

RACP Submission (2015):

"Greater say for Victorians - Improving end of life care" discussion paper November 2015

The Royal Australasian College of Physicians (RACP) welcomes the opportunity to contribute to the "Greater say for Victorians - Improving end of life care" framework. The RACP is currently finalising a position statement on the elements of good end of life care, and looking at ways these elements can be embedded into physician training and Continuing Professional Development. The position statement will also inform the RACP's advocacy efforts to promote high quality, patient-centred end of life care in both adult and paediatric medicine. This submission draws on this work, as well as the Australian and New Zealand Society of Palliative Medicine (ANZSPM) statements on quality end of life care and workforce strategy.

Challenges in end of life care

Most people are dying, after a variable period of decline, from chronic disease, often with multiple co-morbidities and frailty. Patients who are in the last year of their lives may receive input from a great number of medical and non-medical health professionals in a range of care settings (acute, community, public, private), and are likely to present repeatedly. Many patients, such as those with advanced dementia, may no longer be able to express their wishes. Ensuring that patients who are reaching the end of their lives have access to the right care at the right time by the right provider can be challenging.

The RACP recently conducted a survey on Fellows' and trainees' attitudes, knowledge and practice of end of life care and Advance Care Planning (ACP). The survey (while drawn from a limited sample) found that the physicians and trainees sampled felt comfortable and confident in discussing end of life issues and ACP. Although a majority of respondents have taken part in communication skills training, and many have completed training in ACP, they want to continue to improve their skills in these areas.

Of all respondents to the RACP survey, 34% had commenced an ACP conversation with a patient in the past 6 months (of which 6% daily) and 32% had not done any. The survey identified the following potential barriers to undertaking ACP:

- Time constraints (62%)
- Insufficient relationship with patients (46%)
- Health literacy of the patient or family (41%)
- Lack of skills of the doctor (30%)
- Comfort in having end of life or Advance Care Planning conversations (26%)
- Unavailability of appropriate place for discussions (20%)
- Patients aren't interested (18%)
- Language barrier (16%)

Almost a third of respondents (28%) assessed that they lacked knowledge of legal frameworks for ACP, and this may represent a barrier to speaking up when treatment is provided against a patient's wishes.

The responses to the survey also indicate that many patients nearing the end of life are provided with treatment that is inappropriate or against their wishes. About a third of respondents who care daily for patients who may die in the next 12 months, observed treatment being given that was inconsistent with the patient's wishes at least once a week.

Of all respondents, 37% indicated they had observed treatment with little chance of significant benefit being provided to patients at least once per week. This was observed by 44% of trainees.

Only 17% of respondents to the RACP's survey agreed that *most of the time doctors know the patient's preference regarding end of life care.*

One reason for these issues may be that our culture is predominantly 'death denying' ¹. Discussing death and end of life issues is often uncomfortable and sometimes taboo². This can make it difficult to have the regular conversations that are needed about goals of care, and shifting the focus to quality of life. In many cases, by the time such a conversation is considered, the patient is no longer able to express their wishes, and so they remain unknown.

Modern medical care tends to focus on curing which may sometimes conflict with accepting death as a natural event³. Physicians and health professionals have diverse backgrounds and levels of experience with end of life care, and some may feel they have a duty to prolong life at all costs and/or see death as a medical failure^{4 5}.

Fragmentation of care and lack of communication can mean that health professionals are unclear as to whose role it is to discuss end of life care with the patient⁶ ⁷.

What is good end of life care?

Good end of life care⁸ reflects a society which cares about its people and shows moral leadership. Good end of life care is patient-centred, coordinated and focused on rational investigation, prescribing and de-prescribing. It involves early identification, and assessment and treatment of pain and other problems (physical, psychosocial, cultural and spiritual)⁹. It enables patients nearing the end of life to live as well as possible, and then to die without unnecessary prolongation of the dying process. Good end of life care has the potential to extend life, by managing pain and other distressing symptoms, and stopping inappropriate

¹ Lynn, J., H. R. Arkes, et al. (2000). "Rethinking fundamental assumptions: SUPPORT's implications for future reform. Study to Understand Prognoses and Preferences and Risks of Treatment." <u>J Am Geriatr Soc</u> **48**(5 Suppl): \$214-221

² Australian Commission on Safety and Quality in Health Care (August 2013). "Safety and Quality of end of life care in acute hospitals – A background paper ".

