Where the College stands on end-of-life care

Improving end-of-life care is everyone’s responsibility

Too often, patients’ preferences for end-of-life care are not known until it is too late, and they receive treatment that is against their wishes, and may be unnecessary or even harmful. Improving end-of-life care through systems and cultural changes must be a priority.

The 5 elements of good end-of-life care identified by the College are:

1. Diagnosing dying or the risk of dying
2. Respecting patient autonomy
3. Respecting the patient’s best interests when making treatment decisions
4. Managing symptoms
5. Supporting carers and family/whānau

The College is committed to embedding these elements into physician training and advocating for health systems changes that allow them to be fully realised.

Why we need to talk now

The way we are dying has changed

Life expectancy has dramatically increased and with it the age, mode, cause and place of death has significantly changed.

Sudden unexpected death is much less common. Most people are now dying after a period of decline from chronic disease, often with multiple co-morbidities and frailty.

In the last year of life, patients may receive fragmented care and advice through visits to multiple health professionals in a range of different care settings (private, public, acute, community).

We have a ‘death denying’ culture

Discussing end-of-life issues can be uncomfortable and is sometimes taboo. Attempts to prolong life at all costs and a perception that death represents a failure can be barriers to good end-of-life care.

Modern medical care tends to focus on curing, and restoring, which may sometimes conflict with accepting death as a natural event.

Responsibility for end-of-life care discussions with a patient can be unclear when multiple health practitioners are providing care.

Patient wishes not known

According to an RACP survey, physicians believe treatment at the end of life is too often provided:

- inappropriately or against patient wishes,
- with little chance of significant benefit,
- with specialists lacking knowledge of the legal frameworks for advance care planning.

Only 37% of respondents agreed that in their experience, “Most of the time, family members know the patient’s preference regarding end of life care.”
Good end-of-life care

Leads to:
• Better quality of life for the patient before death;
• Preservation of the patient’s dignity;
• A better death from the perspective of the patient and their family/whānau;
• Less psychological burden on the patient, family/whānau, carers and health professionals;
• Less pain, breathlessness and suffering caused by ineffective treatments; and
• A reduction in costs associated with unwanted, inappropriate and ineffective treatment.

Championing change

Systems changes are needed

Embedding the 5 elements of good end-of-life care requires changes at the facility and health systems level to:
• develop sustainable models of care that, for example, give health professionals the time they need to discuss end-of-life care with patients and allow for appropriate social work support, spiritual support, and bereavement care
• Support one doctor or health professional to coordinate care of terminally or chronically ill patients, to minimise fragmentation of care
• Facilitate the identification of patients approaching the end of life
• Streamline patient information, including through e-health records, so that all health professionals involved in the care of the patient have access to key information
• Harmonise legislation on advance care planning across jurisdictions.

Recommendations

The RACP will:
1. Champion the message that patient-centred end-of-life care is the responsibility of all physicians. This includes the capacity to identify patients near the end of life and provide or arrange an appropriate management plan.
2. Lead a public conversation to promote awareness of good end-of-life care and a focus on quality of life rather than prolonging life by any means.
3. Advocate for the widespread adoption of advance care plans and their use across the health system.
4. Foster a medical culture that supports open communication with patients, families and health professionals including whether treatment is in the patient’s best interests.

The RACP encourages physicians and patients to join in and promote the 5 elements of good end-of-life care.

All facts and data in this document are sourced in the RACP policy document: “Improving Care at the End of Life: Our Roles and Responsibilities,” May 2016.

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