



**VICTORIAN LEGISLATIVE COUNCIL STANDING COMMITTEE ON
ON LEGAL AND SOCIAL ISSUES**

Inquiry into End-of-Life Choices

COTA Victoria Policy Council

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Summary Statement

As the peak body representing the concerns and interests of older people in Victoria, Council of the Ageing (COTA Victoria) respects the diversity of opinions and beliefs held within the older population. We place value on public discussion and commend the Victorian parliament on its' Inquiry into current laws in Victoria and other jurisdictions that address citizens making decisions regarding their own end-of-life. We have focused our submission on practices currently being utilised within the medical community as it pertains directly to the experience of older people at end-of-life¹. In particular COTA believes that current systems (both legal and medical) require review and innovation to make real (and informed) choice possible. The exploration of end-of-life decision-making, autonomy and rights (with safeguards against abuse) requires a holistic approach across legal frameworks, medical practice and end-of-life care planning and services.

Whilst the terms of reference are specific, in the context of public discussion and engagement, COTA strongly recommends the Inquiry consider the broader context of access to quality of life until end-of-life to fully assess what constitutes informed choice, dignity and respect in end-of-life choices.

We request the opportunity to attend the Inquiry to highlight current issues as expressed by the lived experience of older Victorians, in making informed choices about end-of-life.

¹ COTA Victoria has consulted with its policy council representatives and collated anecdotal information from two state conferences and a series of Dying of Talk forums held between May 2014 – June 2015.

Introduction

COTA's involvement in *End-of-life Decision-Making*

COTA Victoria has lead and participated in consultations, policy advocacy, program development and community capacity building projects that address end-of-life issues and decision-making. This has ranged from information sessions on Advance Care Planning, small facilitated discussions on powers of attorney and substitute decision making, palliative care and how to initiate end-of-life conversations with family, friends and GP's. Voluntary euthanasia and medically assisted suicide has been consistently raised at forums and community discussions by older people. It is within this context that older people have sought opportunities for discussion on end-of-life care, dying and death. Over the past 18 months, COTA Victoria has taken the approach of facilitating conversations, providing information and supporting the exploration and discussion of what matters most as we approach end-of-life.

What older people want – *The bigger picture to informed decision-making*

Older people want open public discussion on end-of-life issues, care and choices. Since May 2014 almost 300 older people have attended four *Dying to Talk* events run by COTA Victoria in partnership with other organisations (Palliative Care Victoria, Macedon Ranges Shire and City of Casey). The demand for these talks by councils and shires across Victoria is increasing. COTA has responded to its members and more broadly community interest in bringing death and dying out of the private, medicalised and hidden sphere of life back into the public domain. The attendance and participation of older people at these events over the past 12 months has emphasised the importance of public dialogue; exploration of how we understand death is likely to happen; how to plan for what we want and what issues need to be considered in planning for end-of-life care, dying and death.

COTA Victoria's focus in these events has been on supporting older people to share personal stories and ask questions from 'experts' in palliative care, medicine, Advance Care Planning and the funeral industry in a supportive and non-judgemental environment. We have trained older people to play an important role in facilitating conversations at these events.

Dying to Talk participants responded to our evaluation survey expressing appreciation at being able to share their story or experience and discuss their fears and questions with peers in a safe environment. In conjunction with Palliative Care Victoria we collated the qualitative responses of *Dying to Talk* participants on what was their most pressing question on death and dying. A number of recurring themes emerged:

- ***How to start conversations on end-of-life with my family and doctor(s)***
- ***Wanting more information to understand the process (and fear) of dying***
- ***How to make sure my wishes and choices are respected***
- ***How to plan for the unknown when drawing up my Advance Care Plan***
- ***How to keep out of hospital and die at home with appropriate supports (this may include equipment, nursing, allied health, volunteers, family support, respite, palliative care)***

- ***What support or services are there if you are on your own***
- ***Voluntary euthanasia and the right to decide when to 'go'***
- ***What is the role of the Doctor in the death stage***

Whilst Euthanasia was raised at every forum, it was one of a number of issues in the continuum of end-of-life planning, dying, death and grieving. These issues were raised in the context of choice, dying with dignity and having wishes respected.

