

Giving the diagnosis

Prognostic and end-of-life communication is a vital skill for health care professionals caring for patients with progressive life-limiting illnesses, and their families. The Australian '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' (Clayton and others 2007) were developed to address these issues.

Clayton and others 2007

The key recommendations of these guidelines are for health professionals to consider the recommendations conveyed by the acronym PREPARED.

Prepare for the discussion, where possible:

- Confirm pathological diagnosis and investigation results before initiating discussion.
- Try to ensure privacy and uninterrupted time for discussion.
- Negotiate who should be present during the discussion.

Relate to the person:

- Develop rapport.
- Show empathy, care and compassion during the entire consultation.

Elicit patient and caregiver preferences:

- Identify the reason for this consultation and elicit the patient's expectations.
- Clarify the patient's or caregiver's understanding of their situation, and establish how much detail and what they want to know.
- Consider cultural and contextual factors influencing information preferences.

Provide information, tailored to the individual needs of both patients and their families:

- Offer to discuss what to expect, in a sensitive manner, giving the patient the option not to discuss it.
- Pace information to the patient's information preferences, understanding and circumstances.
- Use clear, jargon-free, understandable language.
- Explain the uncertainty, limitations and unreliability of prognostic and end-of-life information.
- Avoid being too exact with timeframes unless in the last few days.
- Consider the caregiver's distinct information needs, which may require a separate meeting with the caregiver (provided the patient, if mentally competent, gives consent).
- Try to ensure consistency of information and approach provided to different family members and the patient from the different clinical team members.

Acknowledge emotions and concerns:

- Explore and acknowledge the patient's and caregiver's fears and concerns and their emotional reaction to the discussion.

- Respond to the patient's or caregiver's distress regarding the discussion, where applicable.

(Foster) Realistic hope:

- Be honest without being blunt or giving more detailed information than desired by the patient.
- Do not give misleading or false information to try to positively influence a patient's hope.
- Reassure that support, treatments and resources are available to control pain and other symptoms, but avoid premature reassurance.
- Explore and facilitate realistic goals and wishes, and ways of coping on a day-to-day basis, where appropriate.

Encourage questions and further discussions:

- Encourage questions and information clarification; be prepared to repeat explanations.
- Check understanding of what has been discussed and if the information provided meets the patient's and caregiver's needs.
- Leave the door open for topics to be discussed again in the future.

Document:

- 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. As a minimum, this should include the patient's general practitioner.

Miller and others 2009b

Telling the patient and family the diagnosis of ALS is challenging for clinicians and patients. Two studies analyzed patient perceptions of this experience (Class III and Class IV). Patients reported lack of empathy, insufficient explanation of the diagnosis and the course of the illness, and lack of information on where to get help. There have been no controlled trials of breaking the news in ALS.

Mockford and others 2006

The longer a physician spends with the patient/caregiver the more satisfied they feel with the service, but some carers feel professionals are incompetent, knowing little about the disease and others, in a US study, describe the physicians who gave the diagnosis as poor, below average or average.

Carers can feel a sense of abandonment and insecurity after diagnosis due to insufficient explanation of the diagnosis, lack of empathy and little support at the time.

They may feel that their needs are not adequately considered at diagnosis and they are not given enough information, although some may not feel able to absorb much extra information at this time

Carers' criticisms of hospital care include having no further follow-up after the diagnosis, poor facilities available in the hospital



for patients who have mobility problems, long waiting times and limited time to talk to a doctor.