Aged Care Association
NEW ZEALAND

Aged Care Association submission to Manatū Hauora | Ministry of Health on the review of the End of Life Choice Act 2019

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About the Aged Care Association

This submission is from the Aged Care Association (ACA), the peak body for the aged residential care (ARC) sector in New Zealand.

New Zealand has over 670 aged residential care facilities, with more than 40,000 beds and 35,000 residents. In comparison, Te Whatu Ora oversees 10,748 public hospital beds.

Our members provide rest home, hospital, dementia, psychogeriatric, respite, and palliative care and care for around 700 younger people with disabilities.

Sixty six percent of beds are run by religious institutions, charitable trusts, family-owned, not-for-profits, and privately owned facilities. Most of the remaining beds are operated by listed companies (34 percent), with less than 1 percent provided by Te Whatu Ora.

Residents may be

- very frail and clinically unstable,
- well but disabled and have very high care needs,
- cognitively impaired or with mental health issues, with some requiring a secure environment,
- receiving end of life care,
- receiving an assisted death.

Funding for aged residential care is a mix of means-tested user-pays and government subsidy.

Aged residential care providers are contracted by Te Whatu Ora to provide care services at a rate that is set annually.

Aged care providers are underfunded and stretched; its workforce is under-resourced and overworked.

The ACA welcomes the opportunity to make a submission to Manatū Hauora | Ministry of Health on the review of the End of Life Choice Act 2019. The Association is available for discussion at any time.

The aged residential care sector

The ARC sector provides services across four care categories:

Rest home care: the resident is assessed as generally able to be independent (are mobile and can feed themselves) but needing assistance with personal care or supervision of activities of daily living. The residents are assessed as unable to safely live in their own homes (or other community settings) either due to their disability needs and/or lack of informal supports.

Hospital level care or continuing care: the resident is assessed as having significant disability, usually in combination with medical problems, which requires 24-hour supervision with registered nurse input for their care.

Dementia care: the resident is assessed as needing 24-hour supervision and care, in a secure environment due to risk of wandering or becoming lost due to memory loss or confusion.

Psychogeriatric care (also known as specialised hospital care): the resident is assessed as needing 24-hour supervision and care. This level of care is for people with major behavioural issues (including severe dementia or addictions). They need a high level of specialist nursing care.

The staffing requirements, including skill level of the workers, vary significantly across these four levels, as the acuity and medical needs of residents also vary.

The Age-Related Residential Care Services Agreement, which is the sector agreement between Te Whatu Ora and ARC facilities, is set annually and negotiated by the Aged Care Association, lays down the requirements for staffing across these four levels. It also specifies the training and certification requirements for care workers across these levels.

Around 70 percent of the ARC workforce is made up of internationally qualified care workers and nurses.

Aged residential care and assisted dying

The End of Life Choice Act impacts the aged residential care disproportionally; of people who chose an assisted death, over 79 percent were over 65, and 20 percent over 85 years.

It is obvious in reading the Act that the aged residential care sector was not considered when the Bill was drafted. The intersection of age, disease, and an institutional setting that is legally home for a resident, means that providing an assisted death has wider implications than the Act considers.

We are concerned that people may be admitted to an aged residential care facility, under either a long term, palliative care or respite contract, specifically to have an assisted death.

Aged residential care facilities are not set up to, and do not wish to become places where people go to have an assisted death. Although we acknowledge it would be hard to police, legislative guidance about how ARC should or shouldn't be used for assisted dying would be helpful.

Conscientious objection

While organisations can choose to have a "conscientious objector" status (Hospice NZ v Attorney-General NZHC1356 [16 June 2020]), for an aged care provider, this is in direct opposition to the right of resident to choose an assisted death in their home.

It would be useful for the matter to be considered, and the Act updated to provide a pathway in these situations.

Eligibility

The ACA does not believe there are any changes needed to eligibility for an assisted death.

Safeguards

Association members have told us about their discomfort that some residents who have chosen an assisted death may have wanted to opt-out but didn't due to a perceived shame or embarrassment about changing their mind, or the pressure of "putting people out".

The ACA supports consideration of how this potential barrier to opting out could be mitigated.

Practitioners

The ACA supports nurse practitioners having the same rights and obligations under the Act as medical practitioners.

Integrating palliative care and assisted dying

The ACA believes more could be done to integrate palliative care and assisted dying. People who have chosen an assisted death should have the same access to palliative care as any other person.

Te Whatu Ora | Health NZ currently only funds six weeks of palliative care for a patient which is not only unrealistic but could also be a reason for a person to feel pressured to choose an assisted death.

Choosing an assisted death but dying before it happens

It would be useful to know why so many people who have chosen to have an assisted death die before that happens. Perhaps more resources are required, or faster and more flexible timeframes.

Culturally appropriate processes for Māori and Pacific Peoples

The ACA would like to see funding available for hui and other culturally appropriate process for whānau/families, especially Māori and Pacific Peoples to access if they wish.

Support for staff and residents

Staff in aged residential care are in a unique position, with enduring and loving relationships a common feature in care facilities across the country.

Specialised support needs to be available for staff and residents who are impacted by assisted dying.