attend as agreed by patient: _____</p> <p>_____</p> <p>Family members contacted by: _____</p> <p>Purpose of Family Meeting:</p> <p>Medical, Nursing, Physiotherapy update <input type="checkbox"/> Discussion on place of care <input type="checkbox"/></p> <p>Discharge planning <input type="checkbox"/> Prognosis/End-of-life care <input type="checkbox"/></p> <p>Other: _____</p> <p>Patient's/family concerns: _____</p> <p>Family meeting leaflet given Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Staff Present</p> <p>MED: _____ NURSING: _____</p> <p>PHYSIO: _____ SW: _____ OT: _____</p> <p>Other team members attending: _____</p> <p>Chairperson: _____</p> <p>Hospice at Home/Home Care notified <input type="checkbox"/> Day Care notified <input type="checkbox"/></p>	
<hr/> <p>Post formal family meeting</p> <p>Feedback given to patient who did not attend the meeting Yes <input type="checkbox"/> No <input type="checkbox"/> By whom? _____</p> <p>If not, why? _____</p> <p>Family Meeting record sheet completed by _____</p> <p>Goals achieved by Patient <input type="checkbox"/> Family <input type="checkbox"/> MDT <input type="checkbox"/></p> <p>Is follow up meeting required Yes <input type="checkbox"/> No <input type="checkbox"/> If yes, when _____</p> <p>Staff debriefing Yes <input type="checkbox"/> No <input type="checkbox"/></p>	



ADDITIONAL RESOURCES

5.1 Understanding the progression of dementia

It is important that healthcare staff have a good understanding of how dementia can affect a person as the condition progresses. This sections aims to provide some general information on the typical progression of dementia. **It is important to remember that each person with dementia is unique and their experience and journey through their condition will reflect that.**

Typical Stages and Symptoms

To understand dementia, it can be useful to consider the condition in four stages; early, moderate, late and final stage. There are typical traits and symptoms associated with each stage but equally these symptoms and stages can fluctuate and overlap. The chart below describes the changes that may present for the person with dementia in the different stages, and has been copied from a publication from the Alzheimer Association in Illinois, USA (86).

Changes in Memory, Thinking, Language and Mood			
Early Stage	Middle Stage	Late Stage	Final Stage
Memory and Thinking Skills			
<ul style="list-style-type: none"> • Difficulty with short-term memory • Loses things • Poor attention • Difficulty with calculations and organizational skills 	<ul style="list-style-type: none"> • Difficulty with short-term and long-term memory • Forget parts of ones history • Has trouble solving simple problems • Becomes disorientated easily 	<ul style="list-style-type: none"> • Mixes up recent and past events • Forgets friends and relatives • Cannot follow a two-step command 	<ul style="list-style-type: none"> • No apparent awareness of past or future
Language			
<ul style="list-style-type: none"> • Trouble finding words or names • Repeats statements or questions 	<ul style="list-style-type: none"> • Has trouble tracking conversations • Has difficulty forming complete sentences 	<ul style="list-style-type: none"> • Unable to carry on a meaningful conversation • Words and sentences often disconnected 	<ul style="list-style-type: none"> • Cannot speak or uses only a few words
Behaviour/Mood			
<ul style="list-style-type: none"> • May become distressed, withdrawn or irritable 	<ul style="list-style-type: none"> • More easily upset or withdrawn 	<ul style="list-style-type: none"> • May express urgent need by yelling/calling out • Difficult to engage 	<ul style="list-style-type: none"> • Severe decline in ability to show emotion
Changes in Ability to Care for Oneself			
Early Stage	Middle Stage	Late Stage	Final Stage
<ul style="list-style-type: none"> • Needs help with household affairs such as cooking and paying bills • Trouble managing money and medications • May get lost or confused when driving 	<ul style="list-style-type: none"> • Needs reminders or practical help with personal care • Slowed walking and reaction time • No longer safe to drive • Fatigues easily 	<ul style="list-style-type: none"> • Loss of control of bowel and bladder • Trouble with balance and coordination • Sleeps often 	<ul style="list-style-type: none"> • Needs total assistance with personal care • Unable to walk and shows little movement • Poor appetite and has swallowing problems • Sleeps most of the time

Progression of Dementia

Three important influences on the life-span of dementia are the type of dementia, the stage of dementia, and whether the course of deterioration is rapid or slow (43,88).

Life expectancy of the person with dementia

Although dementia is a progressive, life limiting and an incurable condition, it is not possible to clearly predict a person's life expectancy and this uncertainty can be very challenging for the person with dementia and their relatives/friends. Although, specific life expectancy cannot be provided, there are some indicators below that healthcare staff can provide on the probable life expectancy of the person:

- 4.5 years is the **average** survival time for a person living with dementia (88). However, some people can live for 20 years post diagnosis.
- Half of the people with **late stage** dementia will die within 1.3 years (43).



5.2 Factsheet and prompt for good practice guide

FACT SHEET **1A** 1B

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

June 2015

 **The Irish Hospice Foundation**
Striving for the best care at end of life for all

FACT SHEET 1A **1B**

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.



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

6.3 Leaflet on Communicating with people with dementia

COMMUNICATING

with people with dementia around end-of-life

Communication is key to good end-of-life care

People living with dementia retain their personhood, including their preferences and their desire to make decisions for themselves. Good end-of-life care involves asking people what they want and giving them choice. But can people living with dementia make choices and decisions about their end-of-life care?