COTA acknowledges that the expressed views above are not representative across a number of culturally and linguistically diverse communities. Engaging with communities such as the Aboriginal community on end-of-life decision-making requires greater understanding of cultural beliefs, spirituality, dying and death. For other communities and individuals' the role of religion is central to considerations of end-of-life decisions and 'individual' choice. For the purposes of this submission we acknowledge this diversity and seek to explore the area of 'informed choice' for all.

TOR 1: The current legislative framework that applies to citizens making decisions about their end-of-life

COTA Victoria notes the following laws and codes as relevant to individuals making end-of-life decisions. We also note a range of policy frameworks and protocols that intersect with laws relevant to this Inquiry.

Bills on legalising assisted dying have been put forward in state parliaments of Tasmania, Victoria, South Australia, NSW and Western Australian, but all have failed to pass.

The *Medical Treatment Act 1988(Vic)* addresses patient suffering and the Doctor's role by encouraging a focus on *maximum relief from pain and suffering*' and focusing on palliative care.² This includes attending to the physical, psychological, social, cultural, spiritual and emotional needs of the dying person, according to Palliative Care Victoria.³

Doctors withdraw treatment when there is no foreseeable benefit to the patient. To do otherwise would not be ethical and probably not legal. This is clearly within the law and is not considered assisted suicide or euthanasia. Legal debate arises re who decides what treatment (or withdrawal of treatment) is made in the 'best interest' of a patient without capacity. The role of the substitute decision maker and the assessment of what treatment or withdrawal of treatment in regards to the 'best interest' of a patient is fraught.

*Medical practitioners often face choices about whether to discontinue treatment or provide additional pain relief. They know that in these circumstances, death will probably occur earlier. Medical practitioners commonly provide treatment that both alleviates symptoms and may lead to an earlier death.*⁴ The doctrine of 'double effect' becomes invoked in these instances.⁵ At issue is the 'intention' behind the administration of a lethal dose of a drug. Where a Dr's primary intention is to relieve pain and not deliberately hasten death, this is considered lawful.

Timebase Legislation research summarises⁶: *the broad(ening) concept of Euthanasia...in the current era of hi-tech medicine...now (sic)... encompasses a broad range of interventions ranging from mercy killing (with or without explicit consent) through the shades of assisted suicide (by doctors and others), into the use or abuse of sedation (terminal sedation, double effect) and decisions to withdraw life-prolonging treatments (burdensome ones such as mechanical ventilators, or harmless ones such as pacemakers) and finally to decisions not to start treatments that might prolong life.*⁷

² Neven-Gorr, H. (2015)

³ Ibid (Palliative Care Victoria Cited)

⁴ Swerissen, et al, Grattan Report (2014), p15 cites Seale (2006) survey of UK medical practitioners that 32.8% had alleviated symptoms with possibly life shortening effect.

⁵ For a detailed exploration of this principle please refer to Stanford Encyclopaedia of Philosophy www.plato.stanford.edu

⁶ <http://www.timebase.com.au/products/LawOne.html>

⁷ Ibid

The law has intervened in all jurisdictions to put a bright line in this spectrum, identifying the point at which we should see an activity as “illegal”. But the position of this bright line differs widely across the globe. In Australia, it currently lies somewhere in the area between terminal sedation and the double effect (the use of a drug knowing it may kill, but not intending death by its use).⁸

Rights, autonomy and the Common Law

COTA has worked internationally and nationally in recognising the importance of human rights for older people and the concomitant cultural change associated with recognised ‘rights’. COTA advocates for the right of older people to be treated with dignity and respect and to be empowered to make informed decision-making about their end-of-life care.

