



SUBMISSION

Greater say for Victorians: Framework for end of life care in Victoria

**Prepared by
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INTRODUCTION

COTA Victoria appreciates this opportunity to provide feedback on the development of Victoria's new end of life care framework and improving end of life care.

The revision of the framework is an opportunity to reaffirm and promote the importance and value of quality of life until end of life for all. Through public consultations and community discourse, guiding principles can also promote and communicate the universal values of dignity, respect, humanity, community, choice and care – in end of life. Historically, COTA Victoria's work has been underpinned by similarly aligned values that

- **Enable older Victorians' voices to be heard in all aspects of life.**
- **Enshrine dignity and human rights for all people.**
- **Empower and facilitate the engagement and involvement of older people in all levels of our activities.**
- **Promote understanding and respect for the diversity of older people.**
- **Provide older people with accurate and timely information to assist them to make informed decisions and live full lives.**

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, sexual orientation, gender identity, and disability, level of capacity, faith, socioeconomic and geographical location. Variations in the quality of end of life care do exist across Victoria.¹

Focus of submission

This submission addresses the central question of: What principles should guide the End of Life Care Framework? As the key representative organisation for older people in Victoria our comments and feedback on the five feature areas in the discussion paper, is informed by the voices of older people within our community.

We understand the scope of the discussion paper is to address the changing context of end of life care. Whilst COTA believes the longevity revolution provides significant opportunities for society, we are also aware of its challenges in terms of chronic illness and complexity of care towards end of life. There is also the need to better align our end of life care with a humane and dignified death as defined and chosen by the person dying, their carers and loved ones. We believe the role of communities alongside palliative care services and primary health care providers are central to person centred end of life care.

¹ 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>

COTA Victoria also acknowledges the concurrent Parliamentary Inquiry into End of Life Choices. We make reference to this work as many older people argue enabling genuine choice requires the option of controlling how and when one dies as they approach end of life.

For COTA Victoria's detailed response to the Victorian Parliamentary Inquiry into End of Life Choices we refer the Department of Health and Human Services (DH&HS) to our recent submission to the Parliamentary Inquiry (2015).²

The voices of older people

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).

In conjunction with Palliative Care Victoria we collated the qualitative responses of *Dying to Talk* participants on what was their greatest concern about end of life, dying and death. A number of recurring themes emerged which relate to end of life care and planning:

- *How to start conversations on end of life with family members and doctor(s)*
- *Wanting more information to understand the process (and fear) of dying*
- *How to make sure personal wishes and choices are respected*
- *How to plan for the unknown when drawing up an Advance Care Plan i.e. "How do I know? What if I change my mind?"*
- *How to keep out of hospital and die at home with appropriate supports*
- *Understanding what support or services there are if you are on your own*
- *Voluntary euthanasia and the right to decide 'when to go'*

The following statements made by participants are also worth noting in developing principles to guide end of life care:

"The issue for me is not death but how I die ... the pain management"

"I want my loved ones around me and to die with dignity"

"I don't want intrusive surgery if I am dying... how can I ensure this doesn't happen?"

The attendance and participation of older people at these events over the past eighteen 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.

Placing the person dying, their wishes and the involvement of their loved ones and chosen carers at the centre of the framework is the starting point to developing the guiding principles for improved end of life care.

² http://www.parliament.vic.gov.au/images/stories/committees/lsc/Submissions/Submission_821_-_Council_of_the_Ageing.pdf

KEY RECOMMENDATIONS

1. A framework that considers the role of rights, patient autonomy and ethics for end of life decision making can be used to educate and guide health professionals, the person dying, carers, loved ones and the broader community³.
2. Principles phrased in the first person will place the person and their loved ones central to the end of life care framework.
4. The framework needs to reflect an integrated, collaborative cross-sector approach to end of life care.
5. The framework provides an opportunity to communicate the values of humanity, collaboration, honesty, dignity, respect, informed choice and empowered decision making in end of life care.

