



The Perron Centre
Suite 2, 61 Kitchener Ave
Victoria Park WA 6100
ABN 79 970 893 100

PO Box 923
Victoria Park WA 6979
www.cotawa.org.au

P: (08) 9472 0104
F: (08) 9253 0099
E: admin@cotawa.org.au

24 October 2017

Dr Jeannine Purdey
The Principal Research Officer
Select Committee on End of Life Choices
Legislative Assembly
Parliament House PERTH WA 6000

Dear Dr Purdey

The Council on The Ageing WA COTA (WA) welcomes the opportunity to contribute to the Joint Select Committee's deliberations on the need for laws in Western Australia to allow citizens to make informed decisions regarding their end of life choices.

COTA (WA) was formed in 1959 and has a strong track record of representing the concerns of older people and advocating on their behalf. The current debate occurring across Western Australia about the need for assisted dying legislation reflects the diverse views and experiences of our constituency. As COTA (WA) is a membership and community based organisation, we understand the strong, passionate and diametrically opposed views that exist about any suggested legislative change which would enable assisted dying, and commend the Parliament of Western Australia for endeavouring to navigate through this complex person-centred and community issue.

COTA (WA) strongly supports individual end of life decision-making based on informed choice and supported by a legal framework that respects individual autonomy and provides safe guards for those members of our community who are vulnerable. In an environment where addressing elder abuse is a major community issue, we would be extremely concerned if any legislative changes resulted in older people being pressured into choosing assisted dying because of limitations within the aged care or health sectors, or because of dysfunctional families.

COTA (WA) promotes end of life planning as the most effective way that all people, especially our constituency of older people, can ensure that their wishes are understood by those close them, as well as by their health care professionals, and then acted upon if required. For some years we have facilitated end of life planning and information sessions and are aware of other not-for-profit organisations that deliver this service.

End of life planning, by its nature, is deeply personal and confronting for most people. As individuals, families and a community, we often struggle with talking about death and dying, let alone understand or fully utilise existing legal and administrative processes such as Advance Health Directives (AHD) and Advance Care Plan (ACP) to articulate our end of life wishes. By avoiding and not considering our end of life planning, individual decision-making frequently occurs at times of personal crisis and great vulnerability.

The concept of a “good death” is unique to each individual based on values, life experiences and expectations. For most people this (in part) means being able to die without pain and suffering. There is robust evidence from multiple sources that for most people, pain and suffering can be managed through the provision of good quality end of life care, including palliative care. We also understand that for some people existing medical and other interventions do not work.

We are concerned that the use of the term “dying with dignity” and its association with one end of life option -assisted dying- is misleading and in our view unhelpful. Language is a critical building block to developing clarity when discussing and planning end of life options. The Victorian State Government Ministerial Advisory Panel on Voluntary Assisted Dying in its final report (July 2017) notes the significance of language (in part) as follows:

“Often advocacy groups use the term ‘dying with dignity’ to describe voluntary assisted dying. The Panel reject this label for voluntary assisted dying. The Panel is of the view that using the term ‘dignity’ is problematic because it implies that people in similar circumstances who do not choose voluntary assisted dying are living, and will die, in an ‘undignified’ manner. Many people, and their families, who are being supported by palliative care would say this support enables them to have a ‘dignified’ death.

Dignity is a personal characteristic. It cannot be conferred on someone because they have made a particular choice about how they want to die. Many people would prefer to live as long as possible, even with a painful disease or disability; this is not ‘undignified’. Voluntary assisted dying allows individuals to make choices about the end of their life. The focus is on individual choice because there is no right or wrong answer, and an individual is best placed to decide what is most appropriate for them.

Suggesting there is dignity in choosing voluntary assisted dying, but not in other choices people make about how they want to live or die, suggests there is a ‘right’ and ‘wrong’ approach. Dying with dignity is not simply a quality of a particular choice about how a person dies; human dignity is inherent.’

