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Human Research Ethics Committee

Contact details:

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Submission to the Queensland Government Health and Environment Committee Re: proposed Voluntary Assisted Dying Bill 2021

Thank you for the opportunity to make this submission. I congratulate everyone involved in the development of this Bill; I think it is the best such proposal yet presented to any Australian Parliament.

There are a number of areas where it is better than the current legislation in other States, two which I believe require amendment and one major omission. I will address each of these in turn.

Areas which are better than the current legislation in other States:

- **Option to have doctor administer the medication, not dependent on physical incapacity of the patient**
s50, allowing a person to self-administer the VAD medication or to have their administering practitioner do so, where the practitioner advises that it is inappropriate for the person to do so themselves, is a much better option than requiring the person to self-administer unless they lack the capacity to do so, for several reasons:
 - In my discussions with people who would want the option of VAD, many are afraid that they might not do it correctly and would end up in a worse situation than the one that prompted their request. This could be because their hand might shake and they could spill some of the medication, or their anxiety could cause them to choke on the medication, or vomit it back up.
 - Dr Roger Magnusson's excellent book "Angels of Death: The Euthanasia Underground" includes many cases of a patient or carer mis-administering the medication, with disastrous results.

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- In research I conducted some years ago in the Netherlands, several doctors described assisting their patients with euthanasia (as it was called) and said “It is the most intense care I can give my patient” or “I promised my patient I would walk with him as far as possible on his end-of-life journey”. On such a journey, if the medication does not have full effect, for whatever reason, an experienced medical practitioner can provide additional medication if necessary.
- **Residency exemptions**
s12 is a very sensible provision; it is important that a person who is approaching the end of life as a result of a terminal illness, has the best support possible at such a time. This includes someone who wants to access voluntary assisted dying. If a person’s familial or social support networks are in Queensland but they live in another State or Territory, then the ‘compassionate grounds’ requirement is satisfied.
- **Conscientious objection (including of ‘entities’)**
While the provisions of Part 6 of the legislation, from s84 – s 97, allow a registered health practitioner (Division 1) or ‘entity’ (Division 2) to exercise their conscientious objection to being involved in VAD in any direct way, I applaud the fact that the legislation, as proposed, goes to great lengths to ensure that they cannot purposely impede a person’s access to information about, or access to, VAD.
However, I expect the Committee – and the Parliament – to receive strenuous arguments relating to these provisions. My research found that many health care providers and entities who have strong religious or ethical objections to VAD would consider even allowing someone to provide such information, or allowing a resident to consult with a coordinating practitioner or be provided with VAD in their facility – or to transfer the person to another location where they can access such things - to be equivalent to “aiding and abetting” someone to perform an activity which the provider or entity considers morally unacceptable.
Subdivision 4 is an appropriate, but not entirely adequate, response to the above issues. I recommend that it be a requirement that a statement be included in the Information Packs that are generally sent out to everyone who makes enquiries about moving into a residential aged care facility, and also be sent to anyone who is seeking admission to a hospital palliative care unit or hospice.
- **Eligibility/Time to death prognosis**
While the “blanket” provision for eligibility in s10 (1) (ii) is better than the 6 mth/12 mths provision in the legislation in other States, why is it necessary that any “time to death” provision be included? It is generally accepted that prognosis is one of the most difficult (if

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not impossible) skills for a medical practitioner to acquire. A patient might be told that they have 2 years to live, and die within 6 months, or be told that they only have a few months to live and still be alive 5 years later. If someone has been diagnosed with a terminal illness and has “unbearable suffering”, why do they have to continue to suffer until they meet some arbitrary timeline? Being diagnosed as terminally ill and having “unbearable suffering” which cannot be relieved in any manner acceptable to the patient, should be sufficient to qualify for voluntary assisted dying.

Areas requiring amendment

- **Health care worker not to initiate discussion about VAD**

The heading of s7 and the provisions in part 1 of this section could be confusing to a health care worker who is not accustomed to reading legislation, as it initially reads as if *any* health care worker cannot provide such information unless the patient specifically asks for it.