³ Australian and New Zealand Society of Palliative Medicine (ANZSPM) (February 2014). "Position statement on Quality End of Life care - Part 1 - Essential elements for quality, safety and appropriate clinical care at the end of life".

⁴ Monash University, A. C. f. H. R., The University of Melbourne, (February 2013). "End of life care: Leadership and Quality in end of life care in Australia."

⁵ Katelaris, A. (2011). "Time to rethink end of life care." <u>Medical Journal of Australia</u> **194**(11): 563.

⁶ Australian Commission on Safety and Quality in Health Care (August 2013). "Safety and Quality of end of life care in acute hospitals – A background paper ".

Australian Commission on Quality and Safety in Health Care (January 2014). "Draft National Consensus Statement Essential Elements for Safe and High-Quality End of life Care in Acute Hospitals - Consultation Draft."
 For further information about quality end of life care, please refer to the Australian and New Zealand Society of Palliative Medicine (ANZSPM) Position Statement (February 2014): Quality End of Life care - Part 1 - Essential elements for quality, safety and appropriate clinical care at the end of life ".

⁹ World Health Organisation (WHO) website, *Definition of Palliative Care*, (last accessed 02/06/15 http://www.who.int/cancer/palliative/definition/en/)

treatments that may have harmful side-effects. In all cases, end of life care should be personalised to the individual patient and circumstance.

The RACP has identified five elements which are essential for the provision of high quality patient-centred end of life care:

- 1. Diagnosing dying or the risk of dying
- 2. Respecting patient autonomy and providing personalised care
- 3. Ensuring that medical treatment decisions respect the patient's best interests
- 4. Managing symptoms
- 5. Supporting carers and family

Response to discussion paper

What principles should guide the development of a Victorian framework for end of life care?

What are the most important features of the kind of end of life care you would want for yourself or your loved ones?

This response also addresses other questions raised, including:

How do we ensure that end of life care is person-centred and inclusive of the needs of families and carers?

How do we best support self-determination in end of life care decision making?

How do we improve equity of access to end of life care and design a system that responds to the diverse needs of the community?

How do we better support discussion, planning and preparation for death and dying?

How do we ensure that people, including families and friends, are well informed about options for end of life care and are able to make legally binding decisions about the care they want?

The RACP recommends that the following principles are taken into account when developing the framework for end of life care:

- The experience of the patient, their family and carers must be at the centre of end of life care.
- In healthcare, end of life care is everyone's business and everyone's responsibility.
- Doctors must have the skills to identify patients at risk of dying, and those nearing the end of life.
- Death is natural part of life and cannot always be avoided. Assisting patients to die well is an important outcome of end of life care.

- Knowing when to stop, withhold or limit treatment that is inappropriate or potentially harmful to the patient is a key component of good end of life care.
- Good communication is essential to providing good end of life care. Communication is a skill that can be taught, learnt and assessed.
- All patients should have the opportunity to discuss their treatment goals, preferences and values, including children and adult patients who may have fluctuating capacity to make decisions about their own care.
- Advance Care Planning is a dynamic process involving conversations, not just a document, and it can change over time.
- Health professionals must consider the cultural, spiritual and psychosocial needs of the patient and should acknowledge that: at the end of life, these needs can be more important than medical needs.
- Good end of life care is not only beneficial for the patient but also improves long term carer outcomes.
- There are also cost savings associated when unnecessary and unwanted interventions are avoided.

Feature area 1: enabling genuine choice

How do we ensure that people with a life-limiting illness are involved in, and have genuine choices, about decisions regarding their medical treatments and care for both current and future medical conditions?

It is important that patients are asked to consider possible end of life contingencies, and to consider appointing a medical power of attorney, while they are still well and have the ability to express their goals, preferences and values.

