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Briefing to the Legislative Counsel

Law and Justice Committee

Voluntary Assisted Dying Bill 2021 (NSW)

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Introduction

I thank the Committee and the Parliament for allowing us the opportunity to give evidence. I would also like to acknowledge the traditional custodians of the land on which we meet and to show my respect for elders past, present and emerging.

I am here today to speak on behalf of Catholic Health Australia. Nationally, its members constitute Australia's largest non-government grouping of health and aged care services accounting for approximately 10 percent of hospital-based healthcare in Australia. Its members also provide around 25 percent of private hospital care, 5 percent of public hospital care, 12 percent of aged care facilities, and 20 percent of home care and support for the elderly. In NSW, CHA members provide about 8,000 residential aged care beds, 1,800 public and private hospital beds and care for 14,000 home care consumers

I am from one of CHA's members Catholic Healthcare where I have worked as Chief Legal Counsel for over 12 years. Catholic Healthcare provides residential aged care, retirement living and services for older people in their homes, in the community and on the streets. Most of our 40 residential aged care homes are in NSW as are our community and other services.

Today I want to draw your attention to concerns I have, and many aged care providers have, about the VAD Bill and its potential intersection with abuse and coercion of older people. I know that you will have heard or read evidence on this topic before and I wish to share with you some stories from my own experience as Chief Legal Counsel of an aged care provider and point out some key issues with the Bill that I believe must be addressed.

To start, let's review some information about the aging population and available services.

The Australian population is ageing. There is a shortage of aged care workforce and this shortage is expected to increase. There is also a shortage of supports and services for older persons, particularly in regional and rural areas. including community aged care and home nursing services and specialist services such as palliative care services. The Royal Commission into Aged Care highlighted the very significant shortfall in home care packages available for older people, the lack of respite care services for older people also the lack of healthcare services for aged care. The Royal Commission also pointed out the very significant stresses this lack of services put on carers.

Bearing all this in mind, the recent NACAP Presenting Issues Report 2020/21 from the Older Persons Advocacy Network (OPAN), identified, among it 8 top presenting issues facing older people:

- The abuse of older people; and
- In the case of diverse and marginalised older groups – family and financial abuse, among other things.

It is against this background that that I turn to the NSW VAD Bill which deals with people at the end stages of their lives where they are at their most vulnerable, and arguably many of their carers can also be under tremendous pressure.

In my view, the VAD possibility heightens the risk of abuse and coercion of vulnerable older people.

You see, a vulnerable older person could consider assisted dying out of lack of support to meet end of life aged care needs, isolation and loneliness leading to depression and despair, and a desire not to be a burden to others.

They may not have access to information and people who could support them in older life including the provision of end-of-life care, free of any pressure to 'choose' assisted dying.

We know this happens, internationally. Canada introduced VAD and euthanasia in 2016 and has published its first national report on the scheme:

More than a third of people dying by VAD or euthanasia in Canada said **a desire to not to be a burden was a factor in their decision.**

A further 13% cited loneliness and the lack of social support as a factor. COVID has shown just how socially isolated the elderly in our society can be.

Then, there are the cases where, as identified in the OPAN report, for various reasons, family members or other close persons to the older person will take advantage of the older vulnerable person either knowingly for their own ends, or unknowingly.

In my professional practice, I have seen a number of such cases ranging from:

- asset stripping of residents
- family members trying to make advanced care directives to forego medical interventions for relatives lacking capacity.
- Residents lacking capacity being taken by family members to solicitors to have their wills changed.
- earlier this year, I came across a forged guardianship order, giving the purported guardian powers that the tribunal never authorised
- to cases of physical neglect and abuse.

One case I will share with you arose from an inquest involving an older individual at end of life.

The client lived in an isolated area with his carer and their son. The attending community nursing team observed that the carer was sometimes erratic, sometimes absent and there were constant issues with the delivery of the morphine – it ran out too early, the vials were smashed, the box was dented. Ultimately the client was given a morphine patch to address their pain.

6 months later the client turned up in the ED, covered in scabies, monstrously undernourished and blood tests showed that he had not had pain relief. He died. A witness at the inquest stated that she had never seen a person who was not already dead in a more wretched condition. This was a case of abuse.

As the evidence unfolded it became apparent that the carer was a morphine user, was not attending police drug tests and the totality of the evidence suggested that the carer was taking the morphine to support their own habit.

In reading Hansard last night, some of the comments made seemed to indicate that the use of VAD for the personal gain was almost fanciful. Cases like this point out the lengths that some people will go to further their own ends, VAD presents another opportunity.

One pertinent feature of this case was the sheer number of people who visited the house and saw the client. This included the community nursing team, a GP, social workers visiting (the son was under DOCS), help in the home services and at least one sister of the carer, as well as police undertaking welfare checks. So how was the abuse missed by all these people?

In my view, this was because abuse was not obvious. It only became apparent over time when evidence from different people observing different things is brought together and the totality of the evidence enables the abuse to become apparent.