Patient autonomy or self-determination (the right to control one’s own body) and the development of Common Law regarding informed consent was confirmed in 2009 by *McDougall J* of the New South Wales Supreme Court.⁹ Relying on English authority he stated that: *It is in general clear that, whenever there is a conflict between a capable adult’s exercise of the right of self-determination and the State’s interest in preserving life, the right of the individual must prevail.* Case law mostly derives from patients unable to give consent where substitute decision makers and Doctors were in conflict over ‘best interests’ and withholding and withdrawing life sustaining treatment.¹⁰

Does an individual’s right to control one’s own body extend to an individual’s right to access what they define as ‘a good death’ at a time and place of their choosing? What are the consent and informed consent implications for the broader community, in particular those that are vulnerable or subject to influence? There are considerable legal, ethical, emotional, cultural and religious considerations in exploring these questions that COTA will continue to engage older people on.

COTA notes the following legislative frameworks, protocols and jurisprudence as relevant to end-of-life decisions:

- The Victorian Charter of Human Rights (which refers to *Your right to life (section 9)* and *Your right to protection from torture and cruel, inhuman or degrading treatment (section 10)*)¹¹
- The Declaration of Geneva (no longer contains a ban on assisted suicide and voluntary euthanasia)¹²

⁸ Ibid

⁹ *Hunter and New England Area Health Service v A* [2009] NSWSC 761 [5] cited in O’Neill, N., et al Chapter 11 The Development of the Law Relating to Medical Treatment of Incapable People" [2011] SydUPLawBk 13; (2011).

¹⁰ For details on the development of Common Law and the practice of decision making refer to O’Neill, N. et al, Chapter 14 The Proper Practice and Law relating to decision-making about Treatment and Care at the End of Life " [2011] SydUPLawBk 16; (2011)

¹¹ <http://www.humanrightscommission.vic.gov.au/index.php/the-charter>

- Advance Care Planning, Advance Care Directives
- The Victorian End-of-Life Care Coordinating Program (VEC) ¹³
- The Medical Board of Australia's *Good Medical Practice: A Code of Conduct for Doctors in Australia, 2014*
- *The Medical Treatment Act 1988 (Vic)*

¹² Stokes, M., *The Conversation*, (July 2014)

¹³ Provides a care plan framework for the Dying Person in Victoria. This is a clinical tool to support evidence-based person-centred care delivered during the last days and hours of life. The Care Plan for the Dying Person – Victoria (Care Plan), must comply with the recently endorsed (April 2015) *10 Core Principles for the Dying Person*: International Collaborative for Best Care for the Dying Person' located [here](#).

TOR 2: Practices being utilised in the medical community including palliative care

Impact of longevity on end-of-life decision-making

Due to longevity there has been a significant historical shift in how people die. Approximately two thirds of Australians now die when they are old, mostly from chronic disease and disabilities towards the end-of-life¹⁴. This significant historical and social change to the context and experience of dying means there is time to know and explore more about how we feel about dying and there is more time in experiencing the stages of grieving our own end-of-life. Contemplating what choices are available over these stages is a significant and profound shift.¹⁵

What is not considered in the practical focus of laws and services is how to address the emotional and spiritual content of this significant shift in how we are dying. We need to consider the extended time period that older people and those diagnosed with a terminal illness have to contemplate dying and death.

What constitutes a 'good death' or 'dying well'?

As we are now more likely to know when we are going to die in the near future, we have an unprecedented opportunity to plan and consider how we want to die and what will support a good death. However, people are not considering or planning their end-of-life care and preferences. In the last year of life, many do not receive enough palliative care and find themselves caught up with interventions and a confusing range of services and health professionals.

So what is a good death? How we can best meet the needs of those that are dying – not just to die well, but to live well until they die? According to the Grattan Institute *“A good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs”*

Current public discussion refers to 'dying well' and a 'good death' as ideally including a range of options and supporting people involved in the dying process (Doctor's, nurses, palliative care staff, family members, support services). These terms indirectly question our current culture of the 'medical management of death' and the systems and decision-making junctures that have evolved in our medical and palliative care practice and service delivery.

Diversity within our population additionally requires culturally sensitive end-of-life care and an understanding of the underlying values and preferences of culturally and linguistically diverse communities to death, dying and end-of-life decision-making.