Regardless of the legislative context for ACP, it is essential that conversations about the goals, values and preferences of people with life-limiting illnesses are initiated as early as possible. Preferably, this should be done by the doctor with the most established relationship with the patient, and where possible a senior doctor with experience of such discussions. The results of these conversations should be recorded and communicated to family and carers, and between different members of the treating team.

These plans should be revisited periodically and with changes of circumstances, such as a move to a residential aged care facility. Health practitioners must have the core skills to initiate and facilitate these discussions, and to manage expectations in a sensitive manner, including situations where aggressive treatment is not in the patient's best interests. They must recognise that different patients have different preferences, and there is no 'one size fits all' approach.

Clear, sensitive communication and a culture of respect for patient choices may be more beneficial than legislative changes that mandate certain medical decisions based on directives or other documents which may be out of date or may not reflect current circumstances. Use of patient-controlled records, or simply providing patients with a copy of relevant documentation, can assist with this.

The RACP notes that legislation on ACP varies between states and territories within Australia, and that this may lead to confusion for patients moving between jurisdictions, and health professionals practising in more than one jurisdiction.

The RACP recommends that governments:

- Initiate and support systems changes to give health professionals the time they need
 to discuss end of life care with patients and to conduct and document family
 conferences including goals of care discussion, appropriate multidisciplinary support,
 spiritual support, and bereavement care.
- Minimise fragmentation of care in the health system by supporting one doctor or health professional to coordinate care of terminally or chronically ill patients
- Streamline patient information so that all health professionals involved in the care of the patient, whether in the public or private healthcare sector, have access to key information including: discharge summaries, treatment and management plans (including Advance Care Planning and resuscitation orders)
- Make information regarding substitute decision maker appointments, advance care plans and goals of care plans accessible to health professionals (including ambulance officers) in e-health records
- Ensure that facilities have systems in place to receive, update and action Advance Care Plans
- Harmonise legislation on Advance Care Planning across jurisdictions and health care settings

How do we ensure people have options regarding where they want to be cared for, where they want to spend the last days of their life and where they want to die?

As the Minister's forward notes, many people currently die in hospital when they would have preferred to die at home. The RACP recommends that governments:

- Provide adequate resources in the community to support patients wishing to die at home, in a hospice or in a Residential Aged Care Facility. This includes respite care.
- Ensure patients can access specialist palliative care support as needed, at any time of day or night

However, it must be acknowledged that there are trade-offs between right place of care and other factors such as good symptom management and the burden placed on families. End of life care in hospital may be preferred by some patients, families and carers and should not be seen as a 'failure'.

Feature area 2: supporting individuals, families and carers

How do we improve the experience of people with a life-limiting illness and give them access to the support they need?

Better integration of care is likely to improve the experience of people with a life-limiting illness, their family and carers¹⁰. There should be a focus on co-ordination between inpatient and community services, and harmonisation of models of care. The RACP notes that the structure and funding of community palliative care services is variable, and that there is a division between state and federally funded care. Use of evidence-based support plans should be promoted, including bereavement follow-up plans. Health services should put in place systems to measure and benchmark outcomes of end of life care, so that feedback can be used to improve care. Innovative models of care must be developed to address the unmet needs of different patient groups, such as those with non-malignant conditions¹¹ ¹² ¹³ ¹⁴.

The RACP's advocacy in this area includes promoting the role of physicians in supporting patients being cared for at home, and working in multidisciplinary teams to provide advice to General Practitioners and community nurses who visit the home.

The RACP is also advocating for effective strategies to engage, promote, support and, where necessary, mandate the use of eHealth across health sectors and professions in order to ensure electronic patient records provide the right information to support patient centred care.

How can community services and specialist health teams assist people and their families or carers to be safe and enjoy the highest possible quality of life for as long as possible?

Firstly, it is crucial that patients at risk of dying are identified. Doctors must have the skills to proactively screen patients for those at risk of dying within 6-12 months, and should be familiar with the various trajectories of decline 15 16. They must be able to recognise patients in the 'active dying' stage, in their last weeks, days or hours of life, so that appropriate care can be provided.

