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**Submission to the Queensland Parliament
Inquiry into aged care, end-of-life and
palliative care and voluntary assisted
dying**

April 2019

About The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 17,000 physicians and 8,000 trainee physicians, across Australia and New Zealand.

The College represents a broad range of medical specialties including general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric 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.

The RACP welcomes the opportunity to provide a submission on the issues paper intended to inform the inquiry into aged care, end-of-life and palliative care and voluntary assisted dying convened by the Queensland Parliament's Health, Communities, Disability Services and Domestic and Family Violence Committee. The College has chosen to comment on several issues most relevant to its remit and expertise.

End-of-life and palliative care

It is widely acknowledged that too often, end-of-life care is not meeting the needs of patients and their loved ones. If patients nearing the end of life are not identified and their needs and wishes are either not clearly expressed or not respected, inappropriate and even harmful investigations and treatments may be provided in the last weeks, days or even hours of life.¹ This can increase or prolong suffering for the patient and cause distress for the families, carers and health professionals. There are several barriers to good end-of-life care, including systemic and cultural issues.²

Good end-of-life care is patient-centred, culturally appropriate, coordinated and focused on rational investigation, symptom management and de-prescribing. It involves early identification, assessment and treatment of pain and other symptoms, and enables patients nearing the end of their lives to live as well as possible, and without unnecessarily prolonging the dying process.³ Well-designed and integrated end-of life care has also been demonstrated to be more cost-effective than other therapeutic strategies and to deliver better outcomes for affected families.⁴

End-of-life care is fundamental to the work of physicians as well as other health professionals. Palliative care specialists provide clinical leadership to embed good end-of-life care in medical practice and drive cultural change that is needed to ensure that care is truly patient-centred and maintains patient dignity and respect. The RACP is at the forefront of delivering comprehensive end-of-life and palliative care training to its members.

The RACP recognises that all physicians are likely to be involved in the identification and care of patients who are nearing the end of their lives, and it is the responsibility of every physician to ensure that good patient-centred end-of life care is delivered. Good end-of-life care must be embedded throughout the health system, recognising that not all patients require, or can access, specialist palliative care, and that ongoing funding shortages and variations in health care delivery across Australia make it necessary for non-palliative care clinicians to provide good end-of-life and palliative care to thousands of patients. Training for all clinicians is thus required to recognise the need for palliative and end-of-life care, overcome misconceptions around such care and reluctance to refer and to provide appropriate end-of-life care to all patients in all settings. This is especially crucial as health professionals less comfortable with end-of-life care have been shown to offer their patients lower levels of both primary and secondary palliative care.⁵

The RACP recognises the important contribution of national palliative care⁶ projects including the updated National Palliative Care Strategy 2018 announced in March 2019 following extensive stakeholder consultation

1 Cardona-Morel, M, Kim, JHC, et al, 'Non-beneficial treatment in hospital at the end of life', International Journal for Quality in Health Care, 2016

2 Hawley, P, 'Barriers to Access to Palliative Care', Palliat Care 2017

3 Australian and New Zealand Society of Palliative Medicine, Position Statement on quality end-of-life care, 2017

4 Smith, S, Brick, A, Evidence on the Cost and Cost-Effectiveness of Palliative Care: A Literature Review, Palliat Med, 2014

5 Hui, D, Cerana, MA, et al, 'Impact of oncologists' attitudes toward end-of-life care on patients' access to palliative care', The Oncologist, 2016

6 Palliative care is a subset of end-of-life care; however, not all palliative care deals with end-of-life cases.

and acknowledges the Commonwealth funding allocated to palliative care in recent Commonwealth Budgets. While these measures will help to improve quality, coordination and access to palliative care, the RACP has recently called on the Australian Government to commit to secure, long-term funding to facilitate progress in end-of-life workforce development and quality of care and to ensure that national palliative care initiatives continue to be funded as part of mainstream health care. In light of the ongoing concerns regarding the capacity of the Queensland service and support system for palliative care and the projected need for all levels of palliative care to increase in line with the state's growing and aging population⁷, the RACP calls on the Queensland government to continue to engage with the Australian Government to commit appropriate funding to meet the mounting demands on the palliative care system across the state.

