25 End-of-life care

The capacity to save lives through advances in treatments, especially the use of CPR (cardiopulmonary resuscitation), intensive care and life-support systems, is one of the ‘miracles’ of modern medicine. These advances have brought with them challenging ethical and legal dilemmas for the medical profession, the community, legislators and the courts. The most common issues relate to the care of patients, often elderly, who are seriously and possibly terminally ill and with, or for whom, decisions must be made about resuscitation and withholding or withdrawing treatment. The inherent difficulties are easily aggravated by problems in communicating with patients and their families. This is particularly so where deterioration has occurred suddenly and/or where there has been no prior discussion of the possibility of such events or of the patient’s wishes and the available realistic options. These difficult situations can be averted or ameliorated by earlier discussion of advance care planning, and doctors can be aided by better documentation of the discussion and the resulting plan [1,2]. Much of this chapter is taken up with these issues, including professional responsibilities in end-of-life care, futile treatment, refusal of treatment, advance care planning, not-for-resuscitation orders, withdrawing or withholding treatment and the role of the courts.

The chapter also addresses physician-assisted suicide, particularly from the perspectives of the current law and the views of the medical profession, but does not enter into the wider social, ethical and philosophical debate surrounding euthanasia. Additionally, it addresses the diagnosis and care of patients in post-coma unresponsiveness (previously known as a ‘vegetative state’) [3].

25.1 Professional responsibilities in end-of-life care

Caring for patients who are ill and coming to the end of their life is one of the most important roles undertaken by clinicians. The responsibilities are enunciated clearly by the Medical Board of Australia in its code of conduct as follows:

> Doctors have a vital role in assisting the community to deal with the reality of death and its consequences. In caring for patients towards the end of their life, good medical practice involves:

3.12.1 Taking steps to manage a patient’s symptoms and concerns in a manner consistent with their values and wishes.

3.12.2 Providing or arranging appropriate palliative care.

3.12.3 Understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient.

3.12.4 Understanding that you do not have a duty to try to prolong life at all cost. However, you do have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that your patients receive appropriate relief from distress.

3.12.5 Accepting that patients have the right to refuse medical treatment or to request the withdrawal of treatment already started.

3.12.6 Respecting different cultural practices related to death and dying.

3.12.7 Striving to communicate effectively with patients and their families so they are able to understand the outcomes that can and cannot be achieved.

3.12.8 Facilitating advance care planning.

3.12.9 Taking reasonable steps to ensure that support is provided to patients and their families, even when it is not possible to deliver the outcome they desire.

3.12.10 Communicating bad news to patients and their families in the most appropriate way and providing support for them while they deal with this information.

3.12.11 When your patient dies, being willing to explain, to the best of your knowledge, the circumstances of the death to appropriate members of the patient’s family and carers, unless you know the patient would have objected [4].

Similar advice from the United Kingdom’s General Medical Council was given in its document *Good medical practice* [5] and expanded on in a 2010 document on the topic [6].

25.2 Good-quality end-of-life care: a ‘good death’

Patients and their families identify a ‘good death’ as one that avoids or minimises suffering, does not prolong dying, achieves a sense of control, relieves burdens on family, and strengthens relationships with loved ones [2,7,8].

The Australian Medical Association’s position statement on the doctor’s role in end-of-life care identifies the following features of good-quality end-of-life care:

- the patient is treated with respect, dignity, and compassion;
- the patient is free from unnecessary suffering as far as is possible;
- the patient is cared for in his/her environment of choice;
- the patient’s goals and values for end-of-life care are respected;