



SUBMISSION ON EXPOSURE DRAFT OF THE MEDICAL SERVICES (DYING WITH DIGNITY) BILL 2014

**Prepared by
COTA National Office**

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COTA

COTA Australia is the peak national policy body of older Australians. Its members are the eight State and Territory COTAs (Councils on the Ageing) in NSW, Queensland, Tasmania, South Australia, Victoria, Western Australia, ACT and the Northern Territory. COTA Australia focuses on national policy issues from the perspective of older people as citizens and consumers and seeks to promote, improve and protect the circumstances and wellbeing of all older Australians, promote and protect their interests, and promote effective responses to their needs.

INTRODUCTION

COTA welcomes the opportunity to provide comment to the Committee on this exposure draft.

Within COTA, at the national and State and Territory levels there have been many debates on the issues around voluntary euthanasia. It is an issue which often comes up in discussions with older people. It is interesting to note that when the then Minister for Mental Health and Ageing undertook his national series of conversations with older people about aged care in 2011 the issue of voluntary euthanasia was raised at most of them.

Some of the State and Territory COTAs have been active participants in discussions around advanced health directives, end of life care and voluntary euthanasia, seeing their role as one of facilitating community discussion on these issues. We went out to all the State and Territory COTAs asking them for their views on the legislation and their comments are included in this submission.

After much deliberation COTA has decided that it will take a neutral position on the issue. We know that there are divergent views on this issue across the COTA membership and the older population more generally and have decided that it is a matter of personal conscience.

For that reason we are not commenting on whether or not the Commonwealth should legislate on this issue but rather looking at the principles that should be applied if there were to be agreement to have such legislation and how the legislation proposed meets those principles.

ISSUES

We have attached the submission by COTA Tasmania to the proposed model for Voluntary Assisted Dying which was considered by the Tasmanian Parliament in 2013 as this raises many concerns that are also relevant to this legislation. They make the important point that it is imperative that older people's wishes and beliefs be respected.

Dying with dignity

COTA has some concerns around the use of the term dying with dignity in this context. It could be taken to imply that the only way to die with dignity is to use these services. COTA believes that everyone should have the right to die with dignity regardless of the cause of or setting for their death. All end of life care should have that as its goal and many people die with dignity without medical intervention that hastens that death which is what the Bill is promoting.

We suggest that the title of the Bill should be amended to better reflect the idea that it is about assisting people to die. The Tasmanian proposal in 2013 used the term “Voluntary Assisted Dying” and there are many variations on that that better reflect the intent of the legislation.

Definitions

COTA thinks the definition in Clause 4 of illness which includes “degeneration of mental... faculties” is not consistent with the requirement to be of sound mind and competent at the time of making a request. We think this needs to be clarified.

We also think that requirement for “treatment to be unacceptable to the person” needs to be clarified.

Choice

The COTA Tasmania submission stresses the need for people to make an informed choice about care options, including assisted dying. We think clause 12 in the proposed legislation which outlines the pre-conditions to providing dying with dignity medical services are robust and provide for a number of checks and balances to ensure the person understands the decision they are making

One issue which always comes up in discussion is around knowledge of and access to appropriate palliative care. This is covered in 121(h) (i) and (ii) and again in 12(2).

We note the requirement at 12(2) that possibly a fourth medical practitioner could be involved to give information on palliative care options if the designated first practitioner does not have special qualifications in the field of palliative care. We think this may be too onerous and does not acknowledge that it could be difficult for people living in areas without access to specialist palliative care services. It could also be seen as taking away an element of choice from the person who wants to have access to medical services to assist them to die.

We are concerned that the requirement in 13(3) which says the medical practitioner must not proceed if they think palliative care options have not been exhausted talks only about pain and suffering does not mention quality of life.

The meaning of “to a level acceptable to the person” in this clause needs to be clarified. It also does not address the issue of what should happen when the palliative care options referred to are available but “the person” does not wish to accept them?

We also think this provision could be considered to undermine much of the rest of the legislation and take the choice to access services away from the individual. It does not meet the basic test of respecting people's wishes.

The draft legislation does not discuss the role of advanced health directives in showing people's wishes on treatment under certain circumstances. The existence of an advanced health directive indicates the person has thought about quality of life issues associated with certain medical conditions. We are not suggesting that people could include a request to access dying with dignity in their health directive but we think some consideration should be given to its existence particularly in relation to 13(3).

We have some concerns with clause 12(1)(j) which requires the medical practitioner to be satisfied the person has considered the implications for their family. This undermines the basic principle of respecting an individual's right to choose. It is also not clear how the medical practitioner could satisfy themselves with regard to this.