To ensure that these investments lead to sustained improvement in end-of-life care, it is imperative that all state and territory governments endorse palliative care and end-of-life care as a key priority for the Council of Australian Governments (COAG) Health Council agenda. As palliative care spans multiple sectors, including health, aged care, community care, disability care and mental health, endorsement from COAG will be important to improve access to palliative care across a range of settings in accordance with consumer-directed care. To further ensure effective service delivery, the Queensland government should follow the recommendation of Palliative Care Queensland and commit to the development of an Integrated Palliative Care Service Delivery Plan. The Plan would serve as a central service delivery model and equitable population-based funding framework designed to remedy reported lack of care coordination across care settings and time, inconsistent models of care, ineffective funding and inequitable resource allocation models, workforce shortages and other issues related to poor integration and coordination across the sector.⁸

It is crucial that adequate resources are allocated at a state level towards supporting patients wishing to die at home, in a hospice or in a residential aged care facility. The RACP calls on the Queensland government to work with Australian Government on the development of flexible, population-based, integrated models of care that improve the provision of palliative care services in non-hospital settings.

Therefore, the RACP recommends to the Committee that the Queensland government should:

- Work closely with the Australian Government to provide secure, long-term funding to improve the volume, co-ordination of and delivery of community specialist palliative care services across the life span (including paediatric palliative care services), in ways which support integration with hospital services and are delivered in conjunction with equitable access to flexible and rapidly responsive social and community services.
- Engage with the Australian Government to secure long-term funding to develop and implement models of care which improve the availability of palliative and supportive care services, with a strong focus on non-cancer services in hospitals and in non-hospital settings such as residential aged care facilities, in people's homes and in rural and remote communities and among other underserved populations.
- Champion and endorse population-based palliative and supportive care, including end-of-life care, as a COAG priority.
- Develop a Queensland Integrated Palliative Care Service Delivery Plan as a central service delivery model and equitable population-based funding framework to remedy poor integration and coordination of service delivery and funding models across the health sector.
- Foster a state-wide culture that supports open communication between patients, families and health professionals and promotes the widespread adoption of advance care plans in the health system.

Voluntary Assisted Dying

In recent years, several proposals to legalise voluntary assisted dying have been considered by Parliaments in Australia and New Zealand. As evidenced by recent public inquiries and sustained reform attempts, including this Queensland Parliament inquiry, there is significant community interest in having voluntary assisted dying as an option at the end of life.

⁷ Palliative Care Outcomes Collaboration Queensland Reports, University of Wollongong, 2017

⁸ Submission to Queensland Health Review of Palliative Care Services, Palliative Care Queensland, 2018

In November 2018, following an extensive consultation and drafting process involving a wide range of its members, the RACP issued a Statement on Voluntary Assisted Dying. The following response is based on the statement, which we encourage the Committee to consult in full on the [RACP website](#).

The RACP Statement

The RACP respects and supports all its members and does not believe it is appropriate or possible to enforce a single view on a matter where individual conscience is important. The RACP recognises that legalisation of voluntary assisted dying is for governments to decide, having regard to the will of the community, to research, and to the views of medical and health practitioners.

Legislative change related to voluntary assisted dying will affect individual members in different ways. Different clinical settings require ethical and clinical considerations to be made carefully, deliberately and systematically. Our members are not unanimous in their support or opposition for legislative change. The existence of divergent views constrains the RACP from developing a single position on the legalisation of voluntary assisted dying.

The RACP takes the following unified positions if and where voluntary assisted dying is legalised:

- Every patient should have access to timely, equitable, good quality end-of-life care, with access to specialist palliative care where appropriate. These services must not be devalued.
- On the specific issue of a competent adult in the last stages of incurable illness requesting voluntary assistance to die, the RACP supports a clinical approach of critical neutrality to encourage reflective dialogue.
- Although physicians should not be forced to act outside their values and beliefs, they also should not disengage from patients holding different values and beliefs without ensuring that arrangements for ongoing care are in place.
- Patients seeking voluntary assisted dying should be made aware of the benefits of palliative care. Referral to specialist palliative care should be strongly recommended but cannot be made mandatory. Voluntary assisted dying must not be seen as part of palliative care.
- Legitimate concerns exist around protection of vulnerable individuals or groups. Government, society and physicians must ensure that specific groups have equitable access to palliative and end-of-life care and that relationships of trust are not jeopardised. Specific regard must be given to cultural and Indigenous experience.
- All physicians must affirm the value of all patients' lives, exploring reasons for requests for voluntary assisted dying while remaining alert to any signs of coercion and reduced capacity.
- Assessments must not follow a 'tick box' approach. They must be underpinned by adequate physician-patient relationships, including appropriate training, skill and experience.
- Support, counselling and conflict mediation services must be available for individuals, families and health professionals involved.
- There must be rigorous documentation and data collection to enable review of any scheme and to assess changes in practice and the impacts on health professionals, patients and families.

