



**Submission to the
Standing Committee on
Legal and Social Issues:
*Inquiry into End of Life
Choices***

July 2015

National Seniors

Australia

Submission 509

About National Seniors Australia

National Seniors Australia is a not-for-profit organisation that gives voice to issues that affect Australians aged 50 years and over. It is the largest membership organisation of its type in Australia with more than 200,000 members and is the fourth largest in the world.

We give our members a voice – we listen and represent our members' views to governments, business and the community on the issues of concern to the over 50s.

We keep our members informed – by providing news and information to our members through our Australia-wide branch network, comprehensive website, forums and meetings, bi-monthly lifestyle magazine and weekly e-newsletter.

We provide a world of opportunity – we offer members the chance to use their expertise, skills and life experience to make a difference by volunteering and making a difference to the lives of others.

We help our members save – we offer member rewards with discounts from thousands of businesses across Australia. We also offer exclusive travel discounts and more tours designed for the over 50s and provide our members with affordable, quality insurance to suit their needs.

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Recommendations

National Seniors Australia recommends:

Issue 1: Definition of End of Life

1. National Seniors recommends that a clear and unambiguous definition of 'end of life' be developed with input from health and legal professionals and the community, for inclusion in legislation, for use by health professionals and for the purpose of community education.

Issue 2: Advanced Care Planning & Directives

2. National Seniors recommends that Victoria immediately introduce legislation to enable the use of legally binding Advance Care Directives, with Directives requiring mandatory compliance by health professionals and family members.

3. National Seniors recommends that Victoria promotes a national approach to advance care planning legislation including the development of a common template for Advance Care Directives.

Issue 3: Appropriate Protection for Health Professionals

4. Legislation specifically protecting all relevant health professionals who comply with legally binding Advance Care Directives and other relevant legislation should be amended as needed to ensure full protection.

Issue 5: The Need for Education of Health Professionals

6. National Seniors recommends that the Victorian Government make funds available for a comprehensive education programme for health professionals about end of life law and its application in caring for the dying.

Issue 6: Improving Palliative Care

7. National Seniors recommends that the Victorian Government develops a comprehensive, holistic, fully funded, palliative care programme available to people dying at home, in residential care or in special facilities.

Issue 7: Community Consultation about Death with Dignity

8. National Seniors recommends that the Victorian Government, following legislation to establish Advance Care Directives, undertake wide community consultation to assess community views about medically assisted suicide within very strict parameters and which may lead to an exposure draft for comment or possibly a plebiscite.

Introduction

National Seniors Victorian Policy Advisory Group plays a key role in identifying emerging issues and trends affecting the over-50s throughout the State. It also acts as a conduit between National Seniors members within the State, relevant community organisations and the Victorian Government.

Currently, over 46 per cent of Victorian voters are aged over 50¹. Within a few years the majority of voters will be aged 50 and over.

There is a high level of community interest in the law surrounding end of life. While modern society has benefited from increased longevity and has reduced the frequency with which individuals see death at close hand, everyone knows they will face death and many have experienced the drawn out and distressing death of loved ones.

National Seniors therefore welcomes the *Inquiry into End of Life Choices* as an opportunity to examine issues of great importance to Victorian seniors and to the broader community.

Many countries and other Australian states and territories are addressing end of life issues. National Seniors believes that it is important for Victorian residents to have the same opportunity to make choices about their own death.

In this submission we set out key issues and recommendations for consideration by the Standing Committee on Legal and Social Issues.

Please note that National Seniors Australia does not have a policy that supports physician assisted euthanasia.

Issues and Recommendations

Issue 1: Definition of End of Life

1. National Seniors recommends that a clear and unambiguous definition of 'end of life' be developed with input from health and legal professionals and the community, for inclusion in legislation, for use by health professionals and for the purpose of community education.

Currently, in Australia, there is no legally defined or commonly agreed definition of the term 'end of life'. This is one of the first issues that the Inquiry needs to address - it is essential that there is common understanding of the term among health professionals, legal professionals, policy makers and the community generally.

