



Australian
CareAlliance

"Care and Compassion: Opposing Assisted Suicide."

LAW AND JUSTICE COMMITTEE

Inquiry into the Provisions of the Voluntary Assisted Dying Bill 2021

Hearing 10 December 2021 – Australian Care Alliance

ANSWERS TO QUESTIONS ON NOTICE

Ms Campbell undertook to provide on notice more information about the membership of the Australian Care Alliance. A question was also directed at Dr John Daffy, in his capacity as Treasurer of the Australian Care Alliance, about its funding.

In response to both these questions we provide the following information:

The Australian Care Alliance was formed in March 2018 by health professionals, lawyers and community activists who had worked together informally to oppose the passage of the *Voluntary Assisted Dying Bill 2017* through the Parliament of Victoria.

Australian Care Alliance Inc. was registered on 29 April 2018 with Consumer Affairs Victoria as an incorporated association with the following purposes:

- (a) to nurture informed conversations about dying,
- (b) to promote equal access to excellent palliative care, suicide prevention services, and support for disabled persons,
- (c) to promote the protection of the elderly and other vulnerable persons from abuse and wrongful death,
- (d) to promote alternatives to euthanasia and assisted suicide,
- (e) to support community education initiatives and the education and support of health professionals in the pursuit or furtherance of the above purposes,
- (f) to conduct research into attitudes towards and experiences of dying and end-of-life situations in Australia and overseas,
- (g) to monitor and scrutinise the operation of laws relating to euthanasia or assisted suicide, and
- (h) to do all things incidental to the preceding purposes.

Australian Care Alliance Inc. operates under the Model Rules; has 8 committee members; held its most recent Annual General Meeting on 13 October 2021; lodged its most recent annual financial statement on 8 December 2021; and is rated as a Tier 1 association for financial reporting purposes (total annual revenue less than \$250,000).

Revenue is derived from donations and fund-raising events. No single donation has exceeded \$12,500.

Australian Care Alliance Inc. supports a broader, informal Australian Care Alliance of several dozen medical practitioners, including palliative care specialists and psychiatrists, current and former legislators, researchers and community activists across Australia who work together for the purposes set out above.

ANSWERS TO SUPPLEMENTARY QUESTIONS

- 1. Can you please comment on the implications for the professions of medicine and nursing and the overall medical, health and aged/residential care ecology of New South Wales by describing Voluntary Assisted Dying, as provided for in the *Voluntary Assisted Dying Bill 2021*, as “care” or “patient-centred care”?**

“Patient-centred care” is an appropriate approach to medical care, including palliative care, because medicine, since the time of Hippocrates has included a commitment by a physician to *“benefit my patients according to my greatest ability and judgement, and [to] do no harm or injustice to them”*.

This commitment puts the patient at the centre when physicians seek to use our ability and judgement to benefit the patient.

This is fully consistent with the Hippocratic tradition not to *“administer a poison to anybody when asked to do so, nor [to] suggest such a course”*.

This millennia-old approach to the duty of the physician was affirmed by the World Medical Assembly at its 70th General Assembly in October 2019 <https://www.wma.net/policies-post/wma-resolution-on-euthanasia/> :

1. The WMA reiterates its strong commitment to the principles of medical ethics and that utmost respect has to be maintained for human life. Therefore, the WMA is firmly opposed to euthanasia and physician-assisted suicide.

2. For the purpose of this declaration, euthanasia is defined as a physician deliberately administering a lethal substance or carrying out an intervention to cause the death of a patient with decision-making capacity at the patient’s own voluntary request. Physician-assisted suicide refers to cases in which, at the voluntary request of a patient with decision-making capacity, a physician deliberately enables a patient to end his or her own life by prescribing or providing medical substances with the intent to bring about death.

The attempt by proponents of legalising euthanasia and physician assisted suicide, who choose to ignore the firm opposition of the World Medical Association to these life-ending practices, to co-opt the notion of *“patient-centred care”* to their cause is specious and without merit.

Agreeing to provide or administer a lethal poison to a person is not and never can be *“patient-centred care”*. It is in every case an abandonment of the patient by affirming that the patient would be better off dead and that no further patient-centred care will be offered.

Authentic patient-centred care stands in solidarity with the patient until the end of life, including offering holistic palliative care when further treatment is no longer indicated or has been refused by the patient.

