End of Life Care

POSITION STATEMENT

College position

It is the goal of general practitioners to provide continuity of care throughout the life of their patients including during their final years. Perhaps the last gift a doctor can give their patient (and their closest friends and family) is an experience in their last months and weeks that is in accordance with their wishes.

In cities, the final phase of care for patients is often the province of palliative care specialists and allied health practitioners, however in rural and remote communities the general practitioner remains very much at the centre of care. This continuity presents the opportunity for rural doctors to provide a much more supportive experience and one which is aligned with the preferences of their patient.

Definitions

Advanced Care Planning

An ongoing and interactive process of understanding and making explicit a person's views, preferences and decisions about their future care, for example, what kind of treatments they agree or do not agree to, where a person would like to be cared for when they die, or what kind of funeral they would prefer. This can be supported by legally binding documents, such as an Advance Care Plan / Directive, or Medical Power of Attorney, or less formal documents.

End of Life Care

People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions whereby they are at risk of dying from a sudden acute crisis, and
- Life-threatening acute conditions caused by sudden catastrophic events.

Providing quality care for these people presents a distinct range of clinical, legal and ethical considerations.

End of Life Care

The following general principles define the appropriate role of the rural general practice doctor in caring for their patients approaching the end of life:

- Recognise the right of patients to have their beliefs, needs and wishes with regard to end of life care respected.
- Your patient's comfort and dignity is the ultimate priority of care provision.
- Seek to ensure continuity of care to the patient, as well as their closest friends and family, throughout their end-of-life period and for friends and family in their bereavement.
- Offer a central point of communication in all matters relating to the patient's care, for the patient and their carers.
- Work constructively with the entire healthcare team and advocate for patients (in accordance with their preferences) at all stages and locations of care.
- Facilitate communication between other members of the healthcare team.
- Recognise and support carers in their role as integral members of patient's care, recognising that they too may have health care needs which need appropriate management.
- Advocate for advance care planning and take active steps to encourage patients to communicate their wishes with respect to end of life care to the people who are important to them.

Advanced Care Planning

An Advance Care Plan details a patient's future medical preferences and provides guidance to family, carers, close friends and healthcare providers when a person is no longer able to make their own decisions.[1]

Discussing End of Life Care and Advance Care Planning with patients

ACRRM encourages rural doctors to have an initial discussion with all patients which they identify as approaching their end of life, informing them of their options with regard to Advance Care Planning, inquiring on any plans that are already in place, and where appropriate assisting them in documenting their wishes.

It is important that the rural doctor emphasises and respects the right of patients and carers to have their beliefs, needs and wishes recognised and respected with regard to end of life care including the choice to not engage in Advance Care Planning.

It is also important for this conversation to be repeated particularly as the patient's condition changes and for the doctor to respect the possibility that a patient's views may change as they respond to new circumstances and assist with the modification of the Plan accordingly.

End of Life Law for Clinicians is a free training program for medical practitioners, medical students, nurses and other allied health professionals about the law relating to end-of-life decision making. ACRRM encourages members to utilise this free resource.[2]

Care for Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander groups possess unique cultural practices, traditions and laws, which bring special considerations for end-of-life care. A guiding principle during this stage of care is that each patient has a unique set of needs and values that should be identified and addressed. As such, recognising cultural identity and significance to person and family is part of providing a competent service. The general practitioner will enhance the quality of their care through their awareness of distinct cultural differences to perceptions of health, illness, the dying process and death.

Consideration should be given to opportunities to engage Aboriginal and Torres Strait Islander Liaison Officers, Aboriginal Health Workers or Aboriginal and Torres Strait Islander Health Professionals in the care process.

My Health Record

Patients can ensure their Advance Care Planning documentation is available to treating doctors if it is ever needed by adding to their My Health Record.