A Dublin study (Cahill and Diaz-Ponce, Journal of Aging and Mental Health, July 2011) concluded:

*“The findings support the evidence that **people with a cognitive impairment and even those with advanced dementia can often still communicate their views and preferences about what is important to them.**”*

“Not knowing where I am doesn't mean I don't know what I like.”



Why do we communicate?

To be human is to communicate. It is at the heart of our relationships. Communication and relationship are also the key to good care, to person-centredness and to good practice.

People with dementia are no different. Like other people, people with dementia need to communicate with a range of people on a daily basis, including their relatives, healthcare staff,

WHAT MAKES FOR GOOD COMMUNICATION?

- Being able to see & hear the other person
- When both parties respect each other
- Good listening / minimal distraction
- When it's two-way, rather than one-way
- Using the right words/a clear message
- Message sent/received at a good time

GPs and others. Poor communication with people with dementia in residential care can put them at risk of unnecessary suffering. Poor communication can also mean that people with dementia are deprived of choice, control, and even respect. Communication is key to identifying and meeting needs.

Communicating with people with dementia can be challenging, as their condition may make it difficult for them to concentrate, their language

skills may vary from day to day, they may struggle to remember what has been said, they can find it difficult to make sense of metaphors, idiom, abstraction, and they may also suffer from other age-related communication difficulties such as loss of hearing. So, the sorts of things that we normally rely on to make our communication effective (see box above) may not always work when we are communicating with someone with dementia.

A leading cause of communication problems is making assumptions about the other person. In the case of people with dementia, unhelpful assumptions can include things like “they are always just caught up in their own world” or “I've worked with people with dementia before so I know what this person wants” or “this person has now become so dependent, it's best to treat them like a child now”. The reality, of course, is that there is huge diversity amongst any group of people with dementia and, like anyone else, someone with dementia will have some good days and hours and some bad ones, some happy times and some difficult times. Their dementia does not make them less of a person.

One thing we do know about communicating with people with dementia is that they are more attuned to the emotional content of a message or an interaction. There is also good evidence that the emotional memory of people with dementia stays intact, long after they may have lost their ability to remember things or to engage in conversation. **They may not remember what we say to them but they will remember how we made them feel.** This is important for both carers and for family members/friends who visit people with dementia but who can often feel dispirited because the person cannot remember who they are.

*We don't remember days,
we remember moments.*

– Cesare Pavese

TRUTH-TELLING OR COLLUDING?

Should a person with dementia, who has significant short-term memory loss, be ‘corrected’ when they forget distressing news (for example, if they go looking for a long-dead loved one)?

No lie is needed if the response is to the emotions rather than the facts.

For example, distressed woman with dementia says to staff member “I'm looking for Mikey [dead husband]... Have you seen him?” Staff member replies to the emotional content “I'm not sure. You look a little troubled, shall I walk with you?”

(from Laura Green blog - <http://linkis.com/wp.me/Q7zmC>)

“They may not remember what you say, but they will remember how you made them feel.”

VERA

A simple way of remembering some of the core elements of person-centred communication – developed* in 2011 for student nurses who were looking for guidance on how to interact with people with dementia.

VALIDATION of the person – requires a basic acceptance that the behaviour exhibited by the person has value. For example, with a man who is trying to exit the building because he says he’s late and has to get to work: “so you’re trying to get to the office, John?”

EMOTION – paying attention to and validating the emotional content of communication rather than the (at times, unintelligible) verbal content. Requires empathy and focus on non-verbal elements. “You sound a bit anxious about this”

REASSURANCE – letting the person know that s/he is safe, through our words, our tone, touch, and our general way of being with them. “We’ll make sure you’re OK, John, that you won’t be in trouble if you’re a bit late.”

ACTIVITY – engaging with the person to occupy them and to learn more about them. “OK, John, let’s get to work here – can you help me tidy these papers?”

Blackhall, A. et al (2011) VERA framework: communicating with people who have dementia. Nursing Standard, Vol. 26 (10), pp 35-39

TIPS FOR COMMUNICATING WITH PEOPLE WITH DEMENTIA

- Try not to enter their world full of anxiety and busyness. Regardless of what you say, how you are will affect them. If you can, calm yourself down before entering ‘their world’.
- Get their attention by making eye contact with them. Make sure they can see and hear you easily.
- Speak clearly and calmly and at a slightly slower pace.
- Avoid speaking sharply or raising your voice, as this may distress the person.
- Use short, simple sentences. If you need to ask them something, express one idea at a time. Giving people choice is important but presenting too many options can be confusing and frustrating. Use simple yes/no questions (“would you like to wear this?”) and avoid asking double-ended questions (“would you like to wear this or will this make you too warm today?”).
- Show respect. Don’t talk to the person as you would to a young child.
- Try to laugh together about the inevitable misunderstandings and mistakes – it can help.
- Try to include the person in conversations with others. Being included can reduce feelings of exclusion and isolation.
- If the person doesn’t understand what you are saying, try
 - breaking it down into smaller parts
 - using words or pictures or objects to help them understand you and express themselves.
- If the person says something you know to be incorrect, try not to contradict them directly or ‘correct’ them. Instead, try to see behind the content to the feelings or meaning that they are expressing.
- If the person has a difficulty finding a word for something, ask them to explain it in a different way. For example, if they can’t remember the word ‘watch’, they might offer ‘arm clock’.
- Pay close attention to their body language – they may be “speaking volumes” by their facial expression, by the way they are holding themselves or sitting, or by repetitive movement. In a way, all of their behaviour could be communicating something.
- If they are feeling low or sad, don’t try to “jolly them out of it” – often, the most respectful way to respond is just notice and acknowledge that they seem to be down, and to just be with them in their sadness, empathising rather than ‘fixing’.