While not recommending a specific definition, National Seniors proposes that 'end of life' be specifically linked to a medical diagnosis that a particular condition will result in death. The

¹ The Australian Electoral Commission (AEC). 2013. *Elector Count by Division, Age Group and Gender for all States and Territories Australian Government*.

definition should not set a time frame within which death is expected to occur. The following description provides an example of the type of definition favoured by National Seniors:

*End of life care is defined as care that helps those with advanced, progressive, incurable illness to live as well as possible until they die. The end of life care phase may last for weeks, months or years.*²

A definition should be developed by a panel of multi-disciplinary experts and community representatives. It is important that a clear definition is included in legislation to ensure that all parties engaged with a person at the end of life understand the circumstances to which legislation applies.

Issue 2: Advanced Care Planning & Directives

2. National Seniors recommends that Victoria immediately introduce legislation to enable the use of legally binding Advance Care Directives, with Directives requiring mandatory compliance by health professionals and family members.

3. National Seniors recommends that Victoria promotes a national approach to advance care planning legislation including the development of a common template for Advance Care Directives.

Advance Care Planning Australia reports³:

- About 85 percent of people will die after chronic illness, not a sudden event
- Up to 50 percent of Australians will not be able to make or express their own decisions when they are near death.

Doctors and family members will be unaware of any treatment preferences at this time if these have not been discussed and recorded earlier. Often, families are unaware of their loved one's views about what they would want when too ill to speak for themselves. Families often feel burdened by the concern that they will make a wrong choice. If there is not a clear statement of a person's wishes, aggressive treatments that the person might not have wanted may be provided.

While some forms of advance care planning are available in Victoria, the State generally lags behind other progressive western nations and states in enabling and supporting advance care planning for end of life choices.

Enduring Powers of Attorney (Medical Conditions) and Refusal of Treatment Certificates (RTCs)⁴ are necessary but not sufficient components for comprehensive 'end of life' choice.

² Cumbria and Lancashire End of Life Care Network. 2011. *Key definitions of end of life care*.

Available at http://www.endoflifecumbriaandlancashire.org.uk/info_patients_carers/definitions.php

³ <http://advancecareplanning.org.au/advance-care-planning/for-everyone/>

⁴ As allowed under the *Medical Treatment Act 1988*

Of particular importance is the fact that RTCs do not apply to new medical conditions occurring after the RTC has been prepared.

It is important that Victorians have the opportunity to prepare comprehensively for end of life by preparing legally binding Advance Care Directives as is the case in South Australia. Legislation giving citizens the right to prepare Advance Care Directives and clarifying the responsibilities of health professionals and family members to follow Directives is needed immediately in Victoria.

The provision of medicine to alleviate pain, where there are unintended consequences of withdrawing water, nutrients etc., may still be necessary and should be allowed under legislation.

Appropriate safeguards (e.g. covering witnessing of Directives) would need to be in place to ensure protection from elder abuse. Severe penalties should apply for any coercion in relation to Advance Care Directives.

The capacity to request euthanasia should be explicitly excluded from Advance Care Directives.

Clearly, it is preferable that such legislation is common across Australia but Victoria should not wait for agreement before introducing legislation. This issue would be appropriately referred to the Council of Australian Governments with the goal of establishing common provisions in all states including a common template for Advance Care Directives.

Issue 3: Appropriate Protection for Health Professionals

4. Legislation specifically protecting all relevant health professionals who comply with legally binding Advance Care Directives and other relevant legislation should be amended as needed to ensure full protection.

It is important that all relevant health professionals are fully protected by law for adhering to Advance Care Directives.

Medical Practitioners, nurses and others caring directly for the dying work in extremely difficult and often emotional environments. Families may pressure health professionals to intervene in ways that conflict with the wishes set out in an Advance Care Directive.

It is essential that all health professionals are totally protected from potential law suits for following the documented wishes of a dying patient.

