

August 5, 2024

Manatū Hauora / Ministry of Health

• e mail: derek.senior@health.govt.nz

Dear Mr Senior

Initial submission on the review of the End of Life Choice Act

The Australian and New Zealand College of Anaesthetists / Faculty of Pain Medicine (ANZCA) is committed to setting the highest standards of clinical practice in the fields of anaesthesia, perioperative medicine and pain medicine. As one of the largest medical colleges in Australasia, ANZCA is responsible for the postgraduate training programs of anaesthetists and specialist pain medicine physicians, in addition to promoting best practice and ongoing continuous improvement that contributes to a high-quality health system.

The issue of legalised voluntary assisted dying (VAD) for terminally ill people is a very important one for anaesthetists and specialist pain medicine physicians who may be involved from time to time in end-of-life discussions and decisions.

The New Zealand Committees of the college would like to provide our own feedback on the operation of the Act – of necessity the scope of this has been limited by a very short time frame. We would have preferred the time to seek meaningful feedback from across New Zealand to reflect the views of ANZCA and FPM Fellows, trainees, specialist international medical graduates individually and as members of key committees on their experience of the operation of the Act, however, *Given the really short time given for this consultation,* our New Zealand senior clinical leadership were consulted via a quick survey for their views on the very specific questions you have posed. These are presented with the caveat that the number of responses is small, and the question format superficial compared to the complexity and nature of the content.

ANZCA has approached the issue of assisted dying from the perspective of patient advocacy: seeking to protect patients' rights and to ensure that patients can exercise these rights.

ANZCA is also concerned to continue to ensure that medical practitioners, in particular specialist anaesthetists and pain medicine physicians, are protected appropriately under the Act, and not required to undertake activities which they deem inappropriate or contrary to their personal beliefs or their professional responsibilities towards their patients.

Of the respondents, eight were anaesthetists, and 4 were pain specialists (3 were joint anaesthetist and pain specialists). Only *one* had had direct professional interaction with operation of the Act.

Your questions are précised in black, and the answers received are summarised in blue below:



Increasing clarity in the Act

We are interested in hearing about any areas in the Act that you consider could be clearer. For example, this might involve increasing clarity about what should happen during parts of the process, or what particular terms or rules in the Act mean.

Most respondents expressed the view that there was sufficient clarity about how the Act operates. There was a request to more explicitly clarify the exact pathways and differences between an "attending medical practitioner" and an "independent medical practitioner" – particularly in relation to knowledge of a patient or their whanau. There are still concerns regarding the extent of the responsibilities of anaesthetists and pain specialists under the Act, in particular the extent to which an individual practitioner's own moral code could be infringed upon by the Act.

The majority feel the Act is clear and understandable for medical practitioners.

We are also interested in hearing about any areas where you consider that the way assisted dying is currently provided may be inconsistent with what is set out in the Act.

There was concern that delays and deteriorations can in effect deny patients the right to exercise this choice. Prospective predictions for end of life are often inaccurate and any minimum timeframe should be applied with caution, as these create the risk of prolonging avoidable suffering. Overall, no greater specificity is required as "end of life" is subjective, difficult to predict and uncertain.

Alleviation of patient suffering should take priority; no period of **intolerable** suffering is "acceptably short". Critically, a patient's perception of their intolerance to suffering and their decision to end their life are more important than a specified time in days or years.

Balancing access and safeguards

While some safeguards apply to general health services, assisted dying includes some specific safeguards not associated with other health services. This is because there are no opportunities to rectify a situation if someone is assisted to die when they should not have been.

There is a balance to be struck in providing for safeguards to protect people, while also limiting barriers that might prevent eligible individuals from accessing assisted dying. There will be different views about exactly where the balance between these should lie.

We are interested in hearing your views on whether you consider that the Act provides sufficient safeguards to ensure that people only receive assisted dying if they:

- are eligible yes to ONLY, but note not always, e.g. when denied by availability / time constraints
- actively seek and consent to it: Consent YES, but some lack the wherewithal to seek information
- are competent to consent to it, YES
- that this consent is provided without pressure from others. YES. If anything, relatives try to override the patient's requests.

Are there any changes that could be considered to improve safeguards in the Act for those accessing assisted dying, or those providing assisted dying?