LISTEN, TALK, CONNECT

Understand that this disease is, in many ways, like all others. Trying to reason with the symptoms (‘argue’ with the person) will not work.

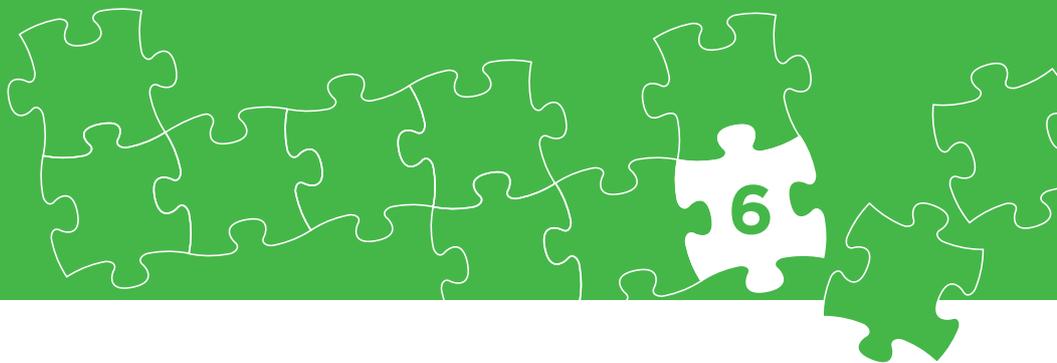
Don’t be afraid of silence. Just being with the person may bring great comfort (to them and to you).

Help the person to be happy in the time that they are living in. Follow them, go with their mood and don’t try too hard to change it. If they are describing their wedding day, ask them more about that special moment.

If you only see the person occasionally, try to avoid saying or “you remember me, don’t you?”. This is often our first reaction, based on our need for reassurance. Instead, make it easy for them by telling them your name and asking simple questions to understand where they are at that moment.

Adapted from Care UK





APPENDIX 1

Membership of the Project Advisory Group

Mary Manning	Nursing and Midwifery Planning and Development, ONMSD
Grainne McGettrick ¹ /Emer Begley	The Alzheimer Society of Ireland
Anne Quinn	5 Steps to Living Well with Dementia Project, South Tipperary, Genio
Caroline Clifford	Carlow/Kilkenny Psychiatry of Later Life Team, HSE
Jacinta Kelly	North West Hospice, Sligo
Jean Barber	St Michael's Hospital, Dublin
Carmel Hoey	Clinical Care Programme for Older People, HSE
Prof Willie Molloy	University College Cork and University Hospital Cork
Dr. Suzanne Timmons	University College Cork and University Hospital Cork
Cecelia Hayden	St.Vincent's Hospital, Athy, HSE
Aideen Lawlor	St. Mary's Hospital, Dublin, HSE
Lasarina Maguire	Stewarts Care, Palmerstown, Dublin 20
Carmel Collins	Irish Hospice Foundation
Deirdre Shanagher	Irish Hospice Foundation
Marie Lynch	Irish Hospice Foundation
Hilary Maher	Irish Hospice Foundation
Sarah Cronin	Irish Hospice Foundation

¹ Emer replaced Grainne in November 2014

Expert Advisory Group for this guidance document

Anne Quinn	5 Steps to Living Well with Dementia Project, South Tipperary, Genio
Jean Barber	St Michael's Hospital, Dublin
Dr. Suzanne Timmons	University College Cork
Cecelia Hayden	St.Vincent's Hospital, Athy, HSE
Lasarina Maguire	Stewarts Care, Palmerstown, Dublin 20
Carmel Collins	Irish Hospice Foundation
Deirdre Shanagher	Irish Hospice Foundation
Marie Lynch	Irish Hospice Foundation
Sarah Cronin	Irish Hospice Foundation

APPENDIX 2

METHODOLOGY

Development of the guidance document

This guidance document was developed using the following steps:

1. The IHF Project Advisory Group established an Expert Advisory Group to develop this guidance document (See appendix 1 for membership of the group).
2. A narrative literature review took place using English language articles selected through a systematic search strategy (see below). Consensus within the group was achieved through a process of reflection based on the experience of the group members in the field. The group identified core themes during this process.
3. Literature review completed based on themes identified in step 2 (see below for details).
4. Collation of key themes to inform the key considerations and the guidance by the Expert Advisory Group.
5. Draft 1 of the guidance document prepared for comment by Expert Advisory Group.¹
6. Draft 2 of the guidance document prepared for external consultation (see Appendix 3 for list of submissions received).
7. Feedback from external consultation to develop final draft. A consultation report was prepared and made available on request.
8. Final version published.

Literature Review: The literature review informing this document was based on three comprehensive literature searches of journal articles using two online databases. The review included articles published in the last 10 years within peer reviewed journals. They were filtered for relevance by the development team (Carmel Collins, Deirdre Shanagher, Niamh O'Donnell and Joanna Leneillon). A hand search of international and national policy and best practice guidelines which was ongoing throughout the process in order to inform and populate the resources.

¹ This group sought the views of Dr Margaret Clifford, Consultant in Palliative Medicine, St Joseph's Hospice, London. Her suggestions were incorporated into the final document.

