



**New Zealand
Aged Care Association**

Submission to Parliament's Health Select
Committee

on the

Petition of Hon Maryan Street and 8,974 others
relating to medically assisted dying

1 February 2016

Introduction

1. This submission is from the New Zealand Aged Care Association (NZACA), the peak body for the aged residential care sector in New Zealand. With over 580 members, we represent 90% or approximately 33,500 beds of the country's aged residential care (ARC) sector. Our members range from the very small stand-alone care homes to the large co-located sites that include care services and retirement villages. Our members' services include rest home, hospital, dementia and psychogeriatric care, as well as short-term respite care.
2. Advocating and lobbying to government to shape policies and create an environment that helps our members provide outstanding quality care is at the heart of what we do. We also provide leadership on issues that impact on the success of our members, for example, the work we are currently doing on the Equal Pay Case. We also produce valuable research, professional development opportunities, information and publications to help our members make informed business decisions, improve capability and keep them up to date with sector developments.
3. This submission relates solely to older citizens in aged residential care facilities where they receive professional oversight of their well-being, and not to older citizens in general, be they in the care of family/whanau and others who live independently in the community.
4. We have a small team of five staff based in Wellington and led by Chief Executive, Simon Wallace, a representative Board of ten members chaired by Simon O'Dowd and a network of thirteen branches around New Zealand.
5. Any enquiries relating to this paper should in the first instance be referred to Simon Wallace, NZACA Chief Executive at simon@nzaca.org.nz or by phone on 04 473 3159.
6. The Association wishes to be heard by the Committee in support of this submission.

Background information

7. At present, 35 % of New Zealanders live out their final years and die in aged residential care facilities.
8. In 2015 it is projected that 31.4% of all deaths will be of people aged 85 - 94 years. It is projected that by 2068 this figure will rise to 78.4%.
9. If current patterns of end- of- life care continue, and all the indications are that it will, most of the deaths over age 85 will occur in aged residential care facilities after an extended period of care.
10. These deaths are likely to be occurring to people with more co-morbidities (a number of conditions) and a high prevalence of dementia.

Our position

The NZACA and its members are committed to the contentment and welfare of their elderly residents. In line with other jurisdictions, the NZACA opposes the introduction of medically assisted dying.

11. As our position states, NZACA members are wholly committed to the contentment and welfare of their residents who need and deserve quality care at the end of their lives. Our job is to make these people as comfortable and pain free as possible. At the same time, we also support the emotional and physical needs of the families and whanau of these residents.

The factors that contribute to the desire to end one's life

12. As people live longer their frailty increases and this can contribute to the desire to end one's life. Researchers refer to the 'third age', the decade following retirement when one is in "fairly good condition". This is when people go travelling, write books, enjoy their families and take up hobbies. We used to die at the end of that decade....."Fairly worn out, but quite happy". (note 1)
13. Now many people live an extra decade or two, even three - typically, with "withering health and independence". The older person will generally be very frail, possibly doubly incontinent. Sight, hearing and ability to orient oneself in time and space may all be severely compromised. The older person may be experiencing a lot of physical as well as emotional pain. This is the 'fourth age'. (note 2)
14. The NZACA takes the view that as providers of care our members must always strive to meet the needs of this group so they do not have the desire to end their life. The focus is on adding quality to the years lived.
15. And yet our elderly New Zealanders are vulnerable. They may inwardly feel pressured by their desire, or their families' encouragement, to make a decision to die. This may be motivated, personally or externally, to leave some inheritance intact. Around 50% of abuse cases handled by Age Concern New Zealand are financially driven. Age Concern has found that financial abuse against residents in aged residential care falls into three main categories:
 - Families not making available to residents for use the 'comfort money' that is paid by Work and Income
 - Not paying the pension the resident receives over to the care facility (this makes up a portion of the care fee)
 - Just not paying fees as families believe the parent's money belongs to them (note 3).
16. In California in 1992, when the campaign to have the right to receive assistance from physicians in dying was at its height, there was an exemption proposed so that the right did

not apply to patients in nursing facilities - this was proposed in order to protect the elderly from the financially related pressures that have been referred to above.