And it is against this background that I return to the VAD Bill and my worry about the ways in which this VAD legislation might play into situation like this.

As we know, clause 16 of the Bill sets out the eligibility criteria which includes that the person has decision making capacity in relation to voluntary assisted dying, the person is acting voluntarily, and the person is not acting because of pressure or duress.

Also, as we know, the dictionary defines pressure or duress as including abuse, coercion, intimidation, threats and undue influence, and under various clauses of the Bill, it is the practitioner who must assess that the patient meets the eligibility criteria.

Given what I have seen, I really wonder how one practitioner seeing the patient once or twice could properly assess whether the patient was acting freely or under coercion? How could they know what pressures were brought to bear overtly or covertly and over what period? The Bill does not seem to provide any guidance on how to determine whether the person is acting voluntarily or under coercion and sometimes abuse and coercion are very difficult to see. How is the practitioner meant to assess this?

The risk of coercion/lack of voluntary action is exacerbated when the person's interactions take place over videoconference and the patient's signature on the written declaration can be made electronically.

As I have already mentioned, earlier this year I found a forged Guardianship Order. Interestingly, the clinical team had considered the Order to be authoritative for some time as it bore the seal of the Tribunal and contained many of the usual clauses. I was the only one to observe and question the highly unusual language in one section. How is the VAD practitioner meant to pick this up?

In another case many years ago, a non-English speaking female patient was given a tubal ligation on the say so of her interpreter husband. The woman herself thought she was having quite another procedure. The husband didn't want to have any more children and lied to both his wife and the treating practitioner. This wasn't picked up until much later. How is the VAD practitioner meant to be alive to these sorts of occurrences. Unfortunately, these things do happen and VAD presents another opportunity.

And there is no requirement for the VAD practitioner to engage with people who may know the patient quite well such as their regular GP or their usual service providers, who may be more alive to patterns of behaviour by the patient and by others that might give rise to questions or concerns to be investigated. These are the people who are most likely to be aware of concerns and best able to

articulate them. Yet there is no requirement for consultation.

And then the time between the first and last request can be as short as 5 days, which is almost half of that of other jurisdictions.

Moving from questions of coercion, were there time, I could tell you of a number of inquests where an elderly person had been assessed as having capacity to do particular things that led to their death but expert opinion provided in the inquest hearing disputed the assessment of capacity. One case concerned an elderly person, a former RN, who wished to attend to her own care. Her GP assessed her as having this capacity, the nursing staff at the Home relied on the GP's assessment but the psychogeriatrician who gave evidence as an expert witness was very firmly of the view that the resident did not have capacity. His view was believed

I am involved in an inquest at the moment, the findings are to be handed down later in December where an elderly person was assessed by a psychiatrist in hospital as having capacity but the expert psychogeriatrician said in evidence it was very clear that she did not have capacity, noting the very specific ways in which assessments of capacity in older persons need to be conducted.

If GPs and psychiatrists cannot always accurately assess capacity in older persons, how the VAD practitioner meant to come to some meaningful view on these things.

Now The VAD Bill presumes capacity under s 6 and this is consistent with other approaches of the law that presume capacity in a range of circumstances.

However, given the cases I have been involved in, and the wildly differing views that practitioners can take when dealing with capacity in older persons, I wonder whether this blanket presumption is advisable particularly in the case of older persons, in a process as complicated and significant as a decision to end one's life. This must particularly be the case when other provisions of the Bill come into play such the ability for the medical practitioner to communicate with the patient via audio visual link, through an interpreter and through gestures only.

Palliative care

To conclude, I would like to say a few words on the topic of palliative care, particularly in the context of older persons.

The evidence of the inadequacy of palliative care in NSW is well documented. In its current form the Bill says the system must have regard to the principle that a person who is a regional resident is entitled to the same level of access to VAD as a person who lives in a metropolitan region (existing s

4(1)(i)). Yet it makes no analogous provision for regard to be had to the principle that people in regional areas are entitled to the same level of palliative care as those who live in a metropolitan region. Inequity of access to palliative care will increase the potential for people to seek access to VAD.

We feel that it is uncontroversial that the principles set out in section 4 should include the principle that a person who is a regional resident is entitled to the same level of access to palliative care as a person who lives in a metropolitan area. Section 4(1)(h) provides that a person is entitled to genuine choices about the person's care, treatment, and end of life irrespective of where the person lives in New South Wales and having regard to the person's culture and language, however, the Bill's drafters apparently consider this to be too general to cover the specific right of a person to equal access to VAD (hence the inclusion of the existing s 4(1)(i)). It is also too general to cover the specific right of a person to the same level of access to palliative care, regardless of where they live.

It can also be argued that the absence of readily available quality palliative care is subtly coercive, pushing those who are most vulnerable to choose VAD in the absence of another viable option.

Much more could be said about the shortcomings in the Bill and the need for further safeguards. My colleagues on this panel today will address several other issues requiring reconsideration by this Parliamentary Committee and the Upper House.

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