Details on these reviews are as follows:

	Advance Care Planning and dementia	Palliative Care needs of people with ID	Communication and dementia
Databases used	PUBmed CINAHL	PUBmed CINAHL	PUBmed CINAHL
Search terms used	<p>PubMed (“Advance Care Planning”[Mesh]) AND (“Dementia”[Mesh] OR “Frontotemporal Dementia”[Mesh] OR “Dementia, Multi-Infarct”[Mesh] OR “Dementia, Vascular”[Mesh] OR “Alzheimer Disease”[Mesh] OR “Lewy Body Disease”[Mesh])) AND “Health Personnel”[Mesh]</p> <p>CINAHL: ((MH “Health Personnel+”)) AND ((MH “Dementia+” OR (MH “Dementia, Vascular+”) OR (MH “Dementia, Multi-Infarct”) OR (MH “Dementia, Senile+”) OR (MH “Alzheimer’s Disease”) OR (MH “Lewy Body Disease”)) AND (“Advance Care Planning”)</p>	<p>PubMed (“Palliative Care”[Mesh]) AND (“Intellectual disabilities”[Mesh] AND “Intellectual Disability”[Mesh] OR “End of Life Care.”</p> <p>CINAHL: Intellectual disability AND end-of-life Care</p> <p>Intellectual disability AND Palliative Care OR Intellectual disability AND terminal</p>	<p>PubMed (“Dementia “[Mesh]) AND (“Terminal Care “[Mesh] AND “Communication”[Mesh]</p> <p>CINAHL HEADINGS (“Dementia”) and (“Communication”) and (“Terminal Care” or “Palliative Care”)</p>
Number of articles generated	36 + 19 + 55=110	13 +12 +5=30	107 +67= 174
Number of relevant articles	12	30	91 +20 =111

Themes: All of the findings from the above literature reviews were analysed using a thematic framework by Carmel Collins (IHF) with oversight from the Expert Advisory Group. Further details on these literature reviews are available from the IHF on request from sarah.cronin@hospicefoundation.ie

The themes which emerged from the literature reviews in facilitating conversations when planning future and end-of-life care were as follows:

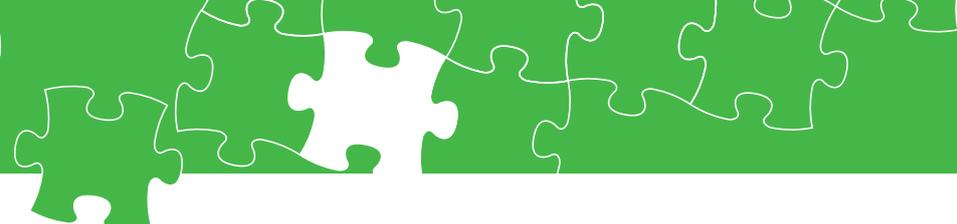
- Client centred care
- Communication techniques
- A tailored approach to communication
- All healthcare professionals should be involved in facilitating discussions
- Knowledge of dementia and end-of-life is crucial
- Staff barriers to engaging in discussion around end-of-life care.

Collation of Themes/Consensus Building: These key themes were presented to the Expert Advisory Group who, over a six month period, considered and reorientated the scope of the themes based on their clinical practice and experience. Finally, the document was circulated for feedback to the Project Advisory Group of workstream 2 and subsequently to specialists, frontline service providers and service users.

Handsearches of additional Information: In order to enrich and further inform the guidance document, further searches of; bibliographies of papers used, key Irish and international reports were undertaken, in addition to a hand search of national and international healthcare policies and best practice guidelines.

Limitations

Literature was examined for relevance. Strength of evidence was not explicitly graded due to the nature of the subject matter being discussed. Therefore, it was difficult to explicitly link recommendations or guidance to the supporting evidence at all times, as recommended in NCEC guidelines (89). Evidence on effectiveness and cost effectiveness was not explored due to time and resource constraints. In order to facilitate stakeholder involvement and participation in the development of the document, a consultation took place with external stakeholders. Thirty-five submissions were received from a range of organisation, allied health professionals, carers and a person with dementia. This process further enhanced and refined the content of the guidance document. Appendix 3 has a list of submissions received.

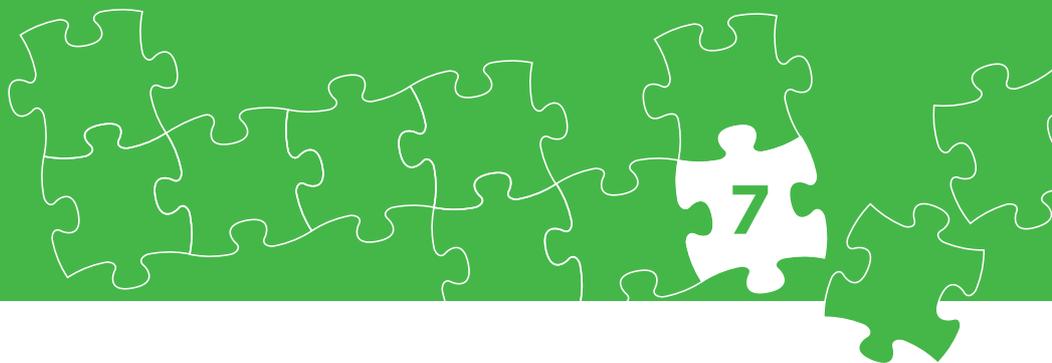


APPENDIX 3

LIST OF SUBMISSIONS RECEIVED

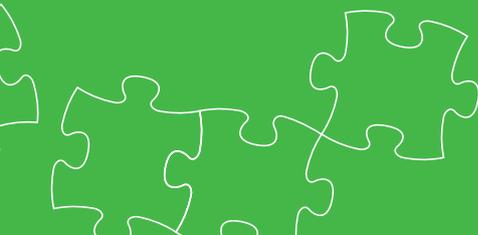
A total of 35 submissions were received. Personal submissions included submissions from allied health professionals, a person with dementia, family carers and two people working in academia. An international expert on Dementia, Professor Jan Oyebode, Professor of Dementia Care, University of Bradford was invited to and gave feedback as part of this consultation process. The organisations which gave feedback are listed in the table below.