Guiding Principles

*I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me, and the people who are important to me including my carer(s).*⁴

We refer to the UK's recent *Ambitions for Palliative and End of Life Care framework* as it sets out six positive ambitions in calling for an integrated and collaborative approach for better end of life care at the local level.⁵ The focus of the ambitions paper is on the experience of the dying person, from their point of view and their carers and family members. The six *ambitions* (or vision for care) are written in the voice of the person dying. This narrative, first person approach expresses a vision for good end of life care as a lived experience thus engendering meaning to each statement.

To quote directly⁶:

1. Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me; those who care for me know that and work with me to do what's possible.

³ COTA draws on the Irish Ethical Framework for End of Life Care for this recommendation.

<http://hospicefoundation.ie/publications/ethics>

⁴ www.endoflifecareambitions.org.uk Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020, p9 cited from: National Voices and The National Council for Palliative Care and NHS England (2015). *Every Moment Counts: A narrative for person centred coordinated care for people near the end of life*. London: National Voices

⁵ Ambitions for Palliative and End of Life Care Ibid.

⁶ Ibid p11

2. Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

3. Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

4. Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

5. All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

6. Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

The UK Ambitions paper outlines eight foundations or preconditions to realising the above ambitions. In summary these include personalised care planning; shared records; evidence and information; involving, supporting and caring for those important to the dying person; education and training; 24/7 access; co-design; and leadership.⁷

COTA believes the UK Ambitions paper articulates a vision and a set of guiding principles applicable to Victoria's End of Life Care framework review.

In supporting the 5 outcome areas identified in the discussion paper *Greater say for Victorians-Improving end of life care*, COTA Victoria makes the following points:

Outcome 1 Enabling genuine choice and informed decision making⁸

This is an area COTA advocates strongly on as our work is predicated on 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. Issues of equity and access to information and choice are impacted by a range of life factors.

⁷ Refer to Appendix A for notes on these foundations or building blocks.

⁸ COTA believes informed decision making is a precondition to enabling genuine choice.

Anecdotally, older people are asking for more support and opportunities to understand how best to manage end of life decisions – when this is required. COTA understands that enabling genuine choice is not just about providing information. It requires:

- Truthful and timely information and the communication of uncertainties
- An ethical framework to guide and support decision making across the health profession and to support carers, substitute decision makers, family members and the person dying.
- Support and time to discuss a person’s values, priorities and decide what matters most as they approach end of life.
- The involvement of carers, loved ones and substitute decision makers.
- Engaging and responding to the cultural and information needs across the community, including non-English speaking background communities and Aboriginal and Torres Strait Island people.
- Junior and less experienced staff in hospitals being trained or resourced to have conversations. Hospitals and acute settings are not currently set up to support an “end of life” conversation.
- Adequate resourcing and accessible advice when immediate decisions are required.
- Listening and responding to questions from the person dying and their family.
- Building community capacity on end of life issues through investment in community engagement, education, palliative care health promotion and death literacy programs.
- Collecting qualitative and quantitative data to gain understanding and insights into the decision-making outcomes for families and carers.
- Strengthening and integrating palliative care services and support across service systems and communities.

The context of how people are dying has changed. As a result we need to consider the extended time period that older people and those diagnosed with a life limiting illness have to contemplate dying and death. In particular how this impacts on decision making and the changes we may want to make over this time. Context and what defines quality of life may change over time and age.

Rights, autonomy and informed decision making

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 professionals 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-offs are acceptable in their

decision making process.⁹ This means Doctors communicating clearly the prognosis and impact of treatments. Quality of life (as defined and valued by the person dying) should direct what care decisions are made.