Palliative Care

17. With deaths in aged residential care increasing faster than for any other place of death in New Zealand, the support provided to our care homes is becoming increasingly critical and the way the sector is funded does not reflect this new reality. We believe this needs to change and it is vital adequate government support is provided to help our residents 'die well' and to provide support to families through the bereavement process.
18. The NZACA has welcomed government and individual DHB palliative care initiatives this year, but there needs to be better recognition of the palliative care provision that we are providing. In our 2016/17 negotiations with the DHBs we will be advocating for a distinct palliative care supplement and for consistent reimbursement for palliative and end of life care across all end of life care settings. Currently a person dying in a public hospital or hospice in New Zealand has all their costs paid, while those in our members' care homes are means-tested.
19. If the New Zealand government improved palliative care funding in ARC homes it would reduce the burden on our hospitals. As well as meaning these homes have the resources to provide great care, it would also allow care homes to have the resource they need to support families and whanau.

Views of NZACA members

20. The NZACA canvassed members on the introduction of legislation that would permit medically-assisted dying in the event of a terminal illness or irreversible condition. Respondents were of the view that the more proper position for older citizens in care was to receive additional help/support in the provision of care as they progressed through the natural aging process, rather than the hastening of their death.
21. Our members identified a number of ways carers could further add to the quality of the end of life for older citizens in aged care, and it is on these that they wish to have the Association retain its focus. Suggestions made included:
 - Further education of staff in caring for residents in the 'fourth age'.
 - More hospice involvement – at present 'end of life' may not meet the current hospice criteria.
 - Additional subsidised GP and other specialist visits, so the resident has high level input into their needs. This could include an on-call Palliative Care Nurse to assist where the need arises.
 - Increased staffing at 'end of life' so the resident has a staff member with them when no relative is available, as well as the availability of skilled staff to support the families/whanau.

- The availability of accommodation that is suitable for the families/whanau such as a lounge/bedroom and facilities.
- Further education of the public in relation to Advanced Care Planning (ACP) and the options available.

The attitudes of New Zealanders towards the ending of one's life and the current legal situation

22. Issues raised by NZACA members should medically assisted dying become law, focused primarily on:

- **The personal beliefs of staff.** Staff would need the option of removing themselves from a situation if they felt uncomfortable. However, this would create staffing issues as well as impacting on the employer's ability to attract and/or retain staff.

Members felt that the more they were involved in end of life care, the higher the opposition to medically- assisted dying they became. This reflects the results of a study undertaken in the UK where it was found the opposition to euthanasia and physician assisted suicide was highest amongst palliative care and elderly specialists. (note 4). Likewise in a study in the US state of Washington, medical staff who had the most experience in dealing with terminally ill patients were the most likely to oppose euthanasia and assisted suicide, and psychiatrists, who had the least contact with terminally ill patients, were most likely to be supportive of these practices (note 5).

- **Not all facilities would agree to medically assisted dying.** This may result in residents being placed in certain facilities because medically assisted dying was practised. As a consequence this could result in residents being placed away from their family or local community, or placed in a facility which does not best meet their needs.
- **Impact of introducing changes.** When legislation impacting on the sector is changed, protocols need writing and introduced to staff along with education. This is a significant cost and unless the sector is compensated for it the reduction in money available for the delivery of care becomes an issue.

End

Notes

1. Jana Kralova, The University of Bath GW4 'Dying Well Network'
<https://gw4dyingwell.wordpress.com/>
2. As above
3. Pers Comm. (National Office, Age Concern NZ - Dec 2015)
4. Seale C(April 2009). "Legalisation of euthanasia or physician-assisted suicide; survey of doctors' attitudes", *Palliat Med* **23** (3); 205-12.doi:10.1056/NEJM199407143310206.
5. Cohen, Jonathan S,; Fihn, Stephan D,; Boyko, EdwardJ,; Jonsen, Albert R,; Wood, Robert W, (14 July 1994). "Attitudes toward Assisted Suicide and Euthanasia among Physicians in Washington State", *New England Journal of Medicine* **331** (2): 89-94, doi:10.1056/NEJM199407143310206. Asch & DeKay 1997