Organisation
Ability West
Brothers of Charity Services, Galway.
Irish Association of Palliative Care
Irish Association of Social Workers
Irish Nurses and Midwives Organisation
Irish Society Of Chartered Physiotherapists
Kerry Parents and Friends Association
National Clinical Programme for Palliative Care, HSE
National Clinical Care Programme for Older Persons, HSE
Nursing Homes Ireland
Occupational therapy palliative care and oncology advisory group, Association of Occupational Therapists in Ireland
Office of Nursing & Midwifery Directorate (ONMSD) – five submissions recieved
Psychology Department, Brothers of Charity Service Roscommon
Speech and Language Therapy Department, Dublin North, HSE
St Brendan's Nursing Community Unit, Loughrea, Co. Galway
Sunbeam House Services, Bray, Co Wicklow
The Meath Community Unit
The Memory Clinic, The Daughters of Charity Disability Support Services, Dublin.



REFERENCES

1. Bayer A. Death with dementia—the need for better care. *Age Ageing*. 2006;35(2):101–2.
2. Dr Maria Pierce, Dr Suzanne Cahill, Prof Eamonn O’Shea. Prevalence and Projections of Dementia in Ireland 2011-2046 [Internet]. Genio; 2014 [cited 2015 May 25]. Available from: http://www.genio.ie/files/Dementia_Prevalence_2011_2046.pdf
3. Department of Health. The Irish National Dementia Strategy [Internet]. Department of Health; 2014. Available from: <http://www.memoryclinics.ie/images/uploads/file/national%20dementia%20strategy/National-Dementia-Strategy.pdf>
4. VanDerSteen JT, Hertogh CPM, De Boer M E, Hughes J, Larkin P, Francke AL, et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med*. 2013 Jul;0(0):1–13.
5. The Irish Hospice Foundation H. Palliative Care for All Integrating Palliative Care into Disease Management Frameworks [Internet]. Joint HSE and IHF Report; 2008. Available from: <http://hospicefoundation.ie/wp-content/uploads/2012/07/Palliative-Care-For-All-report.pdf>
6. Tilly J, Fok J. Policy Barriers to Quality End of Life Care for Residents With Dementia in Assisted Living Residences and Nursing Homes. *Alzheimers Care*. 2008;9(2):103–12.
7. Hospice UK. Hospice enable dementia care—the first steps [Internet]. Hospice UK; 2015. Available from: <http://www.hospiceuk.org/what-we-offer/care-support-programmes/hospice-enabled-dementia-care>
8. The Irish Hospice Foundation, Alzheimer Society of Ireland. Building Consensus for the Future: Report of the Feasibility Study on Palliative Care for People with Dementia [Internet]. The Irish Hospice Foundation & The Alzheimer Society of Ireland; 2012. Available from: <http://hospicefoundation.ie/wp-content/uploads/2012/04/Building-consensus-for-the-future-report-of-the-feasibility-study-on-palliative-care-for-people-with-dementia.pdf>
9. O’Shea E, Murphy K, Larkin P, Payne S, Froggatt K, Casey D, et al. End-of-life care for older people in acute and long-stay care settings in Ireland [Internet]. Ireland: National Council on Ageing and Older People (NCAOP) and the Irish Hospice Foundation (IHF); 2008. Report No.: ISBN 1 900378 54 X. Available from: http://www.ncaop.ie/publications/research/reports/103_EOL_Care_Report.pdf
10. Cahill S, O’Shea E, Pierce M. Creating Excellence in Dementia Care: a Research Review for Ireland’s National Dementia Strategy. [Internet]. 2012 [cited 2015 Dec 2]. Available from: <http://www.lenus.ie/hse/bitstream/10147/306721/1/CreatingExcellenceinDementiaCare2012.pdf>
11. Cahill S, O’Shea E, Pierce M. Future Dementia Care in Ireland: Sharing the Evidence to Mobilise Action. [Internet]. Ireland; 2012. Available from: http://lenus.ie/hse/bitstream/10147/234551/1/future_dementia_care.pdf
12. McConville U, et al. Opening Conversations: Developing a model for The Alzheimer Society of Ireland of best-practice palliative care interventions for people with dementia and their carers. Dublin: Alzheimers Society of Ireland; 2011.
13. Kane M. My life until the end: Dying well with Dementia [Internet]. Alzheimers Society UK; 2012 Oct. Available from: http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1537
14. Sampson, E G V, Lee, D B M. Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age Aging*. 2006 Mar;35(2):187–9.
15. Clayton J, Hancock K, Buttow P, Tattersall M, Currow C. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. *Med J Aust* [Internet]. 2007;186(12). Available from: https://www.mja.com.au/journal/2007/186/12/clinical-practice-guidelines-communicating-prognosis-and-end-life-issues-adults#0_elementId-1106382
16. St Vincents Hospital, Athy, Co. Kildare, St Brigid’s Hospice, The Curragh, Co. Kildare. Planning for the Future Project. Initiating “End of Life” Discussions