Advance Care Plans and end of life decision-making

COTA Victoria supports strengthening the role of Advance Care Plans (ACP) in coordinating care at end of life across different health professionals.¹⁰ The precondition for this tool or mechanism to be used meaningfully is its placement within a framework that supports and encourages community, professional and family conversations on personal values and wishes for our end of life care. ACP is not a panacea or checklist for dying well. It needs to be flexible, fit for purpose and assessed according to context. To be effective, ACP requires shared information systems, trigger points and regular revision. Culturally appropriate methods for community engagement on the role of ACP in end of life decision making in communities such as the Aboriginal community additionally requires sensitivity to cultural approaches to dying and the role of family and kin.

Within this context, the role and expectations placed on the substitute decision maker requires support and an understanding of what decision making scenarios may arise. Through COTA's *Dying to Talk* events, older people expressed concern over who would respect their wishes and make decisions that were consistent with their instructions. There was varying levels of awareness of the complexity and emotional challenges of decision making as a Medical Power of Attorney - should that role be called upon in an acute / emergency situation. There was also concern that an ACP may not adequately instruct a substitute decision maker in different scenarios.

COTA supports calls for investing in resources and programs to support end of life ethical decision making and communication skills for substitute decision makers, health clinicians and the general community. 24/7 access to support and ethical guidance is needed for people to act and make decisions in concert with the values and wishes of the person dying.

Decision making and capacity

Where there is a loss of capacity, shared decision making effectively “goes out the window”. In Victoria we are yet to see the impact of recent changes to the Powers of Attorney Act.¹¹ How the new type of power of attorney – the supportive attorney – may be used in regards to fluctuating capacity is yet to be assessed. Enabling genuine

⁹ Gawanda, Atul *Being Mortal*, Profile Books, 2014, refers to trade offs as key to making informed decision - making.

¹⁰ Swerissen, Hal and Duckett, Stephen, Grattan Institute Report No. 2014-10, September 2014 p26

¹¹ <http://www.publicadvocate.vic.gov.au/powers-of-attorney-law-change>: The Supportive Attorney has become available with the commencement (1st September 2015) of the *Powers of Attorney Act 2014*.

choice under these circumstances requires accessing some form of supportive decision making – so the voice of the person dying can still be heard.

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 some older people with a life limiting illness, personal autonomy in exercising choice is currently constrained by the law. For others, rights and autonomy are expressed as having 24/7 access to palliative care and support. Others will accept or seek end of life care in a hospice or institution (where no other alternatives are available). 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.

Outcome 2 Supporting individuals, families and carers

There are models elsewhere in Australia and internationally that can be drawn upon in improving support for individuals, families and carers. These include:

- In Western Australia (WA), a telephone support line for community members and clinicians around end of life decision making and care options was recently piloted by W.A Palliative Care.
- The WA consumer engagement model includes an ACP alert and the integration of ACP across trigger points in the health and patient admission system. This has required a shared file system across a number of health systems.
- Ongoing and expanded workshops and end of life conversations supported at the local community level through the platform of primary health organisations and local government alongside community organisations such as COTA.
- Providing timely out of hours response to pain and distressing symptoms through 24/7 services and support. In particular the provision of emergency palliative care professionals through local or community models of care and / or ambulances. New South Wales' Ambulance service has been piloting emergency palliative care.
- Increasing carer respite and developing more responsive bereavement counselling and support services

Outcome 3 Responding to diversity

End of life decision making and equity of access to care requires a diversity action plan across all outcome areas. Ageism, sexuality, gender identity, culture, language, ethnicity, socioeconomic and geographical location¹² are all areas requiring specific actions. Responding to people from non-English speaking backgrounds additionally requires a commitment to culturally sensitive end of life care and approaches to dying. Engaging with Aboriginal and Torres Strait Islander communities requires an understanding of cultural beliefs, spirituality, dying and death. The lived experience of LGBTI people is important to developing our service responses to death, dying and end of life decision-making for people that have experienced discrimination and trauma as a result of their contact with health and legal systems historically.