Safeguards are needed both to protect patients from hasty decisions or pressure, but also to ensure their clearly and appropriately medically witnessed wishes are enacted, not frustrated by delays and loss of capacity (especially where patients remain aware of, but unable to change intolerable circumstances).

Are there any requirements in the Act that you consider unreasonably or unnecessarily limit access to assisted dying (excluding eligibility rules). What changes could improve access?



Clause 10 of the Act prohibits health practitioners from initiating any discussion with a person about assisted dying under the Act, or from making any suggestion to the person that they exercise the option of receiving assisted dying. We are interested in views on whether practitioners should be able to initiate conversations about assisted dying with a person?

There was strong agreement that doctors should be able to advise patients that this option exists as many patients don't know assisted dying is even an option – "informing people of options does not equal coercion".

Improving the process for assisted dying

We are interested in hearing about whether there are parts of the process to seek and receive assisted dying that you consider could be improved. For example, are there steps or requirements required by the Act that you consider should be removed? Are there any process steps that you believe should be added?

Removing the requirement for ability to consent at point of death, if sufficient evidence of robust advance directive exists, would improve compliance with a patients' explicit wishes would provide much comfort to deteriorating but fully competent patients. This was accompanied by the caveat: "If an advance directive is used to 'consent' (or actually authorise) to end of life, then there will need to be very robust legal safeguards for this. However, this is wanted for those who would want end of life if descent into severe dementia, or loss of ability to communicate occurs."

Roles and responsibilities

We are interested in your views on whether you consider that the roles and responsibilities of the following individuals and organisations are sufficiently clear under the Act, and whether you think any changes should be considered.

Sufficiently clear – though contact details for key people sometimes hard to get hold of easily.

The ministry is also interested in your views on the types of practitioners that should be able to provide assisted dying services, or parts of the service. In your view, should the following types of practitioners be able to provide assisted dying services?

- Junior medical practitioners: Universally NOT supported
- Overseas-trained medical practitioners: The question of recency of migration arose, i.e. when does
 an overseas-trained medical practitioner become "just" a medical practitioner? This answer was
 related to the required knowledge of cultural safety and New Zealand norms. Most though felt that
 any doctors with full general or vocational registration should be able to provide these services,
 according to their own values.
- Medical practitioners operating under supervision. See above, Feedback received stated that only
 those with full NZ registration be able to provide these services.

Currently, completing an online training module is required to access funding for assisted dying. We are interested in your views on whether training for practitioners should be required under the legislation. If so, what type or level of training should be required?

ALL felt training was required. As an example: "Yes, training should be required for all medical practitioners who act in this role - addressing variety of issues from practicalities / legalities / ethics / and managing personal wellbeing". It was also suggested that training be renewed annually (as the occasions when it is used can be very infrequent) Suggestions were made for both online and scenario based.



training, with training on the specifics of informed consent and legal standards refreshed by suitable, regular, online training.

Are the roles and responsibilities of your organisation sufficiently clear in relation to the Act? If not, what should be added or changed to make this clearer?

As a bi-national medical college, we have clear professional guidelines for our fellows, and good legal understanding and concordance across both New Zealand and Australia.

Other feedback

Other suggestions for improvements to the operation of the act included a real need for public awareness of the Act to be improved, and for current uneven access in practical terms (availability of doctors, geography, costs) for patients to be improved.

In addition, the following additional issues were raised in relation to the operation of the Act:

- Rural patients may be disadvantaged by difficulties of access to services (for example, a palliative care
 physician or palliative care services, obtaining two independent medical reviews and, in particular, the
 advice of a medical practitioner who has knowledge of the disease process and its prognosis; and
 psychiatric or other specialist referral), and difficulties in accessing their wishes due to lack of access
 to advanced care plans, living wills, statements on electronic health records and websites in urgent
 care situations.
- Mechanisms should be developed to ensure access to information on End of Life Choices at any medical facility a patient might present to (in their own community or in a centre away from home in cases of a rapid deterioration or trauma while travelling).
- It is essential to ensure accessing assisted dying is not a substitute for good palliative care.

The <u>robust reporting of outcomes</u> by the Registrar (assisted dying) of requests is welcome, and it appears to show that practicalities and delays clearly adversely impact patient choice.

We look forward to the outcome of the review. Please contact us if further clarification is required.

Nāku noa, nā

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(For more information, please contact Leonie Walker, Senior Policy Advisor lwalker@anzca.org.nz)