- for People with Dementia [Internet]. Dublin; 2013 [cited 2015 May 28] p. 25. Available from: <http://hospicefoundation.ie/wp-content/uploads/2014/03/Final-Report.pdf>
17. Regan A, Tapley M, Davis J. Improving end of life care for people with dementia. *Nurs Stand.* 2014;28(48):37–43.
 18. Downs M, Bowers B. *Excellence in Dementia Care, Research into Practice.* 1st ed. Open University Press; 2008.
 19. Steinberg L, Howes J, Danieli E. Dementia and palliative care toolkit for the primary care practitioners. [Internet]. Mount Sinai Hospital, Toronto, Canada; 2013. Available from: <http://sprintseniorcare.org/sites/default/files/documents/PALLIATIVE%20CARE%20TOOLKIT%20%202013.pdf>
 20. Sprinks J. Nurses lack confidence in providing end of life care. *Nurs Older People.* 2011;23(2):6–7.
 21. Dempsey D. Advance care planning for people with dementia: benefits and challenges. *Int J Palliat Nurs.* 2013;19(5):227–34.
 22. Hertogh C. Advance care planning and the relevance of a palliative care approach in dementia. *Age Aging.* 2006;35(6):553–5.
 23. Johnson A, Chang E, Daly J, Harrison K, Noel M, Easterborck S. The communication challenges faced in adopting a palliative care approach in advanced dementia. *Int J Nurs Pract.* 2009;15:467–74.
 24. Clayton J., Butow P, Waters A, Laidsaar-Powell R, O'Brien A, Boyle F, et al. Evaluation of a novel individualised communication-skills training intervention to improve doctors' confidence and skills in end-of-life communication. *Palliat Med.* 2013;27(3):236–43.
 25. Roberts D, Gaspard G. A palliative approach to care of residents with dementia. *Nurs Older People.* 2013;25(2):32–6.
 26. The National Council for Palliative Care. Starting end of life care conversations with people affected by dementia. [Internet]. *Dying Matters*; 2012. Available from: http://dyingmatters.org/sites/default/files/user/Leaflet%2011_WEB.pdf
 27. Lokker M, Van Zuylen L, Veerbeek L, Van der Rijt C, Van der Heide A. Awareness of dying: it needs words. *Support Care Cancer* 2012 20. 2012;1227–33.
 28. Long C. Palliative Care for Advanced Dementia: Approaches that Work. *J Gerontol Nurs.* 2012;35(11):19–24.
 29. Thune-Boyle I, Sampson E, Jones L, King M, Lee D, Blanchard M. Challenges to improving end of life care of people with advanced dementia in the UK. *Int J Soc Res Pract.* 2010;9(2):259–84.
 30. Watson M. Addressing the Palliative Care Needs of People with Dementia. Addressing the Palliative Care Needs of People with Dementia [Internet]. Dundalk; 2014. Available from: <http://hospicefoundation.ie/wp-content/uploads/2014/12/2-Max-Watson.pdf>
 31. The Irish Hospice Foundation. The End-of-Life Care Toolkit for staff working in Residential Care Centres for Older People. The Irish Hospice Foundation; 2015.
 32. Dale G, Larson P, Daniels R, Tobin M. End-of-Life Conversations Evolving Practice and Theory. *J Am Med Assoc.* 2000;284(12):1573–8.
 33. Blancaflor S. Communication and end of life decision making: A resource guide for physicians. Connecticut Coalition to Improve End of Life Care; 2010.
 34. McDonnell M, McGuigan E, McElhinney J, McTeggart M, McClure D. An analysis of the palliative care education needs of RGNs and HCAs in nursing homes in Ireland. *Int J Palliat Care.* 2009;15(9):448–55.
 35. Livingston G, Pitfield C, Morris J, Jacobs H, Manela M, Lewis-Holmes E. Care at the end of life for people with dementia living in a care home: a qualitative study of staff experience and attitudes. *Int J Geriatr Psychiatry.* 2011;643–50.
 36. De Vleminck A, Pardon K, Beernaert K, Deschepper R, Houttekier D, Van Audenhove C, et al. Barriers to advance care planning in cancer, heart failure and dementia patients: a focus group study on general practitioners' views and experiences. *Plos* [Internet]. 2014;9(1). Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24465450>
 37. Government of Ireland. Assisted Decision-Making (Capacity) Bill [Internet]. 2013. Available from: <http://www.oireachtas.ie/documents/bills/28/bills/2013/8313/b8313d.Pdf>
 38. Regan A et al. Improving end of life care for people with dementia. *Nurs Stand.* 2014 Jan;28(48):37–43.