Assessment

The exposure draft includes a three tiered approach involving three medical practitioners one of whom is a qualified psychiatrist. Whilst fully endorsing the need for a thorough process that gives a person many opportunities to change their mind we are concerned that this will slow the process up, particularly for people living in rural and remote areas.

In particular we are concerned that many people have limited access to medical services and would struggle to access a psychiatrist. It may be simpler if they are in hospital but we know 70 per cent of people want to die at home and so we need to have a model that works well for people who are achieving that goal. We think a GP who has had an ongoing relationship with the person might be well placed to do an assessment of mental health.

Administrative arrangements

It is not clear to COTA why clause 17 gives the Secretary (of the Department of Health) the right to refuse a claim for providing the services. Provided that all the provisions of the Act have been met and the medical practitioner has kept all the records listed in clause 19 then it should not be a discretionary process.

This possibility could inhibit the medical practitioner's willingness to perform the service as they would not be sure they would be paid. It also may leave open the need for the family or estate to pay for the service.

Other Issues

One concern that has been raised by COTA members is that the legislation seems designed for people living in cities who have ready access to palliative care and other medical facilities. It ignores the fact that many people in outer regional, rural and remote areas of Australia simply don't have access to those services. Whilst it could be argued that people without access to some palliative care services might find it easier to meet provisions such as clause 13(3) they would certainly find it hard if not

impossible to find the three medical practitioners required to allow a certificate of request to go forward.

People from culturally and linguistically diverse backgrounds living in non-metropolitan areas may be further disadvantaged because of the need in clause 13(2) for an interpreter with professional qualifications. This could be overcome by the telephone interpreter service but it would still be more difficult.

CONCLUSION

COTA does not have an opinion on whether or not this legislation should go forward. What we have tried to identify are some issues that need to be addressed to improve the legislation if it does so.



COTA **TASMANIA**

Submission to Proposed Model

for

Voluntary Assisted Dying

A Proposal for Tasmania

COTA TAS

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Introduction

COTA Tas is the peak body representing the needs and interests of older people in Tasmania. Our vision is for an inclusive society which values, supports and respects older people.

COTA Tas (Council on the Ageing) has a Board of Directors providing governance to the organisation. COTA Tas Policy Council has members appointed by the Board of COTA to look into areas of policy development and issues facing older Tasmanians. Both of these bodies have been involved in the preparation of this submission.

COTA Tas - Our Vision

An inclusive society which values, supports and respects older people

COTA Tas - Our Mission

Promoting, improving and protecting the needs, rights and interests of older Tasmanians with a focus on the vulnerable and the disadvantaged.

Process of development of this submission

At the Board's request a letter highlighting the discussion paper(s) was distributed through the COTA electronic database system, whose membership comprises of members of the organisation and also to interested stakeholders of COTA. This letter was sent after the Board met to discuss this issue and prior to the meeting of the COTA Tas Policy Council.

The letter to stakeholders is attached to this submission in Appendix A.

COTA Tas Policy Council met after this letter was sent and was able to view responses to date to the letter. Responses from our stakeholder group are available in a consolidated form in Appendix B.

COTA Australia Policy Council has also developed a position statement on Palliative Care that has also informed our response. This is available in Appendix C.

The Proposed Model

COTA Tas has discussed the issue of Voluntary Assisted Dying in great depth, and acknowledges that this topic has widely differing views amongst the community. COTA has never formally fully canvassed our members or the wider community on this topic and because of this has taken the view that it cannot formally arrive at a definitive position unless that has taken place. We have taken some feedback as mentioned before and we have made these available for this submission.

However it has been agreed that we approach our response framed in terms of

“..IF the legislation were passed”;

- How would it best be implemented to protect the rights of older Tasmanians,
- It is essential in our view that older people’s wishes and beliefs should be respected, no matter what they may be.

Informed Choice

COTA believes strongly in protecting choice for older people and that it is very important that this is **informed** choice, about all options available to people no matter whether they favour voluntary assisted dying or not. This informed choice also needs to be balanced with **adequate protection** for older people to ensure they are protected from pressure from people they know, and of course importantly from abuse of any kind. It also should be made clear to people in this situation considering voluntary assisted dying, options and pathways are discussed including palliation and encouragement of the use of advanced care directives.

The many steps required in this model would appear to allow several opportunities for people to withdraw from the process if required. It is also a model that clearly identifies that the decision needs to be made by that person, and put in writing, and witnessed by an independent witness.

There was also considerable discussion that appropriate safeguards and conditions should be in place, and it would appear that the proposed model has mechanisms in place to address this.

