

PREPARED MODEL – A GUIDE FOR CLINICIANS

FOR CONVERSATIONS ABOUT THE LAST DAYS OF LIFE

<p>P Prepare for the discussion</p>	<ul style="list-style-type: none"> • Confirm the clinical situation and appropriate treatment options • Try to ensure privacy and uninterrupted time. Mentally prepare yourself • Gauge patient and family readiness to discuss/develop a plan • Negotiate who should be present.
<p>R Relate to the person</p>	<ul style="list-style-type: none"> • Introduce yourself and explain your role • Develop rapport and show empathy, care and compassion • Consider cultural and contextual factors which may influence preferences • Use appropriate body language and actively listen.
<p>E Explore priorities and concerns</p>	<ul style="list-style-type: none"> • Clarify patient/caregiver's understanding of their situation and how much detail they want to know, before giving information • Explore the patient's priorities for care given their situation • Explore the family's priorities and concerns as well as their need for support • Summarize the patient's and family's most important priorities and concerns, and check if you have it right.
<p>↕ P Provide information</p>	<ul style="list-style-type: none"> • Ask permission to discuss what to expect • Pace and tailor delivery of information about the clinical situation and prognosis to the patient's/families' current understanding and wish for information • Explain uncertainty, limitations and unreliability of prognostic information • Offer recommendations for the patient's medical care for the last days of life that are clinically appropriate and, wherever feasible, align with the patient's priorities.
<p>↕ A Acknowledge emotions and concerns</p>	<ul style="list-style-type: none"> • Explore and acknowledge the patient's and caregiver's fears and concerns about dying • Respond to the patient's and caregiver's emotion and distress throughout the conversation • Acknowledge your own emotions – caring for the dying is an emotional time for all including the staff caring for the person. Remember to take time to reflect on the experience and care for yourself and your team.
<p>R Foster Realistic hope</p>	<ul style="list-style-type: none"> • Be honest without being blunt and do not give misleading or false information • Reassure that all support and care will be given to control pain and other symptoms, and ensure the person is as comfortable as possible • Explore and facilitate any last realistic goals or wishes and ways of coping.
<p>E Encourage questions</p>	<ul style="list-style-type: none"> • Be prepared to repeat explanations • Check understanding and if information provided meets needs • Leave the door open for topics to be discussed again in the future • Consider providing the CEC "Asking questions can help" leaflet • If you don't know the answers to questions, acknowledge the importance of the question and facilitate further information from appropriate sources or acknowledge uncertainty (e.g. how long).
<p>D Document</p>	<ul style="list-style-type: none"> • Write a summary of what has been discussed in the medical record • Speak or write to other key health care providers involved in the patient's care e.g. Notify the GP when the patient dies. <p>↕ *The arrows indicate that these steps (E/P/A) are not linear. You will need to respond appropriately to emotions and concerns throughout the conversation.</p>

PREPARED MODEL

FOR CONVERSATIONS ABOUT DYING – USEFUL PHRASES, QUESTIONS AND IDEAS FOR CLINICIANS

Prepare for the discussion

- “Is there anyone else you would like to be here with you while we talk?”

Relate to the person

- Remember we need to honour the dying person. This is a sacred time for them and their family. Small acts of kindness and respect for the person and their family can have a profound impact
- Spend much more time listening than talking
- “If I’ve heard you right, you seem to be saying…”

Exploring understanding, information needs, concerns and priorities

- Use open ended questions to explore (where feasible) the patient’s concerns and priorities about how they are cared for and then explore the family’s concerns and priorities for the patient’s care, and their needs for support
- “What have you been told about what is happening and what to expect?”
- “How much detail would you like from me about what is happening and what to expect?”
- “What is most important to you now about how we look after you?”
- “If [person’s name] were able to talk to us, what do you think [he/she] would want us to know?”
- “Do you (or person’s name) have any spiritual beliefs or cultural practices that we need to know about when thinking about the best care for you (or him/her)?”
- “Is there anything you really don’t want to happen in terms of your care?”
- “Is there anything else we should know about your (or your relative/friend’s) values and priorities in order to take the best care of you (or your relative/friend)?”
- “How can we best support the family?”
- “Are there any special rituals that you would like to arrange after (person’s name) dies?”

Providing information

- Give a warning when breaking the initial bad news. e.g. I’m afraid I have something serious to discuss
- As a guide give no more than 3 facts at a time, then stop talking and allow the person space to respond; avoid jargon
- “Is it OK if we discuss a plan for how best to care for you now and in the future?”
- “We can see from your Dad’s condition (not responding, swallowing, not eating and drinking etc.) that he is starting to die”
- “I’m concerned that (x) may not have very long to live and, while we don’t know exactly how long he/she may have to live, we do know that time is likely to be short”
- “We recommend continuing good care and stopping (or not attempting) treatments that would be ineffective and distressing”
- “When the time comes I recommend allowing you to die naturally and doing everything we can to ensure you’re as comfortable as possible. I recommend not attempting treatments, like CPR, that could cause distress and would not work in your situation”

Acknowledging emotions and concerns

- Sometimes silence can be helpful, consider touch when culturally appropriate
- “What are your biggest concerns at this point?”
- “Can you bear to tell me what’s going through your mind after what we’ve just discussed?”
- “You mentioned you were concerned about …. Can you tell me more about that?”
- “It sounds like this information is different from what you expected. I think this would be very upsetting for anyone”
- “It can be very hard to think about dying. What worries you the most about what we’ve discussed?”

Fostering realistic hope

- If there is uncertainty about whether or not the patient will die soon: “We can prepare in case he/she gets much sicker while still hoping for the best”
- “What are the things you would like to do while you are still well enough?”
- “We will do everything we can to ensure that you are as comfortable as possible”
- “No matter what happens our team will be here to support you”

Encouraging questions

- “Do you have any questions or other concerns? Have I given you the information you need so far?”
- “Don’t hesitate to ask me or the doctors/nurses again about any of the things we have discussed today”
- “If you think of anything else you want to ask me please write it down”