39. National Health Service. National End of Life Care Programme. Talking about end of life care: right conversations , right people, right time [Internet]. National Health Service. National End of Life Care Programme; 2001. Available from: <http://webarchive.nationalarchives.gov.uk/20110218140707/http://endoflifecareforadults.nhs.uk/assets/downloads/TalkingAboutEndOfLifeCare20110124.pdf>
40. Ellis M, Zeedyk S. Rethinking Communication : The connected baby guide to advanced dementia [Internet]. First edition. Dundee: Suzanne Zeedyk Ltd Publishing; 2014. 64 p. Available from: <http://www.connectedbaby.net/product/rethinking-communication-book/>
41. National Health Service. The route to success in end of life care - achieving quality in care homes [Internet]. 2010. Available from: <http://www.nhs.uk/resources/search/publications/eolc-rtscare-homes.aspx>
42. Kumar C, Kuriakose J. End-of-life care issues in advanced dementia. *Ment Health Fam Med*. 2013;10(3):129–32.
43. Mitchell S., Teno J., Kiely D., Schafer M., Jones R, Prigerson H, et al. The Clinical Course of Advanced Dementia. *N Engl J Med*. 2009;361:1529–38.
44. Sutton L, et al. Out of the Shadows: End of Life Care for People with Dementia. National Council for Palliative Care; 2009.
45. Cahill, Suzanne, Diaz-Ponce, A. "I hate having nobody here, I'd like to know where they all are": Can qualitative research detect differences in Quality of Life among Nursing Home Residents with different levels of Cognitive Impairment? *Ageing Ment Health*. 2011;15(5):562–72.
46. National Consent Policy [Internet]. HSE; 2013. Available from: http://www.hse.ie/eng/about/Who/qualityandpatientsafety/National_Consent_Policy/
47. Clayton JM, Butow P, Tattersall MB. When and How to Initiate Discussion About Prognosis and End-of-Life Issues with Terminally Ill Patients. *J Pain Symptom Manage*. 2005 Aug;30(2):132–44.
48. Department of Health UK. Capacity, care planning and advance care planning in life limiting illness: A Guide for Health and Social Care Staff [Internet]. NHS Improving Quality; 2014. Available from: http://www.ncpc.org.uk/sites/default/files/ACP_Booklet_June_2011.pdf
49. National Health Service, UK. Capacity, care planning and advance care planning in life limiting illness [Internet]. United Kingdom; 2011 [cited 2015 Dec 2]. Available from: http://www.ncpc.org.uk/sites/default/files/ACP_Booklet_June_2011.pdf
50. Murphy J, Oliver T. The use of Talking Mats to support people with dementia and their carers to make decisions together. *Health Soc Care Community*. 2013;21(2):171–80.
51. Lámh - Communication Augmentation Sign System Ltd. Using Lámh [Internet]. Online; Available from: <http://www.lamh.org/communication/using-lamh>
52. Commission for Social Care Inspection. See me, not the dementia: Understanding people's experiences of living in a care home. Newcastle - Upon -Tyne: Commission for Social Care Inspection; 2008.
53. Ryan E, Bannister K, Ann P. The dementia narrative: writing to reclaim social identity. *J Aging Stud*. 2009;23(3):145–57.
54. Brush J, Sandford J, Fleder H, Bruce M, Calkins M. Evaluating and modifying the communication environment for people with dementia. *Perspect Gerontology*. 16(2):32–40.
55. Stirling University. 10 helpful hints for dementia design at home [Internet]. Stirling: Stirling University Dementia Services Development Centre; 2010. Available from: <http://www.dementiashop.co.uk/products/10-helpful-hints-dementia-design-home>
56. Torrington J. Lighting for people with dementia. 2007;39(1):81–97.
57. Barnes C, Surr C. Communicating [Internet]. The Alzheimer's Society; 2012 [cited 2015 Dec 2]. Available from: file:///C:/Users/IHF/Downloads/Communicating_factsheet.pdf
58. Harwood, J. Communicating with Patients who have Dementia [Internet]. Elder Care A Resource for Interprofessional Providers Arizona Center on Aging; 2013. Available from: http://aging.arizona.edu/sites/default/files/dementia_patients_-_communication.pdf
59. Veselinova C. Influencing communication and interaction in dementia. *Nursing & Residential Care. Nurs Resid Care* [Internet]. 2014;16(3). Available from: <http://www.magonlinelibrary.com/doi/abs/10.12968/nrec.2014.16.3.162>
60. Jootun D, McGhee G. Effective communication with people who have dementia. *Nurs Stand*. 2011;25(25):40–7.
61. De Vries K. Communicating with older people with dementia. *Nurs Older People*. 2013;25(4):30–7.

