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Tēnā koe

## Implementing the End of Life Choice Act (EOLC) and providing for assisted dying services

The Royal New Zealand College of General Practitioners is the largest medical college in New Zealand. Our membership of 5,500 general practitioners comprises almost 40 percent of New Zealand's specialist medical workforce. Our kaupapa is to set and maintain education and quality standards for general practice, and to support our members to provide competent and equitable patient care.

As a principle the College has neither endorsed, nor objected to physician assisted dying and consider this a matter for individual conscience, within the law. Our doctors are trained and motivated to provide compassionate care and they hold a wide range of views on physician assisted dying. While the College is agnostic about EOLC, it is however, pragmatic about the decision made by the public and intends to ensure patient expectations are upheld in relation to the EOLC Act.

Our main concern is that for there to be real choice the alternate options must be equally funded and equally available. We note the decision by Cabinet to fully fund End of Life Choice, and efforts will be made to ensure access throughout the country. This must be contrasted with fact that palliative care is far from fully funded and there are many parts of the country that effectively have no access to palliative care. A choice between fully funded assistance in dying and underfunded palliative care is not a fair choice, the playing field is not level.

### Implementation

Early implementation of the EOLC raises issues that pose significant risk. The Go Live date for 7 November 2021 was set when the Act was passed. The Act only makes assistance in dying legal as of 7 November 2021, it does not require a fully funded and accessible service by that date. We question the urgency of this work in a period where our health system and services are over-whelmed and there is a risk of implementation failure leading to a regulatory risk due to unprecedented circumstances.

The impact of Covid-19 testing, vaccinations and increased consultations, the health system review and transition, an unexpected rise in the population impacting on the number of general practice presentations, increases in co-morbidity, mental health issues and serious complex presentations. When combined with GP shortages, it shows a general practice workforce struggling to manage the demand for services. General practices are adapting their systems and processes to meet the shift from hospital care to primary GP specialist care. Meeting the demands of patients in our rapidly changing environment as well as preparing for implementation of EOLC on a specified, mandated date, in spite of implementation risks continuing to exist, would add significant stress and impact on other general practice care.

On November 7<sup>th</sup> it will be legal for private clinics to open and provide assisted dying services on a fee for service (to the patient) basis. The service would be best provided either in the patient's home or in a facility staffed fully by clinicians who are happy to provide care, where there is no conflict with the provision of regular clinical care. The logistics of aiding assisted dying in an acceptable way are complex. There is concern about lack of access to appropriate facility space as well as access to services. This concern will not be easy to resolve. Suggesting that access can be arranged for EOLC when we cannot achieve it for most other services is a risk. Without certainty regarding fees, few providers would be willing to take on assisted dying, except on a full user pays basis. In addition, fee's transparency is important for a regulated service to avoid risk of

challenge or misunderstanding at a time of heightened emotional presentation. (The Health and Disability Code of Consumers' Rights)

## Funding Modules

The modular system for funding is clear and enables the different activities to be shared across the system, to achieve the expected outcome for a person seeking EOLC services. We identify time as a significant factor for driving costs and the scope of time and cost may be underestimated and suggest that testing and trialing may need to inform a final funding model. We identify additional points for consideration:

- **Module 1** - In general practice the relationship with a patient and their whānau, the magnitude of the decision to be made and the implications, is likely to be extremely time intensive and extend the 15-minute standard consultation.
- **Module 2** – If the consultation determines that a person is eligible and that a capacity assessment is required, the current wait time to see a psychiatrist is between two weeks and eight months, and dependent on availability within a geographic area. Some people may have to travel outside their area for a capacity assessment and there may be a consultation cost for the psychiatrist.
- **Module 3** – To assist continuity of referrals (to and from a GP to a psychiatrist) a result would normally be followed up. Once a decision is made by a psychiatrist an additional GP consultation would be required to either, take responsibility for providing the service, or referring a person to another provider. It is not clear what would happen if a GP decided not to take on the responsibility for offering Modules 4 or 5 services. GPs have an ethical duty to refer a patient onto an alternate service provider. However, this does not mean an alternate provider is readily available and delays for the patient are likely, and there could be unintended consequences. Similar issues occurred under the previous referral rules for termination of pregnancy.
- **Module 4** – If a GP decides to provide the EOLC service there are multiple considerations such as where the death will take place, scheduling when, identifying who needs to be involved, preparing the space if offsite, meeting with the person and their whānau to plan arrangements, arranging administration of medication supply, and documentation for the death certificate. This is time and labour intensive.
- **Module 5** - Documentation needs to be robust due to potential for EOLC services to be under considerable public scrutiny. We note that the system will include and audit of the health practitioners record, but there is no expectation that they will be expected to review the quality of work undertaken.

## Te Tiriti o Waitangi

We note that the SCENZ Group is to provide oversight of EOLC obligations to Te Tiriti o Waitangi in ensuring that health services are accessible, support equitable outcomes for all, and meet the government's obligations under Te Tiriti o Waitangi. We consider access should not depend on where people live, whether they can afford to pay, nor should they have to fundraise to meet costs, and should not be limited by social or cultural barriers.