This statement should not be taken as support for legislative change. The RACP will continue to highlight concerns about legislative proposals, drawing on both clinical experience and the ethical perspectives of our members. The RACP will continue to advocate for patient and physician well-being in order to support our members and contribute our expertise as medical specialists who care for dying patients.

General recommendations for policymakers

The RACP has concerns about the potential for legalised voluntary assisted dying to jeopardise vulnerable populations, be abused, expose health practitioners to professional risk, harm patients and families and erode trust in the medical profession. If Parliaments in Australia decide that laws should be changed, the development of laws, regulations and guidelines must be undertaken in consultation with medical and health experts, the RACP and other medical and health organisations.

Some key recommendations for policymakers are set out below. These have been developed in consultation with our members as the RACP has responded to previous legislative proposals. The issues relate to the accessibility of good end-of-life care.

The recommendations stated in the RACP's position statement *Improving Care at the End of Life: Our Roles and Responsibilities* (May 2016) should also be referred to in this context, including:

- ensuring that all clinicians are adequately trained to recognise the need for palliative and/or end-of-life care and to refer to or deliver appropriate palliative and end-of-life care;
- supporting system changes enabling health professionals to take the time they need to discuss end-of-life care with patients, and to conduct and document family/whānau conferences including goals-of-care discussions, appropriate social work support and bereavement care;
- providing adequate resources in the community to support patients wishing to die at home, in a hospice or in a residential aged care facility;
- ensuring patients can access specialist palliative care support as needed, at any time of day or night;
- streamlining patient information to ensure health professionals have access to key patient information and documents; and
- funding systems to measure and benchmark outcomes of end-of-life care.

Inequitable access to good quality end-of-life care persists for many Australian citizens. This includes Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds. Other groups that experience inequitable access to care include people with acquired or congenital intellectual disability, patients dying from diseases other than cancers, and people living in residential aged care facilities, some of whom are under 65 years of age, living with one or more chronic diseases. Inconsistent care is more prevalent in rural and remote communities in Australia.

Governments must remain vigilant in the areas of palliative care and aged care and commit adequate resourcing to ensure that good end-of-life care is being delivered to all citizens. Every patient should receive timely, equitable, good quality end-of-life care, including access to specialist palliative care where appropriate.

If and voluntary assisted dying is legalised in Queensland, the government should consider the following recommendations regarding end-of-life care and palliative care:

- The need for palliative care services must not be devalued; indeed, palliative care must be given even greater priority and resourcing than it is now.
- Governments must ensure that all patients have access to good end-of-life care and palliative care as needed. This includes equitable access for populations that currently experience poor access, such as people from rural, regional and remote areas, Culturally and Linguistically Diverse backgrounds, Indigenous backgrounds, people with intellectual disability, patients dying from diseases other than cancers, and people living in residential aged care facilities.
- Governments and oversight bodies must dedicate resources to closely examine voluntary assisted dying requests that arise where the patient has poor options for good end-of-life care, for example in circumstances where symptom relief and a peaceful death cannot be provided to the patient because of limited access to palliative and supportive care.
- Patients seeking voluntary assisted dying must be made aware of the benefits that palliative care can offer at the end of life and referral to specialist palliative care should be strongly recommended.
- However, palliative care referral or consultation following a request for voluntary assisted dying cannot be mandatory given that:
 - consultation or referral to palliative care services, like any medical referral, is not mandated and is a care option that a patient may or may not choose to accept;
 - legalisation of voluntary assisted dying in any form will create significant challenges for palliative medicine specialists, palliative care organisations and health care institutions;
 - voluntary assisted dying must not be seen as part of palliative care - these are distinct practices; and
 - the risk that involvement of palliative care referral and/or consultation is simply seen as, and becomes, a procedural step or “tick-the-box” exercise.

In addition to these general comments, the RACP would like to provide comments in response to several questions posed in the issues paper that fall within the College's remit:

Should medical practitioners be allowed to hold a conscientious objection against VAD? If so, why? If not, why not?

If practitioners hold a conscientious objection to VAD, should they be legally required to refer a patient to a practitioner that they know does not hold a conscientious objection or to a service provider that offer such a service? If so, why? If not, why not?

In general, where objections of conscience have arisen in medical practice in Australia and New Zealand, clinicians have accepted they should refer patients to another practitioner. However, for some physicians the moral impact of referring a request for voluntary assisted dying to a willing practitioner may be felt deeply. The RACP holds that physicians should not be forced to refer, but neither should they hinder patients from accessing such services.