While part 2 states that “a medical practitioner or nurse practitioner” may provide such information, if they also – at the same time – provide information about treatment options and likely outcomes, including palliative care options and likely outcomes, this could leave other health care professionals, such as registered nurses who are not nurse practitioners, or allied health professionals who may be advising patients about care options, in an invidious position. Promoting patient autonomy and supporting informed consent dictates that all patients with capacity have the right to “all relevant information” about their condition and the treatment and other options relating to that. In many situations, e.g., in residential aged care facilities, “a medical practitioner or nurse practitioner” might not be available to speak to the resident, but this section indicates that no-one else, even a Registered Nurse or Care Manager, can provide such information, unless the resident asks for it directly. Many residents might want the information but not know how to ask for it. I think this section is discriminatory!

- **s85 Speech pathologists with conscientious objection**

it is unclear why there is a special provision for this particular group of allied health professionals. I have been told that they are not “registered” in the same way as other health professionals are. However, there are other “care professionals” who are highly likely to provide advice to patients/residents/carers and other family members when someone is approaching the end of life, in particular Social Workers. While they are “registered”, and many Social Workers do work in health-related areas they are not health professionals; they are primarily “social well-being” professionals. They are not therefore, in any accurate sense, covered by the provisions in this legislation relating to health professionals.

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Major Issue in all Australian legislation

- **Discrimination against people with dementia**

While this proposed legislation is the best that has been developed so far in Australia, it does not address the inherent discrimination against people with dementia. Many people have experienced the impact of dementia on someone they loved, and they do not want to experience the ravages of the disease themselves. In a number of large, population-based studies that my colleagues and I conducted in Australia, we asked participants to rate what they thought they would find most distressing if they were terminally ill; from a list of 10 possible options, in every study we did, “loss of mental faculties” came in first, ahead of loss of control, independence, dignity, pain ... In every study we did, death itself came in last.

However, current and proposed VAD legislation in Australia does not offer anything for people with dementia. The time-frame of 12 months to expected death (including, in some States, for a person with a neurological condition) does not address that problem. The time from diagnosis to death for a person with dementia can be 10 years or more and most people lose decision-making capacity well before they have a prognosis of 12 months to death. I strongly recommend that a person who has been diagnosed with dementia be enabled to make their first request while they still have capacity (although preferably not immediately after receiving the diagnosis), and that the request be documented in an Advance Health Directive, or a similar document specifically developed for this purpose, witnessed by their GP and another independent witness (e.g., JP) with very specific instructions about when it is to be actioned. When it becomes clear that the person is at risk of losing “capacity for the matter”, they could confirm that their Advance Directive still reflects their current wishes.

To clarify, a person who has received a diagnosis of dementia could complete all of the requirements for “standard” VAD but the actual assistance would not be provided until they had reached a pre-determined stage of their illness, which could well be after they have lost capacity. Please consider making it possible for a request for VAD, made in an Advance Directive by a person who has been diagnosed with dementia, to be honoured/actioned when the circumstances reach the point - defined in the AD - at which the person wants VAD to be provided to them . This would obviously have to be practitioner-administered.

An alternative option could be, to remove the “expected time to death” requirement for people with dementia, so that their eligibility becomes “diagnosed with a terminal illness, with intolerable suffering that cannot be relieved in any manner that is acceptable to the patient.

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Current situation in the Netherlands: I have discussed this issue at length with colleagues in The Netherlands; in that jurisdiction, requesting VAD in an Advance Directive is permitted, but the reality is that it is seldom honoured! The reason for this, I was told, is that, in the days before the legislation was passed in The Netherlands, when VAD was still a criminal offence but doctors could provide a defence of '*force majeure*' (no other option to relieve suffering), doctors were "hounded" by anti-euthanasia proponents when they assisted a patient to die. Even after the legislation was passed, they were still subject to intense scrutiny, to ensure that they complied with all of the safeguards in the legislation – one of which was that the request had to be "a *current*, repeated request". Although permitted in the legislation, a request in an Advance Directive, made before the person lost capacity, could not always meet the definition of a "*current*" request. I was told that the unintended outcome of this was that, as people with dementia became aware that their request for VAD via an AD would probably not be honoured, some people requested VAD well before they were really ready to die, because they were afraid that, by the time they reached the stage that they deemed that life would be intolerable (however, they interpreted that) they would no longer have the capacity to request VAD.

Therefore, a provision in the proposed legislation would need to make it explicit that the person had capacity when the request was made, had clearly established the conditions under which it was to be actioned and no time-frame from request to action was to be stipulated

(Note: if the proposed Qld legislation allows a request in an AD to be actioned, other sections of the legislation would require amendment).

Best wishes for your deliberations

A handwritten signature in black ink that reads "Colleen Cartwright".

Professor Colleen Cartwright

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