¹⁴ “About two-thirds of Australians now die between the ages of 75 and 95” (cited in Swerissen 2014 P5)

¹⁵ Thanks to Janet Wood (past COTA president) for her insightful reflections.

Strengthening palliative care services and support across communities is critical to end-of-life care and capacity to exercise choice at this time. Greater emphasis and resources are needed to enable informed choice and preferences in end-of-life care.

We note the concerns raised by the Grattan Institute on voluntary euthanasia and assisted dying and how this distracts from a focus on quality of life until end-of-life. We also acknowledge whilst there is increasing public pressure for accessing voluntary euthanasia and assisted dying most end-of-life decisions centre on *the more common situations of withdrawing treatment and increasing pain relief. Preparation to anticipate these choices for how we want to die is critical for dying well*¹⁶. (Grattan Institute P15)

Translating respect and dignity into decision making

Anecdotally we know that when a terminal diagnosis is made, people are often overwhelmed by choices and the array of medical interventions that are available to prolong life and / or treat symptoms. In his book *Being Mortal*, Atul Gawande describes how Doctors in the U.S. have vacated the decision making space and become the informers of a vast and sometimes *dizzying array of options*¹⁷. Patients and families are asked to make choices and decisions without fully understanding the implications or the impact of interventions. Gawanda suggests that the following questions are paramount for an individual to make informed end-of-life decision making:

What are your biggest fears and concerns?

What goals are most important to you?

What trade-offs¹⁸ are you willing to make?

What are you not willing to trade off?

In terms of respect and dignity COTA advocates strongly for older people to be the chief decision-makers (in partnership) with professionals (medico/legal/social workers/spiritual). We believe the role of professions during this end stage needs to be redefined. Defining quality of life and the decisions on appropriate treatments requires an array of professions to act as facilitators in supporting the dying person to 'die well' according to their own values; and to support individuals to consider what trade off's are acceptable in their decision making process. This means communicating clearly the prognosis and impact of treatments by Doctors. We know that medical intervention is generally geared towards prolonging life. Quality of life (as defined and valued by the person dying) should direct what care decisions are made.

In a commentary piece in *The Age*, Medical Oncologist, Dr Ranjana Srivastava discusses the contradiction between the treatments Doctors prescribe to terminally ill patients and what they would choose for themselves. She highlights the correlation between poor patient understanding of their illness and prognosis to the Doctor's ability to communicate and

¹⁶ Ibid p15

¹⁷ Gawande (2014)

¹⁸ For example, 'trade-offs' may mean choosing palliative treatment with symptom management and more time to spend at home rather than invasive medical treatment that 'may' provide extra 'time' with uncertain quality of life. We have 'traded off' time for more control over our dying.

facilitate understanding. *Whilst Doctors have access to the best medical technology and expertise most choose quality of life over aggressive intervention.*¹⁹

The social change in contemplating and living with our own mortality means it is timely to assess what is needed to holistically respond to the more complex ethical decision making now being asked of individuals and professions. There is a need to widen public discussion to include ethical, psycho-social and spiritual dimensions.

Valuing all life. The impact of Ageism in our health care practice.

COTA Victoria advocates strongly for the Human Rights of older people to be recognised by addressing ageism and discrimination across a range of policy domains. End-of-life decision-making and equity of access to care are impacted by age, ageism, socio economic and geographical location.²⁰

In a controversial essay, Karen Hitchcock highlights a range of conflicting practice examples of not valuing life once someone is old.²¹ Hitchcock challenges Gawande's²² view on the overtreatment of older people and refers to the UK as a better comparison in the response of the medical professional in end-of-life decision-making. Whilst acknowledging over treatment does occur, she outlines a strong narrative around the limited treatment options offered to the elderly as part of rationalising health care costs in public hospitals. Hitchcock and Gawande share common ground with the pressing need to improve end-of-life care. The location of their strongest criticism is within intensive care units and public hospitals.