62. Hoe J, Thompson R. Promoting positive approaches to dementia care in nursing. *Nurs Stand*. 2010;25(4):47–56.
63. Afzal N, Buhagiar K, Flood J, Cosgrave M. Quality of end-of-life care for dementia patients during acute hospital admission: a retrospective study in Ireland. *Gen Hosp Psychiatry*. 2010;32(2):141–6.
64. Young T. Devising a dementia toolkit for effective communication. *Nurs Resid Care*. 2012;14(3):149–51.
65. HSE. The National Dementia Training Programme [Internet]. HSE Dementia. Available from: <http://www.hse.ie/eng/about/Who/ONMSD/educating/dementiaeducation/projectssummary.html>
66. Social Care Institute for Excellence. Dementia Gateway - Positive Communication [Internet]. SCIE dementia Gateway. Available from: <http://www.scie.org.uk/publications/elearning/dementia/>
67. The Alzheimer Society of Ireland. Communication: Understanding Changes in Behaviour [Internet]. The Alzheimer Society of Ireland; 2015. Available from: http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/Info%20Pack%20PDF%27s/Communication_Section-B2_website.pdf
68. The Alzheimer Society of Ireland. Understanding and Respecting the Person with Dementia [Internet]. The Alzheimer Society of Ireland; Available from: <http://www.alzheimer.ie/Alzheimer/media/SiteMedia/Helpline%20and%20Information%20Resources/Info%20Pack%20PDF%27s/C1-Alzheimers-Inserts.pdf>
69. Stirling C, Andrews S, McInerney F, Toye C, Ashby M, Robinson A. Talking about dementia and dying: a discussion tool for aged care residential facility staff [Internet]. Hobart: Print Press; 2011 [cited 2015 Dec 2]. Available from: <http://www.caresearch.com.au/caresearch/portals/0/documents/whatispalliativecare/nationalprogram/localPCgrants/Utas-Dementia-and-Dying-Book.pdf>
70. Palliative Care Competence Framework Steering Group. Palliative Care Competence Framework. [Internet]. Dublin: Health Service Executive; 2014. Available from: <http://lenus.ie/hse/bitstream/10147/322310/1/CompetenceFrameworkFinalVersion.pdf>
71. Health Service Executive. Role Delineation Framework [Internet]. Health Service Executive; [cited 2015 Feb 20]. Available from: <http://www.hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme/Resources/role%20delineationframework.html>
72. Henry C, Seymour J. Advance care planning: a guide for health and social care staff. [Internet]. NHS - Department of Health; 2008. Available from: <http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf>
73. Thomas K, Lobo B. Advance Care Planning in End of Life Care. Oxford: Oxford University Press; 2011.
74. Vaughan P. The Importance of Reflection with Improving Care and Improving Standards and the 6Cs [Internet]. Royal College of Nursing West Midlands; [cited 2015 Feb 20]. Available from: http://www.rcn.org.uk/__data/assets/pdf_file/0007/586654/ReflectivePractice.pdf
75. DML Services for Older Persons, Nursing and Midwifery Planning and Development. The DML Integrated Minimum Dataset Resident Assessment Instruments (RAIs), Resident Assessment Protocols (RAPs) and Personal Care Planning [Internet]. HSE; 2010. Available from: <http://www.hse.ie/eng/services/publications/olderpeople/dmlmlds.pdf>
76. National Clinical Programme for Palliative Care, Clinical Strategy and Programmes Directorate. National Rapid Discharge Guidance for Patients who wish to die at home [Internet]. HSE; 2015 [cited 2015 May 28]. Available from: <http://hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme/Resources/Rapid.pdf>
77. National Clinical Programme for Palliative Care, Clinical Strategy and Programmes Division. Palliative Care Needs Assessment Guidance [Internet]. HSE; 2014 [cited 2015 May 28]. Available from: <http://www.hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme/Resources/pall%20care%20needs%20assessment%20guidance.pdf>
78. Quality & Patient Safety Directorate. A Practical Guide To Clinical Audit [Internet]. Health Service Executive (HSE); [cited 2015 Feb 20]. Available from: http://www.hse.ie/eng/about/Who/qualityandpatientsafety/Clinical_Audit/auditfilespdfs/practicalguideaudit2013.pdf
79. Irish Hospice Foundation. What Matters To Me [Internet]. Irish Hospice Foundation; [cited 2015 Feb 20]. Available from: <http://hospicefoundation.ie/education-training/staffdevelopment/what-matters-to-me/>
80. Irish Hospice Foundation. Prompts for Good Practice Just in Time Guidance [Internet]. Irish Hospice Foundation; [cited 2015 Feb 20]. Available from: <http://hospicefoundation.ie/education-training/staffdevelopment/prompts-for-good-practice/>

81. Derksen, E V-D M, Scheltens, P O-R M. A model for disclosure of the diagnosis of dementia. *Dementia*. 5(3):462–8.
82. Kaplan M. SPIKES: a framework for breaking bad news to patients with cancer. *Clin J Oncol Nurs*. 2014;14(4):514–6.
83. Irish Hospice Foundation. Hospice Friendly Hospital Programme. How do I break bad news? [Internet]. The Irish Hospice Foundation; 2013 [cited 2015 Dec 2]. Available from: <http://hospicefoundation.ie/wp-content/uploads/2013/04/How-Do-I-Break-Bad-News.pdf>
84. Shin J, Casarett D. Facilitating hospice discussions: a six-step roadmap. *J Support Oncol*. 2011;9(3):97–102.
85. Shannon S., Long-Sutehall T, Coombs M. Conversations in end-of-life care: communication tools for critical care practitioners. *Nurs Crit Care*. 2011;16(3):124–30.
86. Alzheimer Association - Greater Illinois Chapter. Encouraging Comfort Care A Guide for Families of People with Dementia Living in Care Facilities [Internet]. Alzheimer Association - Greater Illinois Chapter; 2010 [cited 2015 Dec 2]. Available from: http://www.alzheimers-illinois.org/pti/downloads/Encouraging%20Comfort%20Care_SINGLE.pdf
87. All Ireland Institute of Hospice and Palliative Care. The Palliative Hub [Internet]. AIHPC; [cited 2015 Feb 20]. Available from: <http://learningplatform.thepalliativehub.com/course/index.php?categoryid=11>
88. Australian Institute of Health and Welfare (AIHW). Dementia in Australia: National data analysis and development [Internet]. AIHW; [cited 2015 Feb 24]. Available from: <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442454183>
89. National Clinical Effectiveness Committee. National Clinical Effectiveness Committee Guideline Developers Manual [Internet]. Patient Safety First; 2013. Available from: http://health.gov.ie/wp-content/uploads/2014/03/ncec_guideline_development_manual_january13.pdf

The Irish Hospice Foundation

Morrison Chambers
32 Nassau Street, Dublin 2, Ireland

Telephone: + 353 (0) 1 679 3188

Fax: +353 (0) 1 673 0040

Email: info@hospicefoundation.ie

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