Steps to upload an Advance Care Plan to your records:

1. Write your wishes into an advance care plan
2. Discuss your wishes/preferences with your family and loved ones
3. List the names and contact details of a substitute decision maker who can speak on your behalf
4. When completed, save as a PDF
5. Upload to My Health Record following the steps set out here: https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/whats-inside/advance-care-planning

Voluntary Assisted Dying

Voluntary Assisted Dying (VAD) laws are in place in all Australian states and Territories except the Northern Territory.

The laws are similar across jurisdictions with several key differences.

VAD refers to the assistance provided to a person by a health practitioner to end their life. It includes:

- Self-administration—where the person takes the VAD medication themselves (sometimes called physician assisted suicide or dying)
- Practitioner administration—where the person is given the medication by a doctor (or in some states a nurse practitioner or registered nurse) (this is sometimes called voluntary euthanasia).

"Voluntary" indicates that the practice is a voluntary choice of the person and that they are competent/have capacity to decide to access VAD.

There are strict eligibility criteria for requesting access to VAD, and rules prohibiting health practitioners from raising the issue of VAD with patients.

It will be important for States to put in place schemes which will ensure that people living in regional, rural and remote areas are supported and have fair and equitable access to VAD.

The Commonwealth Criminal Code makes it an offence to use a "carriage service" such as telephone, videoconference, email of other form of electronic communication to publish or distribute material that counsels or incites committing or attempting to commit suicide. This part of the Code will require amendment before VAD can be discussed using telehealth services. The College would see value in reviewing this position and to exploring models to improve the access of people in rural and remote areas to safe, quality care and advice.

Palliative Care

Rural Generalists and rural General Practitioners are often key contributors to the palliative care of people living in rural and remote communities. ACRRM Fellowship training encompasses the knowledge and skills requirements for providing generalist services in this field and includes an option to complete palliative care advanced specialised training.

The value and opportunity for these doctors to provide services should be recognised and supported in rural and remote service funding models and clinical frameworks. Rural Generalist Palliative Care providers should be recognised as part of the care team in rural and remote settings. There is also opportunity for this work to be supported through dedicated Rural Generalist item numbers on the Medical Benefits Schedule.

End of Life Care Patient Charter for ACRRM Doctors

Doctors will seek to offer their patients who are nearing the end of their life the highest quality of care and support. They will seek to help them to live as well as they can, for as long as they can.

The doctor's commitment to their patient is to:

- Work together with their patient to support them openly and honestly
- Respect their patient's choices and their right to independence with compassion and understanding
- Ensure their patient's privacy, dignity and confidentiality
- Talk with their patients and the people who are important to them as often as they feel the need including treatment options, diagnosis, prognosis and care
- Coordinate care with treating teams across hospital and community—this will include referral, documentation and communication
- Do their best to manage the patient's pain and symptoms to ensure they are as comfortable as possible
- Facilitate the provision of emotional, spiritual and cultural support in line with the patient's wishes, and
- Support the people who are important to their patient, both as the patient approaches the end of their life and in their bereavement.

The doctor will seek their patient's commitment to:

- Endeavour to let them and their family know their wishes about the remainder of their life. This might include:
- The content of their advance care plan or directive
- Their preferred location of death, and
- Their preferred spokesperson/s.
- Inform them (or, as appropriate, allow their designated spokesperson/s to inform the doctor)
  - If they are experiencing symptoms that are impacting on their well-being, such as pain, discomfort or emotional concerns.
  - If they need information, direction and support.
  - Whenever they would like advice on any current treatment options.
- To participate in their care to the best of their ability.

Endnotes

1 http://advancecareplanning.org.au
2 https://www.eldac.com.au/Our-Toolkits/End-of-Life-Law

Find out more

If you have any queries relating to this Position Statement, please contact us by:

Email: policy@acrrm.org.au
Phone: 1800 223 226
Website: mycollege.acrrm.org.au/contact-us

ACRRM acknowledges Aboriginal and Torres Strait Islander peoples as the custodians of the lands and waters where our members and staff work and live across Australia. We pay respect to their elders, lores, customs and Dreaming. We recognise these lands and waters have always been a place of teaching, learning, and healing.