

## How to discuss prognosis and end-of-life issues

Recommendation	Useful phrases (where applicable)
<ul style="list-style-type: none"> <li>• Use good generic communications skills and establish rapport with the patient and family.</li> <li>• Make eye contact (if culturally appropriate), sit close to the patient, use appropriate body language, allow silence and time for the patient to express feelings.</li> </ul>	
<ul style="list-style-type: none"> <li>• Engage in active listening (eg, attend to the patient fully, reflect what you think he or she has said).</li> </ul>	<p><i>“If I’ve heard you right, you seem to be saying . . .”</i></p>
<ul style="list-style-type: none"> <li>• Show interest in the patient as an individual and as a whole person, as well as the family.</li> </ul>	
<ul style="list-style-type: none"> <li>• Show compassion and use a warm, caring, respectful and empathic manner.</li> </ul>	<p><i>“This has been a tough time for you and your family, and you have faced the challenges of this illness with great courage.”</i></p>
<ul style="list-style-type: none"> <li>• Be willing to initiate and engage in conversations about what may happen in the future and dying.</li> <li>• Ensure the patient and caregiver are aware that they can openly discuss these topics with you or someone else in the health care team if they wish.</li> <li>• Broach the topic in a culturally appropriate and sensitive manner.</li> <li>• Always give the patient and caregiver the option not to discuss these topics or to defer the discussion to another time.</li> <li>• If the patient does not currently wish to discuss these topics, raise them again when the person’s condition or situation changes (See also ‘Timing of discussions’ recommendations).</li> </ul>	<p><i>“Do you have any questions or other concerns?”</i>  <i>“Some people are worried about things that may or may not happen in the future. It can help to talk about this.”</i>  <i>“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 today about this?”</i>  <i>“Often people with conditions like yours have got a lot of questions that are sometimes scary, or sometimes they’re not certain if they want to know the answer. Often the thing they fear or believe is worse than how it really is. So if there’s anything you want to know, feel free to ask me and I’ll answer as best as I can.”</i></p>
<ul style="list-style-type: none"> <li>• Before giving new information, use open directive questions to clarify the patient’s or caregiver’s level of understanding of the illness.</li> </ul>	<p><i>“What is your understanding of your health situation and what is likely to happen?”</i>  <i>“Do you have thoughts about where things are going with your illness?”</i></p>
<ul style="list-style-type: none"> <li>• Consider asking the patient and caregiver what they have been told by other health care professionals and what information they have obtained from other sources (eg, Internet).</li> </ul>	<p><i>“Can you summarise to me what the doctors have explained to you about your illness? Do you think, or did they mention, the illness may affect your health in the future?”</i></p>
<ul style="list-style-type: none"> <li>• If the discussion is prompted by a patient or caregiver question, consider:             <ul style="list-style-type: none"> <li>➤ Clarifying what they are asking and what motivated the question</li> <li>➤ Asking them what they think is the answer first.</li> </ul> </li> </ul>	<p><i>“I am very happy to answer that, but do you mind telling me what made you ask that question?”</i>  <i>“What are you expecting to happen?”</i></p>

<ul style="list-style-type: none"> <li>Elicit and clarify the patient's concerns, expectations and fears about the future, relevant to issues being discussed.</li> </ul>	<p>"What worries you most about . . . [eg, what may happen]?"          "What frightens you about all of this?"          "What do you hope for the future?"          "What is your biggest concern at the moment?"</p>
<ul style="list-style-type: none"> <li>Clarify what the patient wants to know and the level of detail preferred before giving new information.</li> </ul>	<p>"How much would you like to know?"          "Some people like to know everything that is going on with them and what may happen in the future, others prefer not to know too many details. What do you prefer?"          "I am happy to give you as much information as I can based on what you want to know."          "What types of information would you like?"<sup>2</sup></p>
<ul style="list-style-type: none"> <li>Clarify the caregiver's information needs (provided the patient gives consent to discuss the illness with the caregiver), as they may differ from the patient's needs.</li> </ul>	<p>To patient:          "It is also important for [name of caregiver] to have the opportunity to find out the things [he/she] needs to know to be able to take care of you. Are you happy for me to speak with [him/her] about your medical condition?"          "Is it OK with you if I tell your [relative/caregiver] what I've discussed with you?"          "Often [daughters/sons] like to ask detailed questions. Is it okay if I answer your [son's/daughter's] questions? Is there anything I should not discuss?"</p> <p>To caregiver:          "How do you think [patient] is going?"          "What concerns do you have at the moment?"          "What do you understand is likely to happen to [name of patient]?"          "What information will best help you to cope with your caregiving role?"</p>
<ul style="list-style-type: none"> <li>Be aware of cultural differences in information preferences and attitudes to discussing prognosis and dying.</li> <li>Clarify with the patient and family their cultural background or norms.</li> </ul>	<p>"Can you please help me to understand what I need to know about your beliefs and practices to take the best care of you?"<sup>3</sup>          "Is there someone else you would like me to involve or speak to?"</p>
<ul style="list-style-type: none"> <li>Do not make assumptions about information needs based on the individual's cultural background or demographic information, but clarify with the individual and family.</li> </ul>	
<ul style="list-style-type: none"> <li>Regardless of the content of the prognostic or end-of-life discussion, explain the uncertainty and unreliability of prognostic predictions.</li> </ul>	<p>"Every person is different. I can only tell you what usually happens to people in your situation, not exactly what will happen to you."          "I know that often people expect doctors to know what is going to happen, but in truth we can often only take educated guesses and can often be quite wrong about what the future holds, and especially how long it is. What we can be sure about is . . . and what we don't know for sure is . . ."</p>
<ul style="list-style-type: none"> <li>Consider acknowledging the difficulty in living with this uncertainty.</li> </ul>	<p>"A lot of people find it hard not knowing what will happen next or when. Is this something you find difficult?"</p>
<ul style="list-style-type: none"> <li>Tailor the information given according to the patient's or caregiver's level of understanding, concerns and information needs.</li> </ul>	

