

section 2.4: transition of care from cure to palliation

discussing transitions of care

Research indicates that conversations with patients about transitions from curative treatment to palliative and supportive care appear more likely to trigger concerns about dying, loss, grief and abandonment than those experienced at the time of diagnosis.¹ Decisions about whether to continue or discontinue life prolonging treatments can be stressful for all concerned – for the patient, their family and for the treating team.

Prior to the discussion the treating team need to consider what options can actually be implemented and then put time aside to explore what the patient is hoping to achieve. Central to this discussion is the exploration of the burden of disease for this particular person, the risks and benefits of treatment and the opportunity to consider the relative merits of quality and quantity of life. Other factors which may impact on decision making include the previous response to treatment, cultural considerations, age, the presence of co-morbid illnesses and family and financial responsibilities.²

Essential components prior to discussions with patients and families include:

- clear and timely communication between treating teams
- demonstrated respect between teams for the role that each plays across the continuum of disease
- ensuring that all information relating to the patient's illness is available and reviewed in order to present the management options to the patient and family.

strategies for assisting with patient and family concerns

In order for patients and families to feel supported through this difficult stage it is important to reassure the patient that their ongoing care remains the priority, even though the composition of their primary treating team may change.

Offering continuity by presenting the possibility of parallel care with the current treating team and the specialist palliative care team may be reassuring – this is not necessarily an "either/or situation". Knowing that there will be ongoing support, particularly beyond the hospital walls when discharge home is planned becomes critical.

Strategies include:

- explaining that assessment for the patient is ongoing, that reassessment will occur regularly and a plan for active management of all presenting symptoms will be put in place
- allowing patients and family to acknowledge the sadness felt with the changing circumstances and how this may impact on relationships with their treating team
- actively promoting the integral role and involvement of allied health staff such as social work, clinical psychology and pastoral care

- establishing a list of contacts for the patient should their circumstances or condition change – this may include the current treating team, the General Practitioner, community nurse or the specialist palliative care team (if actively involved in the patient’s care)..

cessation of disease modifying treatments

Helping patients to explore choices at this time presents significant challenges and is influenced by our individual comfort level with death and dying, cultural and religious beliefs and the length of the professional therapeutic relationship. It is important to avoid introducing your own personal opinions or beliefs into the discussion.

The role of the clinician is to provide accurate medical information about what can be achieved in a given medical situation and to discuss this in the context of the patient’s beliefs and expectations. Patients should be advised of these discussions in advance to allow time for exploration and questions. This may avoid decisions being made for them as a necessary consequence of acute deterioration and the associated distress this may cause to all involved.

Identifying concepts and principles of palliative care can help patients articulate their expectations. For example:

- I expect pain and other symptoms to be well managed
- I expect to be in my home
- I expect my family to be there
- I expect care that promotes my dignity, independence, and control in dying.

Developing a specific management plan allows patients to have some control over the degree of medical intervention that they would accept should they be unable to communicate their wishes at the time. This relates particularly to resuscitation and ventilation status, nutritional support and treatment of potentially reversible medical conditions and is in the context of those interventions that offer benefit and are technically possible.

identifying points of transition

A number of patterns of decline or illness trajectories have been described for those patients facing life limiting illnesses which focus on functional status and presence of symptoms.

These include:

- a steady decline with a short terminal phase as is often seen in patients with cancer
- a period characterised by long disability and slower deterioration that frequently includes a number of crises before the terminal phase and unpredictable timing of death, such as those patients with chronic organ failure
- a slowly dwindling course to death with associated self care deficits, which usually results from frailty or dementia.

patterns of decline

The diagram below illustrates these three patterns of decline and provides some indication of the possible timing of discussions with patient and their families about future care planning.³

For all conditions at the end of life, whether they include a malignant process or not, the emphasis is on quality rather than quantity as the primary outcome of care.⁴