Conscientious objection affects not only the medical practitioner but the interdisciplinary team treating the patient. Conscientious objection may also occur for other non-medical individuals within multidisciplinary teams or at an institutional level.

Conscientious objection may present issues in certain settings, for example amongst inpatients of an objecting hospital or hospice, those who are unable to go to another clinic, practitioners who would perform voluntary assisted dying but are not accredited at a given site, and patients living in rural areas serviced only by an objecting practitioner(s).

Protections should be available for participating or objecting practitioners who do not wish to be identified. If a public register of practitioners were to be mandated, some practitioners might encounter stigma, victimisation, harassment and other issues relating to the perception by patients, families, colleagues and the broader community. A practitioner may not want to be identified because they are concerned that patients will not come to see them if they are known to be participating in voluntary assisted dying. Conversely, a patient may refuse to see a doctor if they choose not to participate. This could compromise timely assessment and care in a geographical area where there are limited doctors to see.

It should also be recognised that some practitioners may be willing to participate in voluntary assisted dying for eligible patients in restricted ways, e.g. in a limited range of cases, or in only providing a second opinion.

Recommendations regarding conscientious objection:

- Physicians should not be forced to refer, but neither should they hinder patients from accessing such services.
- A central information source on the scheme should be available to assist patient access.
- Should a register of practitioners be developed, protections should be available for both participating and objecting practitioners who do not wish to be identified for reasons of harassment and stigma.
- Provision could be made for practitioners who are willing to participate in restricted ways, e.g. in a limited range of cases, or in only providing a second opinion.

What safeguards would be required to protect vulnerable people from being coerced into accessing such a scheme, and why?

Coercion of patients will be difficult to safeguard against completely. A significant proportion of the terminally ill and elderly are estimated to experience some form of self-perceived burden. Coercion may also arise where individuals with poor access to good end-of-life care may choose voluntary assisted dying even though symptom relief and a peaceful death could have been provided if they had had appropriate access to end-of-life care.

Recommendations regarding consent and coercion:

- Consideration must be given to enabling the exchange of information in formats accessible to the patient such as in the patient's preferred language, via sign language, interpreters, or orally.

- Legislative and regulatory measures must reflect the legitimate concerns that exist around protection of vulnerable individuals or groups, especially where discussions may not be perceived to have been fully transparent.
- Data must be collected, monitored and reported in a manner that can pinpoint abuse at an individual and population level.
- Avenues to report and investigate suspected coercion must be built into any scheme including via coronial review.

Should people be provided access to counselling services if they are considering VAD? If so, should such counselling be compulsory? Why?

How could a VAD scheme be designed to minimise the suffering and distress of a person and their loved ones?

Adequate family support, counselling and conflict mediation services will be required in the event of legalisation. Frameworks for voluntary assisted dying are based on the culture-specific concept of individual autonomy and do not necessarily acknowledge that end-of-life decisions are not made in a vacuum.

The role of and the effect on family, carers and other loved ones are important considerations. What support systems will be provided for individuals, families and health professionals who may be involved and who may suffer personal trauma or other harm because of this involvement, regardless of whether the patient ultimately proceeds with a medically assisted death?

This must be dealt with in any proposed framework. The impact of conflict and bereavement can be considerable, as can the stress on individual doctors receiving requests on a regular basis and at varying levels of involvement. Doctors may, for example, face pressure from patients who are deemed not to meet the criteria for access. Patients may also face pressure or coercion from family members or carers.

Voluntary assisted dying may also lead to enduring conflict and complex grief for remaining family members, carers and health professionals. Physicians may be placed in very difficult situations when an individual wishes to access voluntary assisted dying but family members or other health professionals disagree with their decision: the family may blame the physician if the request goes ahead. Evidence shows that many doctors who have participated in voluntary assisted dying experience emotional distress.⁹ If a proposal is legalised, there is a clear need for education, support and guidance for bereaved family members and health professionals.

Recommendations regarding conflict and bereavement support:

- Time for family/carer conferencing must be available to patients and health professionals to acknowledge the impact on families and to enable family/carer participation and response.
- Support systems must be provided for individuals, families and health professionals who may be involved and who may suffer emotional distress, personal trauma or other harm because of this involvement, regardless of whether the patient ultimately proceeds with a medically assisted death.
- Adequate funding will be required for such family support, counselling and conflict mediation services.

⁹ Stevens, K, 'Emotional and Psychological Effects of Physician-Assisted Suicide and Euthanasia on Participating Physicians', *Linacre Quarterly*, 2006