



PATIENT SAFETY TOOL BOX TALKS®

EFFECTIVE CARE & SUPPORT

END OF LIFE CARE ADVANCE CARE DISCUSSIONS



v1.0

This tool box talk is based on the National Consent Policy (HSE, 2013) and on the Irish Hospice Foundation's End of Life Care Map: <http://hospicefoundation.ie/what-we-do/hospice-friendly-hospitals/resources-publications/>

LEGAL PERSPECTIVE ON ADVANCE CARE PLANS

THE FREEDOM TO DECIDE ONE'S OWN DESTINY IS THE RIGHT OF EVERY COMPETENT PERSON. THIS INCLUDES THE RIGHT TO ACCEPT OR REFUSE MEDICAL TREATMENTS.

BUT IF WE BECOME CRITICALLY ILL, WE MAY NOT BE ABLE TO MAKE THESE DECISIONS. MANY PEOPLE ARE TAKING THE OPPORTUNITY TO PREPARE ADVANCE CARE DIRECTIVES.

ALTHOUGH THESE DIRECTIVES ARE NOT YET UNDERPINNED BY IRISH LEGISLATION, THE LAW REFORM COMMISSION HAS RECOMMENDED THAT ACPs SHOULD BE FOLLOWED "... IF THE TREATMENT IS SPECIFIED, ALL CIRCUMSTANCES OUTLINED ARE PRESENT AND THERE IS NO EVIDENCE THAT AUTHOR HAS CHANGED HIS/HER MIND."

30% of Irish adults claim that they are comfortable discussing death.
67% believe that it is important to record their preferences for end-of-life care.
70% acknowledge the importance of discussing end-of-life care with those close to them.

...Yet, less than 1-in-10 have actually written down or recorded their preferences for care, treatment or their funeral wishes.

Source: Nationally Representative

We all have an idea of how we want our end of life care to be

ADVANCE CARE PLANNING AND DISCUSSION

An advance care planning discussion with a person includes:

- The persons and/or family's concerns or worries about any aspect of end-of-life
- their values and personal goals for care at this time
- their understanding about their illness and prognosis
- Their preferences for types of care/treatment that may be beneficial in the future. True person-centered care means taking the time to find out what the person (patient) wants to know and what are their preferences are regarding their end of life care.

These discussions should, ideally, be happening even before the person is admitted to hospital but, all too often, they are not. So, hospital and nursing home staff often have an important role to play too, especially as broaching the subject may fall to them and it can be a really important part of person-centered care. The discussion is probably even more important in the following circumstances:

- ◆ When it is clear the patient has a life-limiting advanced progressive illness
- ◆ When you can answer 'yes' to the following question - **"would you be at all surprised if this patient was alive in 12 months' time?"**
- ◆ If the patient/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 is a significant deterioration in the patient's condition
- ◆ When a treatment decision needs to be made
- ◆ If disease-specific treatment is not working
- ◆ At the time of referring the patient to specialist palliative care services.

ASK ME WHAT I 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?

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.

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

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

Respecting patient's preferences and choices

Discussing our end-of-life wishes and preferences in good time

DNAR (Do Not Attempt Cardiopulmonary Resuscitation)

A DNAR decision is often a significant aspect of advance care, where a person may decide that they do not want resuscitation attempted in the event of, for example, sudden cardiac arrest. This can be a difficult area and there is evidence of inconsistency in approach to DNAR decisions.

Please see the Toolbox Talk leaflet (No. 3) on communicating with patients and families about CPR and DNAR decisions, or the very comprehensive guidance contained in Part 4 of the HSE's National Consent Policy (May 2013).

RECOMMENDED PRACTICE & SAMPLE PHRASES

The following are some prompts to help you to have conversations with people to help to clarify and capture what they would like for themselves in terms of their future care. (See also the separate **Toolbox** page on DEALING WITH BAD NEWS for more communication guidance.)

- Start the conversation by finding out from the patient what their level of understanding is of their current condition and prognosis – this helps to establish a common ground. If the patient doesn't seem to know, it may be worth summarising for him/her what has happened in the patient's illness to date and then beginning to talk about the current situation.
- Always give the patient the option **not** to discuss these topics or to defer the discussion to another time. **Sample Phrase:** *"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?"*
- Do not make assumptions about the information needs of the patient or of his/her family. Clarify what the patient wants to know and the level of detail they'd like before giving new information. **Sample Phrase:** *"Often people with conditions like yours have a lot of questions that are sometimes frightening or sometimes they're not certain if they want to know the answer. So if there's anything you'd like to know, feel free to ask me and I'll answer as best I can."*
- Explore the patient's concerns, expectations and fears about the future. **Sample Phrase:** *"What is your biggest concern at the moment?"*
- Encourage the patient to ask questions and express their wishes. **Sample Phrases:** *"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?"*
- Offer to support the family (as long as the patient has given consent). **Sample Phrase:** *"Would you like me to tell... what we've discussed?"*
- Consider joint as well as separate discussions with the patient and family (once the patient has given consent) so as to explore and address different people's information needs.
- Once a terminal diagnosis is made, patients can often feel abandoned. It is important to reassure the patient that you/the team will be there for them throughout their illness. If this is not possible, it is vital that alternative arrangements are spelled out and are reliable. **Sample Phrases:** *"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."*
- Emphasize the available support, such as the palliative care team. **Sample Phrase:** *"We have different ways to relieve (pain/nausea/ breathlessness) and other symptoms."*
- It is important to enable the patient to feel control over their illness. Help the patient to identify where control can be fostered, e.g. tidying up unfinished business, arranging to attend a particular event. Encourage patients to share in decision making according to their desired level of involvement. **Sample Phrase:** *"People vary in how they want to make medical decisions. Some people want to make decisions themselves, some want to share decision making with the doctor. What would you like?"*



Speak for Yourself

More help on this topic is available from the Irish Hospice Foundation's Think Ahead website which includes a Conversation Starter kit to help people to think and talk more easily with family and with carers about their end of life care wishes.

See web page <http://www.thinkahead.ie/wp-content/uploads/2013/01/TA-Starter-Kit-edits-3-OM-16.1.13.pdf>