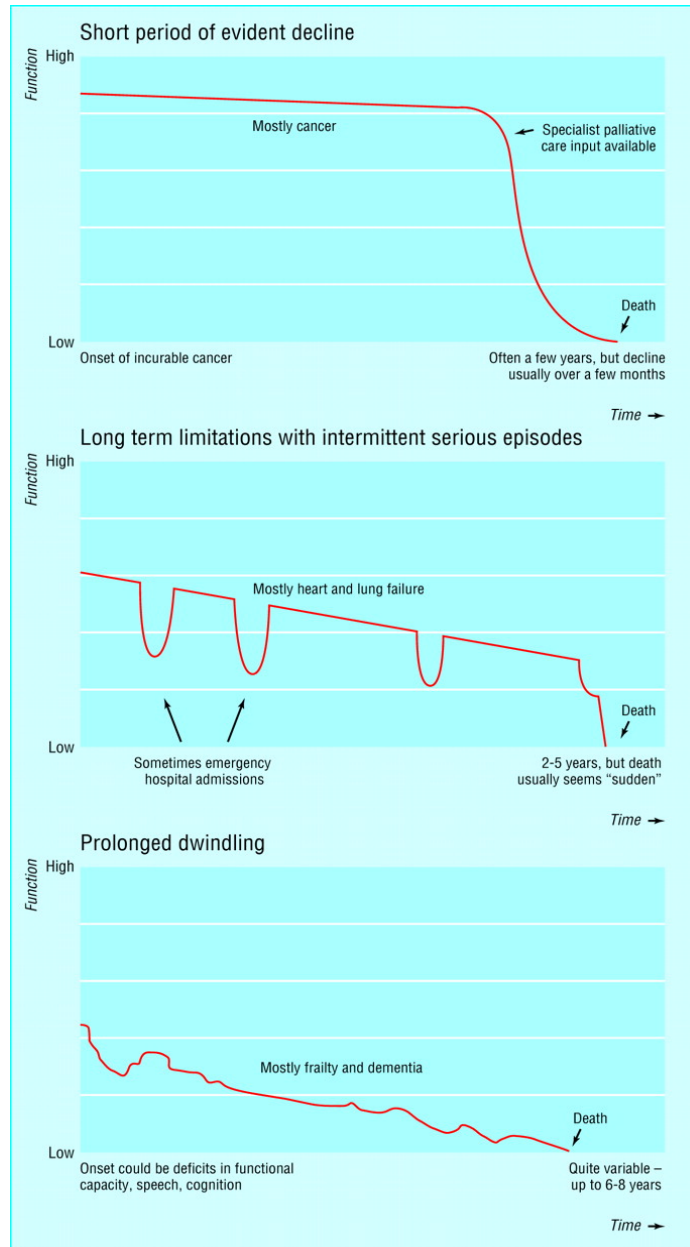


Fig 1 Typical illness trajectories for people with progressive chronic illness. Murray S, Kendall M, Boyd K, Sheikh A, (2005) *BMJ*; 330:1007-1011, adapted from Lynn J, Adamson DM. *Living well at the end of life. Adapting health care to serious chronic illness in old age*. Washington: Rand Health. (2003)

specific issues to consider

- understanding the context of disease for the patient – establishing a shared understanding with the family and caregivers
- identifying the patient's values and beliefs and establishing whether written or verbal wishes have already been expressed
- minimising information from multiple medical specialists and delegating the role of key communicator to one person
- actively sharing the supportive role with other members of the team including the social worker, pastoral care worker and other family members⁵

ethical dilemmas

Ethical issues related to palliative care are well covered in *Therapeutic Guideline – Palliative Care*, Version 2. This section includes ethical matters most commonly related to care of dying patients such as communication and decision-making, disclosure of information, dealing with requests for assistance to die, hydration and feeding, cardio-pulmonary resuscitation and the duty of care. Identifying shared core values amongst those people involved in difficult situations is suggested as an excellent starting point.

The guidelines suggest, "a provider's duty of care is to the patient, and those other duties owed to all other parties are secondary".⁶

related information and resources

*A guide to talking to patients about death and dying*⁷ is available from Palliative Care Council of South Australia Inc – phone 08 8291 4137

Clinical practice guidelines for the psychosocial care of adults with cancer. National Breast Cancer Centre and the National Cancer Control Initiative, National Breast Cancer Centre, 2003.

Guidelines to assist clinicians in responding to terminally ill patients who request hastening of their death have recently been published⁸

Scofield P, Carey M, Love A, Nehill C, Wein S (2006) 'Would you like to talk about your future treatment options?' Discussing the transition from curative cancer treatment to palliative care. *Palliative Medicine* Vol 20; 4 pp 397-406.

Therapeutic Guidelines – Palliative Care, Version 2 – see Family meetings in Loss, grief and bereavement chapter

references

¹ Back A (2005) How should physicians communicate the transition to palliative care. *Nature Clinical Practice Oncology*; 2: 146-13.

² Therapeutic guidelines- Palliative Care, version 2 (2005). Therapeutic Guidelines Limited, Victoria, Australia.

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- ³ Fig 1 Typical illness trajectories for people with progressive chronic illness. Murray S, Kendall M, Boyd K, Sheikh A, (2005) *BMJ*;330:1007-1011. Adapted from Lynn and Adamson, 2003. With permission from RAND Corporation, Santa Monica, California, USA.
- ⁴ Girgis A, Johnson C, Currow D, Waller A, Kristjanson L, Mitchell G, Yates P, Neil A, Kelly B, Tattersall M, Bowman D (2006). *Palliative Care Needs Assessment Guidelines*. The Centre for Health Research and Psycho-Oncology, Newcastle, NSW.
- ⁵ Meier D The inner life of Physicians and the Care of the Seriously ill. Presentation at the Australia and New Zealand Society of Palliative Care, 2006.
- ⁶ *Therapeutic Guidelines- Palliative Care, Version 2* (2005), Therapeutic Guidelines Ltd, Victoria, Australia.
- ⁷ Burgess T, Beilby J, Brooksbank M (2001) Talking to patients about death and dying. Department of General Practice at Adelaide University and the Palliative Care Unit, Royal Adelaide Hospital.
- ⁸ Hudson P (2006) Responding to desire to die statements from patients with advanced disease. *Palliative Medicine* 20: 703-710.