For other individuals' the role of religion may be central to their end of life decisions and 'individual' choice. The approach to discussion and end of life decision-making requires careful consideration and regards to balancing individual rights, needs, cultural norms, religious beliefs and personal expectations.

Outcome 4 Helping people to die well

*"A good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs"*¹³

A framework for end of life care must address dying as a human experience not a medical failure. Our current management of death and funding for end of life care and planning reflects a society where dying is medicalised. An integrated health, palliative and social model of care needs to be developed to meet community expectations.

According to the Grattan Institute 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*¹⁴.

Research and evidence

It is easy to measure place of death but not so easy to measure the pain, suffering and psycho-social support given at end of life. Research and the building of evidence are required to demonstrate why practice change needs to happen and what a good death requires. Data that is qualitative and quantitative to track decision making on end of life and care given – and the experience of families and carers needs to be collected sensitively in a time appropriate way.

According to Professor Imogen Mitchell¹⁵, we need to develop quality measures on

¹² The availability and poor access to palliative care services and trends in ageing in rural and remote communities is further examined in <http://vuir.vu.edu.au/1482/1/Ryan.pdf>

¹³ Grattan Institute p15

¹⁴ Ibid

how to improve dying and death. This will allow us to identify where there are the opportunities (identified points) to improve end of life care. It will also support the development of appropriate models of care and responses at different times around carer stress and when to prepare for the worse. Importantly, where possible, planning for death and supporting the person, their carer and loved ones as they approach death¹⁶.

Integrating palliative care into health, aged care and social systems of care

As end of life approaches care can be urgent and require an ‘acute’ and emergency response to manage suffering. But whose role is it to prevent suffering? How can suffering be better managed? Which service is best placed to provide this? Who else should provide it?¹⁷

There is the need for an immediate and urgent response when this critical decision making space is vacated. Provision of emergency palliative care and support for ethical decision-making needs to underpin this service response. The acute care sector is ill equipped for the dying. For people to die well we must support and implement measures and benchmarks for dying well across all health systems, including: palliative care, accident and emergency departments, intensive care units, ambulance services and primary health providers (GP’s). The integration of palliative care specialists and training is critical to support any ambition to enable people to die well.

A humane and person centred approach to dying well requires strong leadership and workforce training in implementing collaborative models of care. This will result in changing practices and attitudes to end of life care.

Addressing barriers to providing palliative care across aged care service systems

The National Aged Care Alliance identifies a number of barriers and disincentives to providing end of life care to older people at home, in nursing homes and aged care facilities.¹⁸ Whilst palliative care is part of the core business for residential aged care facilities there are funding restrictions in providing palliative care, limited access to palliative care expertise, limited access to general practitioners and PBS-subsidised and non PBS listed palliative medicines. There are also tensions in funding and policy responsibilities between state and federal governments in regards to accessing HACC services whilst in receipt of palliative care services. Barriers to accessing end of life care are further exacerbated for people with dementia.¹⁹

¹⁵ Cited from Professor Imogen Mitchell’s presentation National Outcomes Measures for Advance Care Planning and End of Life Care – Pipe dream or reality? At the 2015 ACP & EOLC National Conference, Melbourne 2015

¹⁶ Ibid

¹⁷ These questions were hotly contested at the 2015 ACP & EOLC National Conference, Melbourne 2015

¹⁸ Aged Care Reform Series Paper, Palliative Care

http://www.naca.asn.au/Age_Well/Palliative%20care.pdf

¹⁹ Refer to Aged Care Reform Paper (Ibid) for detailed recommendations on addressing barriers to end of life care in these settings.

A recent comment posted on COTA's End of life web page demonstrates a number of failings within our current model of care in Victoria ...*I knew my dad was dying. In hospital (the) 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 dad's 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.*²⁰

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.²¹ Within this context, increasing access to palliative services and hospice care continues to be a significant barrier for rural and remote communities.²²

Additionally we need to address the issue of choice when someone is facing a painful and distressing death where the only option is palliative sedation and the complete loss of consciousness, control and choice.

