

Advance Care Planning for Health and Social Care Professionals



This document provides useful tips to health and social care professionals about Advance Care Planning. It will support you to have meaningful conversations with those you care for and understand better what matters most to them.

An advance care planning discussion with a person includes:

- The person and/or family's understanding of their illness/medical condition
- The person and/or family's concerns or worries about any aspect of end of life
- The person's values, beliefs, wishes, preferences and/or personal goals for care
- The person's preferences for types of care/treatment that might be beneficial in the future

Person-centred care means taking the time to find out what the person wants to know. It also means finding out what their wishes and preferences are regarding their end-of-life care

Advance Care Planning should ideally happen before the person is admitted to hospital or a nursing home. However all too often, they do not.

Hospital and nursing home staff have an important role especially as Advance Care Planning is a key part of person-centred care.

Advance Care Planning discussions are probably even more important in the following circumstances

- When it is clear the person has a life-limiting illness
- When the person indicates wanting a conversation: “I’m not getting any better, am I?”
- When you can answer ‘yes’ to the following question - “Would you be surprised if this person was alive in 12 months’ time?”
- If the person/family have expectations which are inconsistent with clinical judgment. For example, the person thinks that they will be able to live independently again
- When there has been a deterioration in the person’s condition
- When a treatment decision needs to be made
- If illness-specific treatment is not working
- At the time of referring the person to Specialist Palliative Care Services

The following are examples of conversations and prompts. It is important to highlight that these conversations may also occur naturally in the day-to-day provision of care. It’s important to be prepared for both scenarios.





Having a conversation

Start the conversation by finding out the level of understanding of the person's illness and prognosis. This helps to establish a common ground.

If the person doesn't seem to know their prognosis or illness, it may be worth asking them:

“What is your understanding of where you are with your health?”

You can always give the person the option not to discuss these topics or to defer the discussion to another time by saying:

“I am very happy to talk to you about any concerns or questions you have about this now or later. Is there anything you would like to ask me about now?”

Don't make assumptions about the person's information needs. Clarify what they want to know and the level of detail they'd like before giving new information:

“Often people with conditions like yours have a lot of questions that are sometimes frightening. Sometimes people aren't certain if they want to know the answer. If there's anything you'd like to know, feel free to ask me and I'll answer as best I can.”

Explore the person's concerns, expectations and fears about the future:

“What is your biggest concern at the moment?”
“What are your worries for the future?”

Encourage the person to ask questions and express their wishes:

“Is there anything else you'd like to discuss?”
“Have you ever thought about where you would like to be cared for in the future?”
“What are your hopes and priorities?”
“What are you willing to sacrifice or not sacrifice?”
“What does a good day look like?”

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Offer to support family or friends (if the person consents):

“Would you like me to tell (name) what we’ve discussed?”

Consider joint as well as separate discussions with the person and their family, once the person has consented. This can help to explore and address different information needs. People can often feel abandoned.

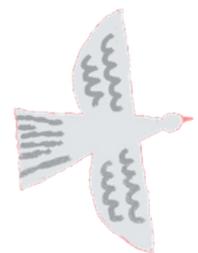
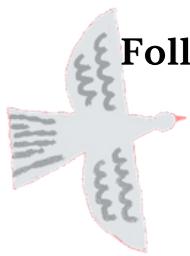
It is important to reassure them that you/someone will be there for them throughout their illness. If this is not possible, it is vital that alternative arrangements are made clear:

“We will do what we can to manage your symptoms and link you in with the services that will support you and your family. You will not be alone in this.”

It is important to enable the person to feel in control. Help them to identify where control can be fostered, for example, speaking with family/friends:

“People vary in how they want to make decisions. Some people want to do this alone; others want to share decision making with their family or doctor. What would you like?”

Following a conversation make sure you write down what has been discussed and record on that person's file.



Questions in the text adapted from Atul Gawande. (2014). *Being Mortal: Medicine and What Matters in the End*.

More information and resources about advance care planning, to include the Think Ahead form, FAQs on Advance Planning and legislation as well as guidance documents are available on the Irish Hospice Foundation website: www.hospicefoundation.ie or contact: Deirdre.Shanagher@hospicefoundation.ie



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