Diagnosing dying is often difficult and uncertain, particularly in non-malignant illnesses, and prognosis can also be uncertain. Physicians and other health professionals do not have to be absolutely sure before they start to think about end of life care. They should acknowledge this uncertainty and discuss it openly with the patient and their family to support awareness and discussion.

Good management of symptoms is key to enabling patients to live well with a life-limiting

¹⁰ Partridge, A., Davinia, S.E, et al (2014) "Developing a Service Model that integrates Palliative Care Throughout Cancer Care: The time is now." <u>Journal of Clinical Oncology</u> JCO October 10, 2014 vol. 32 no. 29 3330-3336. (last accessed 18/11/15: http://bmjopen.bmj.com/content/2/4/e001533.full)

¹¹ Braithwaite M, Philip J, Tranberg H, et al. End of life care in CF: patients, families and staff experiences and unmet needs. J Cyst Fibros 2011;10:253-7.

¹² Braithwaite M, Philip J, Tranberg H, et al. Optimal delivery of end of life care for CF patients families and staff. J Cyst Fibros 2008;7:S100.

¹³ Braithwaite M, Philip J, Tranberg T, et al. An assessment of needs towards the development of a non-malignant palliative care model. Journal of Cystic Fibrosis 2007;6:S74.

¹⁴ Philip JA, Gold M, Sutherland S, et al. End-of-life care in adults with cystic fibrosis. J Palliat Med 2008;11:198-203.

¹⁵ Murray, S. A., M. Kendall, K. Boyd and A. Sheikh (2013). "Illness trajectories and palliative care." <u>International Perspectives on Public Health and Palliative Care</u>: 30.

¹⁶ 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.

illness, and then to die well.

The management of symptoms should be 'holistic' (physical, psychological and spiritual) and focus primarily, but not exclusively on pain and shortness of breath as well as anxiety and depression. As per ANZSPM's statement on quality end of life care, ¹⁷

"This process should be evidence-based and include a careful search for treatment side-effects or drug interactions and putting mitigating strategies in place (e.g. proactively manage constipation, nausea, cognitive impairment, fatigue, decreased function; reduce the risks of poly-pharmacy and institute rational de-prescribing processes based on harm/burden vs. benefit in the context of a realistic prognosis)."

Symptoms can change as the condition of the patient progresses and as new or ongoing treatments or procedures are undertaken. Particularly amongst patients with chronic diseases and comorbidities, symptom management can be complex and require the involvement of multiple treating practitioners.

Health practitioners must have the skills to recognise refractory symptoms and unmet needs, and seek assistance from palliative care specialists when needed.

Supporting carers and family is also an essential part of end of life care. Health practitioners should document a list of family, loved ones and carers, and develop evidence-based support plans including bereavement follow-up plans.

Feature area 3: responding to diversity

How can we provide better information and support to meet the needs of all Victorians, and improve access for groups that are underrepresented in end of life care?

What should be done to provide more culturally appropriate and responsive end of life care for people from culturally and linguistically diverse backgrounds?

It is vital that there is timely and equitable access to good end of life care, including equitable distribution of funding and palliative care beds. Evidence shows that inequitable access to consistent, good quality end of life care for certain groups of people persists. Examples include Aboriginal and Torres Strait Islander populations, non-cancer patients and older people living in residential aged care facilities. Inconsistent care is more prevalent in rural and remote communities in Australia¹⁸.

It is important to consider cultural issues which may impact on communication and care. Western culture is considered to be predominantly 'death denying', and there is a lack of open discussion of death and end of life issues^{19 20 21}. Other cultures may have attitudes to

¹⁷ Australian and New Zealand Society of Palliative Medicine (ANZSPM) Position Statement (February 2014): Quality End of Life care - Part 1 - Essential elements for quality, safety and appropriate clinical care at the end of life ".

¹⁸ Queensland Health: Statewide strategy for end of life care 2015

¹⁹ Hillman, K. (22 November 2011). "End of the care conveyor belt: death in intensive care units." <u>The</u> Conversation.