On COTA Victoria's website, a recent comment posted on our End-of-life page is consistent with Hitchcock's concerns *...I knew my dad was dying. In hospital treatment of me and my dad was disgusting and I find it hard to forget. I don't think hospital staff know how to care for older (89), mentally sound people who are dying. There was no assistance for us at all until dads heart GP was contacted and then two days before he died he was put in a 'quiet' room where we were even easier to ignore. My dad took a week to pass away, most of it in severe pain.*²³

Advance Care Plans and end-of-life decision-making

Victoria is in the early days of implementing Advance Care Planning (ACP). The utility and impact of ACP on end-of-life care, particularly in instances where a substitute decision maker is invoked, requires more research and evaluation. There was varying awareness and understanding of ACP at COTA's *Dying to Talk* events. Participants who were familiar with

¹⁹ Srivastava, R., The Age, Focus section, February 25, 2014

²⁰ The availability and poor access to palliative care services and trends in ageing in rural and remote communities is examined in <http://vuir.vu.edu.au/1482/1/Ryan.pdf>

²¹ Hitchcock, Karen, Quarterly Essay, Dear Life on Caring for the elderly, Issue57, March 2015 details case examples of where life is not valued at end of life for many elderly people.

²² Gawande (2014)

²³ See more at: <http://cotavic.org.au/action-advocacy/end-of-life-issues/#sthash.3KekjdHI.dpuf>

ACP expressed concern over its relevance if they were not able to speak for themselves in particular their fear over Doctors and substitute decision makers overriding their wishes.²⁴

In Victoria, an Advance Care Plan can be overridden under an array of circumstances. The level an ACP is utilised will be contingent on a complex interplay of circumstances. For example: whether an urgent decision is required; the capacity of the individual to make decisions; who decides 'in the best interest' where a substitute decision maker has been invoked; the awareness and attitudes of family members and treating Doctors to what the dying person wants.

Participants also discussed how their personal choices may change to what is recorded on their ACP. According to one COTA policy council member *"Like many my age, I have seen people 'live on' past their wishes until relief came via the need to better manage their pain. But due to common practice and law their anguish and unnecessary suffering was unable to be addressed...I have observed weeks of hopelessness as their bodies were kept functioning by 'comfort' medical intervention. One of the reasons I don't have an Advance Care Directive that would instigate 'Refusal of Treatment Certificate' is that I think it would slow things up. Doctors would be more reticent to implement due to there being documentation. Better to say "Lots of pain-not coping. Not the time for heroics" and hope for quiet understanding"*.

Advance Care Plans can assist and guide coordinating good care at end-of-life across different health professionals.²⁵ This is one mechanism or tool to inform end-of-life decision making. It is not a panacea for dying well. Advance Care Plans must be situated within a framework that supports and encourages community, professional and family conversations on personal values and wishes for our end-of-life care.

How do Australians want to die?

People have clear ideas of what they want around end-of-life care. Most people want to die at home with minimal pain and suffering²⁶. While 70% of people want to die at home, supported by family and friends with appropriate services only 14% do so, making death in Australia more institutionalised than the rest of the world.²⁷

There is clear disparity between what people want and what is happening or being practiced in the community.

In considering current practices being utilised in the medical community, access to in-home, hospice and residential palliative care are critical to issues of autonomy, dignity and respect. There is not sufficient palliative care respite or support to the meet the preferences of the

²⁴ Discussion around how ACP's may operate and be of benefit in nursing homes and institutional care was not discussed.

²⁵ Swerissen (2014) p26

²⁶ When good end of life support services are in place people are more likely to die at home (Jourdhoy (200) Quoted in Grattan Institute 2014 Report P10). Anecdotally, COTA has heard the experience of palliative care in managing pain and symptoms varies widely from positive to inadequate. The inflexibility of palliative care roles and the medicalised roster system was cited by two older people who contacted COTA.

²⁷ Swerissen (2014) p2

majority of people to die at home.²⁸ If services were more focused and resourced to meet people's wishes to die at home and in hospice settings this would address some aspects of controlling our end-of-life. A social model of care for dying at home and dying naturally needs to be considered as part of having choice and control (or autonomy) within the spectrum of support to people dying. Within this context, increasing access to palliative services and hospice care continues to be a significant barrier for rural and remote communities.²⁹

Participants in COTA's *Dying to Talk* events consistently stated they wanted control over the place, timing of death and who is present. They wanted their advance care plans respected and not overridden by Dr's or family members. There was concern expressed over unnecessary medical interventions when quality of life is low and where there was little scope for improvement.