A great deal of discussion amongst the COTA Board and COTA Tas Policy Council focussed on rights of older people (and of course other people in this situation), and about Quality of Life issues for those people who are terminally ill.

Feedback regarding the concept of quality of life in various Culturally and Linguistically Diverse (CALD) communities is that;

'Quality of life' is understood in wide-ranging terms in various Culturally and Linguistically Diverse (CALD) communities.

For some older migrant communities 'Quality of Life' is seen in terms of the right and freedom to make your own **choices in death as well as life**. For other newer CALD communities the right and freedom to make your own choices in death as well as life is not considered a personal matter as the community elders make all major decisions throughout a person's life. These attitudes may change especially in the younger generations as the CALD communities come to terms with living in our society. However every CALD person (as with all Tasmanians) needs to be able to make their own choice as to who is going to make the decisions about their end-of-life experience.

Consultation Points

Consensus was not completely reached on all aspects of the consultation points, so the submission will include some of the discussion points raised.

1. Unbearable or unrelievable as a separate eligibility criteria.

Unrelievable was considered to be an eligible criterion, as it included opinions from those caring for the person regarding "what more could or could not be done" for that person. However it was felt that unbearable was more of a personal decision and it would likely to be implicit in a person's decision to end their life anyway, so no need for a separate criterion. It was acknowledged that degree of suffering was a very important consideration as part of the decision to undergo this process.

Another member of the consultation group felt that both these criteria did not necessarily follow to the justification for assisted suicide.

2. Should eligibility be linked to anticipated life expectancy?

It was agreed that this was too unreliable a basis to be linked to eligibility.

3. **Attending doctor being able to legally administer the fatal dose?**

There was general consensus that this should be the situation with the following caveats:

- No doctor should be forced or pressured into doing it – if it is against their own moral code
- This is already in place when medications to relieve pain and suffering contribute to an earlier end-of-life experience for a person. Our society accepts this scenario as being appropriate in these circumstances, however not all societies agree. Some CALD societies do not believe in changing the dying experience for a person by medical interventions and these people need to be able to **make this decision for themselves within our law.**
- Medical practitioners need the freedom to make decisions with the agreement of the terminally ill person without the fear of legal repercussions. Ideally the decision should be an agreement between the medical practitioner, who has all relative information and knowledge, with the terminally ill person, without the action resulting in impacts upon their practice and on the person's family and friends who support their decision.

4. **Self administration including those unable to do so without assistance.**

Some felt that if they were able to do so this it should be an option, whatever is easier, safer and more comfortable. However, it was stated that a terminally ill person should not have to shorten their lives for fear of not being able to self administer the final medication.

Another member of the consultation group did not agree with this option.

5. **Those unable to sign**

It was highlighted that there should be strong encouragement to allow a decision to be made before this point is reached. It was felt that a range of other options if done in a manner that was legally acceptable should be available, discussion included directives to guardians held with the Guardianship Board.

6. **Independent Consultant**

It was felt that there was merit in allowing access to another opinion, either through another medical practitioner or through an independent consultant with specialist expertise.

7. **Face to face consultation**

Opinion was that this consultation should take place face to face

- “at the very least it affirms their humanity and it is a strong safeguard and better basis for judgment.”
- “This may need to be held in a private meeting with the person without interference from anyone else. However some terminally ill persons from CALD communities will want to have their elders, family and friends involved in the decision making.”

8. Independent Oversight

This was a proposal that saw merit in some eyes, and not in others.

Those for the proposal saw it as an important way of gathering data and analysing the functionality of the proposed model. It was also seen to be having a judgement function and both functions would need to be appropriately resourced. A mix of government/ quasi government and independent panels were considered models of governance.

Other opinion felt this body should be completely independent to the government due to perceptions of government influence and fear of “Police State” in the eyes of some cultural backgrounds.

A strong level of transparency and communication was thought to be important for the model to be effective to allow;

- the monitoring process, and
- capacity and willingness to respond to emerging understandings of how the legislation is working.

Another opinion against the independent oversight felt that this was another level of bureaucracy that was not needed if extensive medical counselling has been given.

Other feedback

There was a strong feeling amongst the formal consultation group of the COTA Tas Board and the COTA Tas Policy Council that this was a deeply individual matter, and that all terminally ill people should be treated with respect and with the “right to experience their death in the best way for them”.

Choice based on life experiences and beliefs was a very strong theme during our discussions on this proposal.

Thank you for the opportunity to respond to the paper. Please feel free to contact COTA TAS if there is any need for clarification or any issues that need further discussion.

Attachments to the submission:

A: Copy of letter to stakeholders

B: Feedback document in response to letter

C: COTA A Health: Palliative Care Position statement