²⁰ Parker, M. (25 November 2011). "Body or soul: why we don't talk about death and dying." Ibid.

death and dying which are distinctly different, and many incorporate well established rituals and practices around death. It is important to provide end of life care in a manner which is sensitive to the cultural and religious beliefs and practices of the patient and family with respect to severe illness, willingness to participate in advance care planning, the dying process and post-death rituals.

This does not preclude thoughtful discussions over issues where usual (cultural) behaviours may not be conducive to what are recognised as best-practice outcomes. It is important to remember that there will be significant diversity both within cultural groups as well as between cultural groups. Therefore it is best not to make assumptions, and to seek information from the patient and family.

Every person has preferences for how, and how much, information is provided to themselves and their family, whether they would like to choose a substitute decision maker, and participate in advance care planning. Therefore these points need to be discussed sensitively with the patient.

Feature area 4: helping people to die well

How do we ensure that palliative care services are able to provide person-centred end of life care for people with chronic disease and complex care needs?

Good end of life care needs to be personalised to each patient's unique circumstances. As discussed above, there are a number of challenges in providing end of life care to patients with complex needs.

There may be difficulties and uncertainties in recognising the end of life in patients with non-malignant diseases, and a greater reluctance to raise end of life issues. Good, patient centred end of life care cannot be provided if patients at risk of dying are not identified and these issues are not discussed.

Patients who have fluctuating capacity to make decisions about their care, such as those with dementia, should still be involved in end of life discussions if they wish. Patients should stay in control of their care, in order to make the decisions that are right for them, as far as practicable. To achieve this they must be supported by healthcare professionals, as well as their substitute decision maker, family and carers, to express their wishes and to participate in their own care to the best of their ability.²²

Unfortunately, even with the best of intentions, disputes may arise between patients, families, guardianship authorities and treating health professionals. There are also times when the patient's wishes conflict with what their treating health professional believes to be

²¹ Lynn, J., H. R. Arkes, et al. (2000). "Rethinking fundamental assumptions: SUPPORT's implications for future reform. Study to Understand Prognoses and Preferences and Risks of Treatment." <u>J Am Geriatr Soc</u> **48**(5 Suppl): S214-221.

The Queensland Clinical Senate, in collaboration with Health Consumers Queensland, has produced *A Charter for care of adult patients at the end of life* (2015). The RACP has endorsed this Charter and it outlines a range of commitments from health professionals and patients to ensure good end of life care can be provided: <a href="https://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB0QFjAA&url=http%3A%2F%2Fwww.health.qld.gov.au%2Fpublications%2Fclinical-practice%2Fengagement%2Fqcs-patient-charter.pdf&ei=Kw1xVeyhHsXUmAXqn4H4Bg&usg=AFQjCNHpzl1j6ddnc_s6J5-MT3xxm4U3Bw&sig2=KA50tU2ZM4on-6HrUFgyPA

their best interests. Good communication is essential to resolving such disputes and preventing their escalation.

What can be done to bring together health services, home care, personal support and support for carers to improve end of life services and better respond to people's preferences and individual circumstances?

ANZSPM has identified the following evidence-to-practice gaps in the domain of coordination and integration of care:

- · Co-ordination across clinical teams, care-settings and time
- instituting processes for safe, easily accessible and timely clinical handover
- Regional registration of end of life patients to allow for optimal tracking and
- coordination of care by identified care planning teams
- more timely access by all treating teams (primary care and non-palliative care specialists) to Specialist Palliative Care for advice when needed
- adequate and timely access to community pharmacy services, including pharmaceutical supplies and appropriately skilled Home Medicines Review²³.

Feature area 5: supporting our workforce

How do we continue to build and support the workforce to meet increasing demand for end of life care?

What is needed to ensure the workforce has the skills required to provide personcentred end of life care?

ANZSPM believes that (as of 2011) there were only half the number of palliative medicine specialists in Australia that were needed. ANZSPM's Workforce Strategy 2011-2015 and beyond outlines a vision of:

- A medical workforce that is committed and skilled to providing safe and quality end of life and palliative care;
- A Palliative Medicine workforce that has the capacity to meet the needs of all people with a life limiting illness;
- A Palliative Medicine workforce that is able to provide leadership and mentoring;
- A medical workforce supported by referral pathways, networks and models of care; and
- Increasing shared care models for earlier referral of patients based on need rather than time or diagnosis.