*People also want to know when death is coming and they want to understand what can be expected. They want to retain control over pain relief and as much as possible other symptoms. They want to have control over where death occurs and be informed on their choices. Importantly they want to have time to say goodbye and leave when it is time to go and not have life prolonged pointlessly.*³⁰

Exercising informed choice

There is a strong push within the community and from COTA's membership that individuals should be able to make an informed choice about their way of dying, particularly when quality of life is compromised. This has been expressed as the 'right' to access voluntary euthanasia and assisted death. For others, accessible palliative care will be preferred. Others will accept dying in a hospice or institution – where there are no better alternatives.

Palliative care, how it is delivered and accessed plays an important role in supporting people to retain control of what happens towards end-of-life and to provide control over pain relief and other distressing symptoms. But it does not cover everything. What may be tolerable for one person may not be tolerable for someone else. Quality of life is subjective. The level of pain and symptom relief and associated choices will differ. COTA believes this needs to be respected.

We know from the feedback on our comment page and our *Dying to Talk* forums, the personal experience of a family member or friends' death shapes personal views on the adequacy/ inadequacy of palliative care and how choice on end-of-life care can/cannot be exercised currently. Anecdotally, older people are asking for more support and opportunities to understand how best to manage end-of-life decisions – when this is required. Coordinating end-of-life care and decision-making requires reframing our current health care system and the degree of specialisation in different areas of intervention.

²⁸ Palliative Care Victoria, 2014 State Election Call to Action 2015 - 2019

²⁹ The Victorian Auditor General's Report into Palliative Care (2015) acknowledges the challenges facing rural services in attracting specialist palliative care physicians.

³⁰ Smith, 2000: Cited in Swerissen (2014) p8

Communication training and public discussion on death

Central to having an effective end-of-life plan is having conversations with family, friends and GP's around our end-of-life wishes.

COTA's *Dying to Talk* participants consistently expressed difficulty in raising the subject of dying and their wishes with family members 'who don't want to know about it'. Opportunities for discussion with peers and at forums were welcomed.

According to the Grattan Institute, Doctors want to provide hope and options for prolonging life. As a result, end-of-life care and conversations are often delayed and medical treatment is provided to meet these expectations rather than what is in the best interest of providing quality of life for someone who is facing end-of-life.³¹ The Medical Board of Australia's *Good Medical Practice: A Code of Conduct for Doctors in Australia, 2014* provides a clear statement of the role of the Doctor in treating patients at the end-of-life as *understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient.*³²

Whilst Doctors recognise when treatment is futile they often fail to communicate this clearly. Communication training and competency should be part of professional training for Doctors. More opportunities for public discussion on death and dying is needed to address public calls for informed choices about end-of-life decisions and to challenge social taboos on talking about death.

End-of-life care measures elsewhere

The Queensland Clinical Senate in partnership with Health Consumers Queensland has developed a Charter for care of adult patients at the end-of-life. This has been adapted from the UK's End-of-life Care Patient Charter and identifies key commitments by health care professionals and the person dying to enable the provision of the highest quality of care and support in living well until death.

COTA also notes the Queensland Health, End-of-life care: decision-making for withholding and withdrawing life-sustaining measures from adult patients³³

³¹ Swerissen (2014) P12

³² Neven-Gorr, H., Treating Patients at End of Life What is the doctor's role? AMA, Vicdoc June / July 2015, page 14-15 https://amavic.com.au/page/Member_Services/Publications__Communications/vicdoc/

³³ Ethics Team, Clinical Policy Unit, Centre for Healthcare Improvement, Queensland Health, Implementation Guidelines for End-of-life-care for withholding and withdrawing life-sustaining measures from adult patients, Part 1, Legal Framework and Clinical Considerations.