Other legislation, such as the Crimes Act, may also need amendment to ensure no criminal charges can be laid.

Issue 4: The Need for Community Education

5. National Seniors recommends that the Victorian Government make funds available for a comprehensive community education programme about planning for end of life.

Until faced with choices about their own death or the death of loved ones, many people do not prepare for end of life. Some make wills, some appoint Powers of Attorney but often legal documents are not kept up to date. Community understanding of the importance of preparation for end of life is low.

An important corollary to 'end of life' legislation is the establishment of a community education programme which is widely available and strongly promoted and advertised. For seniors, this is particularly important and there are many networks through which education resources can be offered – U3A, seniors' organisations like National Seniors Australia, local government etc.

Issue 5: The Need for Education of Health Professionals

6. National Seniors recommends that the Victorian Government make funds available for a comprehensive education programme for health professionals about end of life law and its application in caring for the dying.

It is equally important that there is a comprehensive and shared understanding of end of life issues and end of life law among health professionals. The moral, ethical and emotional issues involved in end of life decision making are many and complex and it is important that professionals have a detailed understanding of the law, guidance in its application, access to advice and are well placed to make decisions in accordance with patient wishes.

Issue 6: Improving Palliative Care

7. National Seniors recommends that the Victorian Government develops a comprehensive, holistic, fully funded, palliative care programme available to people dying at home, in residential care or in special facilities.

Palliative care must be seen as much more than pain management and medical care. It should offer psychological, social and spiritual support, a holistic approach, for both the patient and family or carers.

Palliative care must have the sole purpose of caring for the patient and there should be a Code of Practice or set of standards for providers. The Council of Palliative Care Australia sets out 13 standards for providing quality palliative care for Australians but these remain voluntary.⁵

⁵ <http://palliativecare.org.au/wp-content/uploads/2015/07/Standards-for-providing-quality-palliative-care-for-all-Australians.pdf>

Further work by government is required to introduce mandatory standards as a basis for accreditation. All providers should be required to report against the standards including such matters as length of time in palliative care, pain management and family/carer engagement.

Palliative care should be available in the location chosen by the patient – at home, in residential care or in a special facility. Adequate funding for palliative care in different settings is therefore essential.

Early assessment of the need for palliative care should be available as soon as a terminal illness is diagnosed.

Issue 7: Community Consultation about Death with Dignity

8. National Seniors recommends that the Victorian Government, following legislation to establish Advance Care Directives, undertake wide community consultation to assess community views about medically assisted suicide within very strict parameters and which may lead to an exposure draft for comment or possibly a plebiscite.

The State of Oregon in the USA has for many years had a Death with Dignity Act that allows terminally ill Oregonians to end their lives through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose. The Act was introduced following two plebiscites of voters, the second passing 60 percent to 40 percent. Washington, Montana and Vermont have similar legislation.

The State of Oregon does not have a role in decision making. It is up to qualified patients and licensed physicians to implement the Act on an individual basis. The medication can only be self-administered without assistance. There are rigorous protections in place for both patients and physicians. The Oregon Health Authority collects information about patients who participate and publishes an annual statistical report.

At a Commonwealth level, the Legal and Constitutional Affairs Legislation Committee inquiry into the *Medical Services (Dying with Dignity) Exposure Draft Bill 2014* considered evidence from Professor Margaret Otlowski. Professor Otlowski advised that euthanasia is occurring in practice and, in order to provide safeguards for patients, and also for doctors who provide such assistance, it is essential to put in place a legislative regime that allows appropriate scrutiny, support and regulation.

Once legislation enabling Advance Care Directives has been introduced, it is proposed that the Victorian Government establish a broad consultative process to test community appetite for the introduction of legislation relating to medically assisted suicide within very strict parameters.

The consultation should be conducted by a broad based consultative panel and could include an exposure draft for comment or possibly a plebiscite. It is important that the views of the community at large are canvassed, not just the views of organisations with a pre-existing position.