ANZSPM has identified four priority areas, and outlined a number of strategies to achieve this vision, including:

Attracting and training Palliative Medicine workforce:

²³ Australian and New Zealand Society of Palliative Medicine (ANZSPM) (February 2014). "Position statement on Quality End of Life care - Part 1 - Essential elements for quality, safety and appropriate clinical care at the end of life ".

- Collecting data on current Palliative Medicine workforce and planning for the future
- Attracting new trainees with strategies including centralised training, increased training positions, increased accredited sites, flexible supervision models and mentoring
- Engaging the interest of GPs and other non-Palliative Medicine specialists:
 - Recognising the palliative care needs of patients with diseases other than cancer
 - Improving capacity to provide palliative care for patients with cancer
- Enhancing skills and capability of GPs and non-Palliative Medicine Specialists:
 - o Core curriculum development for undergraduate, basic and advanced training
 - o Encouraging trainees to undertake palliative medicine electives
 - Providing education and training opportunities such as CPD
- Promoting collaborative care between Palliative Medicine Specialists, GPs and other non-Palliative Medicine Specialists:
 - Enabling Palliative Medicine specialists to provide support to GPs and non-Palliative Medicine Specialist, through policy, funding, and shared medical records
 - Providing education and training opportunities for Palliative Medicine Specialists to be leaders, mentors and educators
 - Developing and promoting appropriate referral patterns
 - Developing appropriate models of care including access to support.²⁴

The RACP is committed to embedding the elements of good end of life care into physician training and practice, and to assisting physicians and trainees to develop the skills needed to provide good end of life care to all their patients.

The RACP is of the view that improved ethics training and greater availability of ethics committees or consultation services in hospitals and health services would raise awareness of ethical principles and decision-making tools, assisting health professionals to provide care in line with patients' values and preferences.

Improved access to training in communications skills would increase health professionals' confidence to initiate difficult conversations in a more timely, empathic and patient centred way.

Knowing when and how to stop, withhold or limit treatment that is inappropriate or potentially harmful to the patient is a key component of good end of life care. It is vital that healthcare professionals know and understand the law applicable in their jurisdiction and their obligations with regard to caring for patients at the end of life.

However, it must be recognised that the majority of learning does not occur in formal training situations. For example, physician training is primarily delivered in workplace settings under supervision. Approximately 70% of trainee learning is achieved through experience on the job, 20% by observing role models including supervisors, peers, and other health

²⁴ Australian and New Zealand Society of Palliative Medicine (ANZSPM) (July 2011). " Workforce Strategy – meeting the palliative medical needs of patients in Australia 2011-2015 and beyond".

professionals, and 10% through formal training.

The RACP recognises the power of role modelling, and has developed a number of supervisor training workshops, including a focus on cultural elements such as modelling patient-centred care.

How can we better support the vital efforts of volunteers?

The RACP agrees that the significant contribution of volunteers in palliative care must be acknowledged. Volunteers must have access to appropriate training, support and recognition for their vital efforts.

Conclusion

There must be many facets to a framework for good end of life care, including systemic and cultural change, and more equitable access to specialist palliative care.

However, end of life care is not just the responsibility of specialist palliative care professionals. All medical practitioners, and many other health professionals working in hospitals and the community, have a responsibility to provide good end of life care. The principles of good patient-centred end of life care must be embedded into health professional training and models of care. Health professionals must be supported to develop the core skills required to provide good end of life care, including an emphasis on communication and ethical and legal issues.

About The Royal Australasian College of Physicians

The RACP trains, educates and advocates on behalf of more than 13,500 physicians – often referred to as medical specialists – and 5,000 trainees, across Australia and New Zealand. The College represents more than 32 medical specialties including paediatrics & child health, cardiology, respiratory medicine, neurology, oncology and public health medicine, occupational & environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients. www.racp.edu.au