Individual autonomy and rights in 'dying well'

Supporting people to die well is the outcome of informed choice, dignity and respect in end of life care and decision-making.

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 Doctors 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.*²³

The framework for end of life care from COTA's perspective requires respect for people to control the circumstances around their death so what matters most to them is supported. We also acknowledge the need to balance patient autonomy and an individual's 'right' to control their end of life with group protections in the context of potential elder abuse and current legislative considerations of voluntary euthanasia and assisted dying. Whilst outside the scope of this submission, we believe changing community attitudes and expectations in discussing euthanasia and assisted dying

²⁰ See more at: <http://cotavic.org.au/action-advocacy/end-of-life-issues/#sthash.3KekjdHI.dpuf>

²¹ We refer DH&HS to Silver Chain as a successful model in the provision of home based palliative care

²² The Victorian Auditor General's Report into Palliative Care (2015) acknowledges the challenges facing rural services in attracting specialist palliative care physicians.

²³ Smith, 2000: Cited in Swerissen (2014) p8

needs to be part of ‘the conversation’ on what makes a “good death” under certain, limited circumstances with stringent safeguards.

Outcome 5 Supporting our workforce

Silver Chain in Western Australia provides a model for workforce development and planning across a number of staff and disciplines.²⁴ This service uses a population based approach to service development and planning and provides 24/7 service access and support, personal care and respite provision. To support this service an integrated IT system is used across all areas of its operation. The workforce development and support provided through its operations and systems is a model – particularly for home based palliative care - that can be drawn upon.

Improving the linkages between specialist palliative care services and aged care providers is an important system improvement that will support the workforce in the aged care sector. Projects that provide training and support for informal carers and aged care staff in using syringe driver medications have been shown to support people to die in place – rather than in hospital or aged care settings²⁵.

COTA supports the Human Rights and Equal Opportunity Commission’s call for *Extending advance care planning training to include health workers in the acute and aged care sectors.*²⁶

Whilst Doctors recognise when treatment is futile they often fail to communicate this clearly. Competency in ethical decision making should be part of professional training for Doctors and health clinicians. Training for Drs must include communicating clearly the prognosis and impact of treatments in a timely and sensitive way. 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.*²⁷

The more complex decision-making now being asked of individuals and professions requires training on patient rights and autonomy, the ethics of life prolonging treatments and pain management alongside holistic responses and empathy communication techniques. There is a need to widen public discussion and community education to include ethical, psycho-social and spiritual dimensions to end of life care.

²⁴ Aged Care Reform Series Opcit, p 7

²⁵ Aged Care Reform Paper (Opcit) p9

²⁶ Australian Human Rights Commission: Human rights approach to ageing and health: Respect and choice – 2012 p17-18

²⁷ Grattan Institute(2014) Opcit P12

APPENDIX A

Summary Notes on foundations for end of life care in Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020, UK.

1. **Personalised care planning**, which supports people to express their goals for the time they have left alongside preferences for a substitute decision maker should they lose capacity.
2. **Shared records** to support consistent and informed decision making across a range of systems relevant to end of life care (health, social, legal etc....)
3. **Evidence and information** that will assist in improving service and system responses across sectors.
4. **Involving, supporting and caring for those important to the dying person.** This must include bereavement and pre-bereavement care and the capacity for flexible and responsive support and service delivery.
5. **Education and Training** needs address all those professions involved in end of life care. This includes empathy training, communication skills, and practice values of honesty, transparency and supported decision making where appropriate.
6. **24/7 access to services**
7. **Co-design** systems and services in collaboration with and informed by the experiences and knowledge of palliative and end of life care professionals and organisations that provide support.
8. **Cross-organisational leadership and collaboration** to drive positive change and build shared knowledge and integrate and coordinate services