TOR 3: Legal and medical frameworks in place in other jurisdictions

COTA notes the following countries have legalised assisted dying:

US: Washington State (2009); Oregon (1997); Montana (2010); Vermont (2012); Netherlands (2000); Switzerland (1940s); Belgium (2002); Luxembourg (2009).

Canada, New Zealand, Britain, Scotland are debating the introduction of similar laws.

Research on impact of legalised assisted death

COTA believes investigation into the uptake and impact of voluntary euthanasia and assisted suicide in jurisdictions such as Oregon and The Netherlands needs further consideration. These jurisdictions have been cited as models for the introduction of legalised assisted death. There is considerable research and comparative analysis between Oregon, The Netherlands and other jurisdictions on national notification and reporting procedures. We refer the Inquiry to The Netherlands Rimmelink Report³⁴ and more recent reporting of the impact of legalised assisted death.³⁵

Additionally, the uptake of Euthanasia and assisted suicide in The Netherlands must be contextualised within the practice of palliative care service support and the increase in decision-making power by Doctors who make a determination on 'quality of life' - despite the subjective value of this decision-making. End-of-life decision-making is contingent on end-of-life care options and capacity to exercise and access personal preferences.

COTA also notes a UK medical frameworks outlined in *End-of-life Care Strategy UK*³⁶ and *End-of-life Treatment and Care: Good practice in decision-making*³⁷

³⁴ Refer to: "Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001 Bregje D Onwuteaka-Philipsen, Agnes van der Heide, Dirk Koper, Ingeborg Keij-Deerenberg, Judith A C Rietjens, Mette L Rurup, Astrid M Vrakking, Jean Jacques Georges, Martien T Muller, Gerrit van der Wal, Paul J van der Maas <http://image.thelancet.com/extras/03art3297web.pdf>

³⁵ <http://www.newsweek.com/2015/02/20/choosing-die-netherlands-euthanasia-debate-306223.html>

³⁶ What's important to me. A Review of Choice in End of Life Care. Published by The Choice in End of Life Care Programme Board, February 2015

³⁷ UK General Medical Council, Draft paper for consultation (2009)

TOR 4: The potential impact of federal laws on Victorian legislation

The current Commonwealth *Euthanasia Laws Act 1997*, repealed the Northern Territory's *Rights of the Terminally Ill Act 1995* and prohibited the introduction of similar Acts in the Australian Capital Territory (ACT) and Norfolk Island. This does not apply to States.

The On 24 June 2014 the Senate referred the **Medical Services (Dying with Dignity) Exposure Draft Bill 2014 (the Bill)**, to the Legal and Constitutional Affairs Legislation Committee for inquiry and report by 27 October 2014. Of particular concern to the Committee was the potential for constitutional challenge: It is worth iterating the Committee's Recommendations that highlight the technical issues of:

- *Clarification around the definition of a terminal illness*
- *Consistency of definition around decision-making capacity*
- *The number of medical practitioners required to consider the request*
- *Serious consequences for medical practitioners who relied upon the immunities in the Bill if found unconstitutional*
- *Clarification regarding the definition of a dying with dignity service*³⁸

For further comment on this Inquiry we refer the Inquiry to COTA Australia's submission on this Exposure Draft Bill for consideration.³⁹

³⁸ Under Recommendation 5.3 of the Legal and Constitutional Affairs Legislation Committee for Inquiry into Medical Services (Dying with Dignity) Exposure Draft Bill 2014, 27 October 2014

³⁹ <http://www.cota.org.au/australia/news/newslist/2014/cota-submission-on-dying-with-dignity-bill-2014.aspx>

Issues to Consider Further

COTA Victoria believes more thought and research needs to be given to the following issues and questions:

1. How to build in safeguards for people that are vulnerable and older people (with capacity) who are subject to family pressure and/or who no longer want to be a burden on their family. Further consideration needs to be given to:

- Protocols around explicit consent; informed consent
- Capacity and incapacity in end-of-life decision making (in particular where this is borderline or fluctuating capacity)
- Protections against elder abuse
- Risk management
- Documentation, accountability and transparency

2. Developing clear policy and guidelines when different laws and statutes are ‘triggered’ e.g. Powers of Attorney, Guardianship, Substitute decision-maker under any changes to current legislation.