<ul style="list-style-type: none"> <li>• The discussion may involve correcting misunderstandings regarding information obtained from other sources (eg, media or Internet).</li> </ul>	
<ul style="list-style-type: none"> <li>• Give information in small chunks, at the person's pace.</li> <li>• Check that the patient or caregiver has fully understood what has just been said.</li> </ul>	<p><i>"I want to talk about three things today: the test results; what this will mean for you; and the treatment that is possible. And you might have some things to discuss too. Now, the test results . . . Do you have any questions so far?"</i></p>
<ul style="list-style-type: none"> <li>• Use appropriate language: use everyday terms, straightforward and clear language, and unambiguous words; avoid euphemisms or jargon that could easily confuse, overwhelm and mask the true meaning of the message.</li> <li>• Use the words "death" and "dying" where appropriate.</li> </ul>	<p><i>"Doctors sometimes forget and use words that may not be understood. Please stop me if I am doing this."</i></p>
<ul style="list-style-type: none"> <li>• Provide honest and realistic information in a straightforward manner.</li> </ul>	
<ul style="list-style-type: none"> <li>• Avoid being blunt or giving more detailed information than desired by patients or caregivers.</li> </ul>	
<ul style="list-style-type: none"> <li>• Recognise the impact of the information on the patient (and caregiver) and communicate with empathy and understanding.</li> </ul>	
<ul style="list-style-type: none"> <li>• Do not make promises that cannot be delivered or that are inconsistent with clinical evidence.</li> </ul>	
<ul style="list-style-type: none"> <li>• Try to foster openness and consistency of information given to the patient and the family regarding discussions of prognosis and end-of-life issues.</li> </ul>	
<ul style="list-style-type: none"> <li>• To explore and address differing information needs, consider having joint as well as separate discussions with caregivers when appropriate (if the patient has given consent to discuss his or her illness).</li> </ul>	
<ul style="list-style-type: none"> <li>• Explore the patient's or caregiver's emotional reaction to the information given and the meaning of the information (prognosis) to the person and respond empathically; elicit the patient's concerns.</li> </ul>	<p><i>"It sounds like this information is different from what you expected, and I think it would be upsetting for anyone."<sup>4</sup></i>  <i>"How are you feeling about what we have discussed?"</i>          If visibly upset:  <i>"I can see that this is really upsetting for you."</i></p>
<ul style="list-style-type: none"> <li>• When spiritual or existential issues are raised, validate the importance of such topics and encourage the patient to continue to explore the issues with you, or refer where appropriate.</li> </ul>	<p><i>"These are important issues. Would you like to speak to a member of the hospital support staff such as a pastoral caregiver?"</i>  <i>"... is clearly really important to you. Would it be [useful/helpful] to explore these issues further? Who might be the right person you can do this with?"</i>  <i>"Would you like to talk to someone about spiritual matters?"</i>  <i>"What are the things in life that give you strength and sustain you?"</i>  <i>"Are your beliefs being challenged by your current experiences?"</i></p>

- Check the patient's and caregiver's understanding of what has been discussed and whether they have received the level and type of information they want or need.

*"Have I given you the information you need [at this point/so far]?"*  
*"To make sure we are on the same wavelength, I want to check your understanding of what we have discussed."*  
*"Is there anything I've said that you'd like me to go over?"*  
*"We've spoken about an awful lot just now. It might be useful to summarise what we've said. . . Is there anything from that that you don't understand or want me to go over again?"*  
*"Do you feel you've understood everything that you've been told? Is there anything you would like me to go over again? After all, some of this is pretty technical."*

- Encourage the patient or caregiver to ask questions and revisit the topic in the future when they want further information.

*"Is there anything else you would like to discuss?"*  
*"Is there anything from our previous discussions that you would like to revisit?"*  
*"Don't hesitate to ask me again about any of the issues we have discussed today."*  
*"What thoughts or questions are on your mind right now?"*

- At the end of the discussion:
  - Consider summarising the discussion
  - Record in the medical record what was discussed and/or write to or speak with other key health care professionals involved in the patient's care about the discussion (including the general practitioner)
  - Collaborate within the multidisciplinary team to ensure consistency of information (eg, unit meetings, case review).

*"So, we've talked about . . . at length and also talked quickly about . . . Is that your recollection as well?"*

1. Emanuel LL, von Gunten CF, Ferris FD, editors. Communicating bad news. In: The Education for Physicians on End-of-life Care (EPEC) curriculum. Chicago: The Robert Wood Johnson Foundation, 1999.
2. Schofield P, Carey M, Love A, et al. 'Would you like to talk about your future treatment options?' Discussing the transition from curative cancer treatment to palliative care. *Palliat Med* 2006; 20: 397-406.
3. Rabow MW, Hauser JM, Adams J. Supporting family caregivers at the end of life: "they don't know what they don't know". *JAMA* 2004; 291:483-491.
4. Back AL, Arnold RM. Dealing with conflict in caring for the seriously ill: "it was just out of the question". *JAMA* 2005; 293: 1374-1381.