## Equity

The College considers equity for Māori in EOLC considerations is not simply a matter of levels of public funding: choice is more complex due to the ways in which Māori make and implement decisions. Rangatiratanga, for example, suggests services should be consistent with Māori aspirations and operate on the assumption of both clinical and cultural safety. Findings of the WAI 2575 Stage One Report suggest there are at least five key implications for all health-related legislative and policy instruments, to meet obligations to the Te Tiriti o Waitangi, and the funding approach should ensure cultural support and keeping people culturally safe, e.g.

1. Be compliant with Te Tiriti
2. Recognise tino rangatiratanga
3. Ensure accountability to Māori
4. Ensure that investment in Māori health is commensurate with equitable outcomes
5. Embed equitable and non-racist practices in policy development, delivery, and evaluation.<sup>1</sup>

To be reflective of a Te Tiriti partnership in working towards better outcomes for Māori, Te Akoranga a Māui<sup>1</sup> asks whether wairua was considered during the drafting of the EOLC Act, and advise that:

- Māori oversight will be critical where there could be a need to discuss how a choice to end one's life influences practices, particularly around mate, tūpāpaku, tangihanga, and pāmamae.
- Having someone knowledgeable available to all people, and especially Māori, should be a consideration in the process.
- Tino Rangatiratanga is not the complete individual autonomy which is an underlying assumption of the Act. For some Maori, it is te ringa o Aitua alone which should claim a life. Aitua being the miscarriage of Rangī and Papa in some pūrākau.
- To take one's own life is problematic when it violates tikanga which has an underlying philosophical basis making change very difficult, as we are part of a much larger group with complex connections. We question how this is addressed in the implementation.<sup>2</sup>

### Option 1

We support Option 1 as a pragmatic solution as it would sit alongside the portfolio of services within DHBs, provide a level of external oversight and identity within the health system.

- The wide variation in the time that might be needed to provide the service is ambiguous and has potential to substantially increase costs, e.g., in maternity care there are hidden costs due to the intensive nature of the work, and the fee for service does not adequately cover time.
- Providing travel costs for this service when it is not available for most other GP services is not standard practice except in rural areas. We would like to know more about why this is specified.
- Our members have questioned why exceptions are being made for people who decide to end life, when the same scope of funding is not present for most other services which support life and health.
- There is deep concern about the inequity of what is proposed by comparison with other services, such as dermatology or palliative care which are funded through a combination of private fees and charitable donations, and access is dependent on whether there are willing practitioners available in all geographic areas.
- The concern about lack of access in some areas is appropriate, however, this service will evolve over time and in the first instance, the level of choice may not be available. We note that there seems to be an emphasis on solving all the access and choice issues for EOLC when we do not do this for other services. (Maternity being the exception)
- Without certainty regarding fees, there will be few who will be willing to take on EOLC, on a full user pays basis.
- GPs are bound to meet and apply the HDC Code, including information on rights, risks and costs of a service. The lack of detail on many important aspects of providing a clinical service are still to be resolved. This places GPs at risk of unintentional breaches of the Code and could cause confusion for patients at a time when clarity of decision making is of the utmost importance.

### Research, evaluation

Beyond the effects on people's lives, poor-quality care wastes time and money. Our health system needs better evidence, greater transparency and a deeper understanding of interventions and outcomes to inform future services. Although there are reporting requirements against the Assisted Dying Services Notice 2021, (Section 88), we did not find any evidence of service evaluation built into the EOLC system. Any interventions which transform the delivery of health and are being implemented widely, should be assessed to understand the impact of interventions enables healthcare teams to learn and improve services in the future.<sup>3</sup>

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<sup>1</sup> Te Akoranga a Māui is the RNZCGP Māori representative group. All College members who self-identity as Māori and have Māori whakapapa automatically belong to the group.

## In summary

Implementation of assisted dying is a small component of wider work to improve palliative and end of life care in New Zealand. We note that the Minister of Health has sought proposals to address recognised sustainability, quality and equity issues within palliative care, and we indicate our interest in being involved in providing advice in this area of work.

If you have any questions, or require additional information, please email us at [policy@rnzcgp.org.nz](mailto:policy@rnzcgp.org.nz)

Nāku noa, nā



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<sup>1</sup> Came H, O'Sullivan D, Kidd J, McCreanor T. The Waitangi Tribunal's WAI 2575 Report: Implications for Decolonizing Health Systems. Volume 22/1, June 2020, pp 209 – 220

<sup>2</sup> Carrucan E. Tikanga Maori issues with the proposed End of Life Choice Act 2019. Lawtalk. Issue 943. Sept: 2020.

<sup>3</sup> Delivering quality health service – A global imperative for universal health coverage. World Health Organisation, World Bank Group, OECD. 2018. <https://apps.who.int/iris/bitstream/handle/10665/272465/9789241513906-eng.pdf?ua=1>