The quality of people's end of life options, and therefore their ultimate experience of dying, is dependent on the knowledge and skills of those professionals who are involved in providing information and advice and/or delivering end of life services. In Western Australia, feedback from consumers and their families is that end of life services, especially the quality of palliative care services, are of a high quality.

Access and equity issues still exist – end of life care, including palliative care, is dependent on available funding and having the right resources to support people's end of life choices, for example if they wish to die at home. If Government reaches a decision to develop legislation that supports assisted dying, it is critical that funding to services such as palliative care and rural health services is not reduced as part of budget or other considerations. It would be contrary to the wishes of all Western Australians that assisted dying should become a default option because end of life services are not available to citizens when they need them, regardless of where they live in the State.

In Western Australia, as in other Australian jurisdictions, there are a number of legal and administrative documents available to assist in end of life planning. These documents are independent of each other and can be complex to complete. We refer to Wills, Enduring Power of Attorney (EPA), Enduring Power of Guardianship (EPG), Advance Health Directives (AHD) and Advanced Care Plans (ACP).

Feedback from participants attending COTA (WA) forums and peer education has highlighted that there is confusion about the purpose and need for EPA, EPG, AHD and ACP. Additionally there are surprisingly high numbers of people (estimated 50% over the age of 40 years) without a current or valid will.

Most people we have consulted are unaware that the health system has a "hierarchy of decision makers", in the circumstance where a person is not able to make decisions on his/her own behalf. For most people, completing an AHD requires the knowledge and support of a health care professional – this can be a difficult and challenging process which requires persistence and tenacity. Below is an example of one of our members' experience which we understand to be fairly common:

This week, I made another attempt to complete my Advance Health Directive and Enduring Power of Guardianship and get both documents uploaded into my eHealth record – with frustrating lack of success!

Having looked at both forms and read all the accompanying information sheets, I decided I did not have sufficient knowledge to complete the forms and therefore I should consult my GP (as advised).

My GP (an extremely compassionate and supportive person) said he was not really familiar with the form and asked what sections I needed help with. I needed help with the Treatment Decisions because I was unsure of the possibilities: what “circumstances” should I consider and what “treatment decisions” should I “consent to/refuse consent to”?

The GP said that there were so many circumstances and hierarchies of treatment that he couldn't really help and maybe I was better off talking to someone else: a nurse in emergency care, a counsellor in Palliative Care or Advocare.

Whilst I could understand his point of view (because that was the problem that I had also been having and therefore made the decision to consult my GP), I was no better off. I said I would go and have a look on the internet to see if there was any more help there.

My enquiries about Enduring Power of Guardianship met with the same response.

As an aside, I have been trying (unsuccessfully) to get the medical practice to enter medical data into my eHealth record for over a year now. I have decided to enter what I can myself.

As another aside, I think that I have found something satisfactory on the internet.

There is a fundamental need for better education of health care professionals around end of life planning. If the medical profession does not have the capacity to provide information and advice (for whatever reason), there needs to be a simpler system (than using doctor google or the internet) to obtain the assistance they require to establish an end of life plan.

Being able to locate the AHD or ACP at the time it is needed is a critical issue. The Department of Health recommends a range of actions to ensure that key people including doctors and family know that you have completed an AHD. However most of these rely on the person providing multiple hard copies of the AHD to key people or informing those close to you where you have placed a copy of your documents so they know where to easily find them (for example, on the front of your fridge or wherever you usually put your unpaid bills).

While the above information aims to be helpful and practical, we consider that in this day and age relying on manual systems for critical information that impacts on people's end of life care is problematic and full of risk for the individual.

The Commonwealth has invested extensive resources in establishing an e-health record system which has had limited take up by doctors and patients alike. We consider it as essential that copies of critical documents such as AHD and EPG are recorded on an electronic system.

In conclusion, COTA (WA) would like to thank the Joint Select Committee on End of Life Choices for the opportunity to contribute to this important discussion. If the Committee feels that additional input from COTA (WA) would be useful, please feel free to contact us

If more information is required, please contact Jennette Ward on _____ or _____

Yours sincerely

Mark Teāle
Executive Officer