3. How do we ensure a ‘good death’ with respect to the personal values held by someone with dementia who may no longer have capacity to make decisions for themselves?

4. How can we best value, resource and support ethical decision making and communication skills for those involved in end of life decision making and care? In instances of substitute decision-making, what supports and ethical guidance are needed for people to act and make decisions in concert with the values and wishes of the person dying?

5. **The power and consistency of language** Voluntary euthanasia means, “ending another person’s life at his or her own request.” In practice it has evolved to mean a spectrum of interventions, each with unique moral and legal considerations. Assisted dying means “providing someone with the means to end his or her own life”⁴⁰ Legal Definitions take regard of intent. Dying with Dignity has come to mean the right to choose how and when you want to die with assistance. For others, dignity may include palliative sedation, the location of where you die and who is present. How do we define and understand ‘a good death’ in a model of care for end-of-life?

Community understanding on what these terms mean will facilitate informed and respectful public discussion.

6. As a representative organisation for older people, how does COTA best articulate and define **Informed Choice, Dignity and Respect in end-of-life care and decision-making?**

How do we frame legislative change for choice in the context of allowing people to control the circumstances around their death so what matters most to them is respected and supported? How do we balance an individual’s ‘right’ to control their end-of-life with group protections?

⁴⁰ Swerissen (2014) quote from Demos p14

7. How does our society provide optimum choice and control over end-of-life care when service support systems are stressed and not resourced to meet an individual's need or preference? As a community how do we build our capacity to support families and carers? How do we provide choice regarding end-of-life care and ensure equity of access for people, across the life span, valuing all life until the end-of-life.⁴¹

8. How do we ensure people from culturally and linguistically diverse backgrounds have access to information, choice and control over end-of-life decision-making? Quality of Life issues varies between individuals and cultures. In some culturally and linguistically diverse communities end-of-life is not considered a personal matter but a community issue where elders make major decisions in a person's life. The approach to discussion and decision-making requires careful consideration regarding individual rights, cultural norms, religious beliefs and personal expectations.

⁴¹ Hitchcock, K., (2015) details case examples of where life is not valued at end-of-life for many elderly people.

Recommendations

1. COTA Victoria strongly recommends an integrated, holistic approach to end-of life care and collaborative decision-making. Collaborative decision-making requires the involvement of the patient, their health team and their family and/or friends (as identified by the patient).
2. Invest in communication and ethical decision making training for doctors and health care support staff so that people that are dying or have a life limiting illness are able to make informed choices regarding their own end-of-life care and decision-making.
3. Consideration of legal mechanisms that permit assisted suicide and/or voluntary euthanasia must be contextualised within a framework of Quality of Life until End-of-life with optimum functioning of end-of-life care services and support.
4. Investigate and pilot social models of end of life care to address barriers to equity of access to a range of service and support options.
5. Amend the Medical Treatment Act 1988 (Vic) to remove legal repercussion for Doctors that administer pain and symptom relief to people that are dying and request such relief, where this may hasten death.⁴²
6. Any proposed legislative change **must be** accompanied with:
 - Significant public education programs and professional training programs for those involved in End in Life Care and decision-making.
 - Clear protocols and practice frameworks that protect all vulnerable people and identify and address circumstances of potential elder abuse.
 - Measures that actively mitigate incentives to access assisted suicide and voluntary euthanasia (e.g. valuing the care of older people rather than measuring their worth of life according to age and cost of care. Address inherent conflict in potential elder abuse situations where family members become substitute decision makers with power to decide end-of-life)
 - Tracking and measuring the impact of any change and transparently reporting on the findings.
7. Build community capacity on end-of-life issues (compassionate communities) through investment in community engagement, palliative care health promotion, death literacy programs and public education.

⁴² The use of opiates and sedation at the end-of-life with the knowledge that they may shorten life but not intending death is widely accepted in law as an exception to the crime of murder.

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