- 2. Clause 6 of the *Voluntary Assisted Dying Bill 2021* deals with the matter of decision-making capacity. Sub-clause 6(2) deals with the specific matter of patients, for particular purposes of the legislation, having “presumed capacity”. Can you please comment on the presumed capacity provisions (sub-clause 6(2)) of the Bill and in doing so, express your view about the appropriateness, or otherwise, of such provisions in a bill that provides for the establishment and operation of a Voluntary Assisted Dying procedure? Do the provisions pose any particular and specific threats and dangers to certain patient cohorts?**

Clause 6 of the Bill would provide a presumption that a person has decision-making capacity unless shown not to have it. It defines decision-making capacity primarily in relation to cognitive processes – understanding, remembering, weighing up and communicating.

The presumption that an adult has decision-making capacity may be a reasonable starting point in a whole a range of settings, and in relation to a range of decisions.

However, the decisions to be made under the provisions of this Bill are not ordinary decisions. They are decisions on life and death matters. One of those decisions that could be made under the provisions of this Bill is the decision to request a prescription for a poison in sufficient dose to cause death. Another such decision is the decision to request a medical practitioner or nurse practitioner to end the person’s life directly and intentionally by administering a lethal poison.

These are not ordinary or routine decisions. By their nature, once given effect to, they are irreversible. It is therefore not appropriate to start from a presumption that a person has the requisite decision-making capacity.

Under this presumption, a coordinating practitioner or consulting practitioner would be entitled to simply make no effort, apply no tests, make no inquiries either of the person or of others, to confirm that a person actually has real decision-making capacity – as opposed to merely presumptive legal capacity.

Indeed, unless the person acted in some very obvious way that demonstrated the person lacked capacity it is unlikely that, with this presumption operating, anyone would be identified as lacking the required decision-making capacity.

Including this explicit legal fiction of a presumption that a person has decision-making capacity in this Bill will inevitably lead to wrongful deaths by persons who actually lack this decision-making capacity nonetheless being given access to or administered a lethal poison based on a request that was not truly voluntary because the person lacks the requisite decision-making capacity.

The definition of decision-making capacity in Clause 6 would also allow a person who was profoundly depressed to still be assessed as having the requisite decision-making capacity to choose to end their life or have their life ended by administration of a lethal poison.

Clauses 27 and 38 of the Bill provide that if the assessing practitioner *“is unable to decide whether the patient has decision-making capacity in relation to voluntary assisted dying”* he or she must refer the patient to *“a psychiatrist or another registered health practitioner who has appropriate skills and training to make a decision about the matter”*.

There is no guarantee that all assessing practitioners will be aware of their lack of competence in making such a determination and make the required referral.

There is no provision in the Bill for any assessment of decision-making capacity to be made at the time a lethal poison prescribed for “self-administration” is ingested. This may be weeks or even months after any assessment made during the request process. The person may have since lost decision-making capacity and ingest the lethal poison with less than full awareness and freedom. They may be cajoled, deceived, bullied, or even forced to ingest it. We will never know.

People with disability are particular at risk of wrongful death under this Bill due to the prevalence of discriminatory attitudes – including among medical practitioners – that consider it would be better to be dead than disabled and that the life of a person with a disability is not a life worth living.

The Bill’s provisions for determining decision-making capacity and voluntariness, including the assessing practitioner-initiated referrals under section 21, are not adequate to address these issues for people with disability.

Doctors are less likely to identify depression in people with disability, simply by assuming that it is normal for a person with disability to show signs of depression such as sadness and lack of hope.

Doctors may also easily miss the particular vulnerability of a person living with disability to overt or subtle coercion from family or caregivers who reinforce a feeling that the person is a burden, *“too much trouble”*, *“life is too hard”* and so forth.

A presumption of decision-making capacity may lead to a failure to explore the impact of these feelings on a person’s decision.

One cohort at risk from a presumption of decision-making capacity is virtually co-extensive with the cohort of eligible persons – the terminally ill.

In a landmark study of decision making capacity of persons with terminal cancer and a prognosis of less than six months to live – that is a cohort that would be eligible for euthanasia or assistance to suicide under the Bill – 90% were found to be impaired in regard to at least one of the four elements of decision making – Choice (15% impaired), Understanding (44%), Appreciation (49%) and Reasoning (85%).

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6345171/pdf/nihms937741.pdf>

This study suggests that, at least in the case of persons with cancer and a prognosis of less than six months to live, it would be more prudent to start from the presumption that they are likely to have impaired decision-making capacity unless it is demonstrated to the contrary.

The study also found a significant discrepancy between physician assessments of decision-making capacity compared to the actual decision-making capacity as tested on the MacCAT-T scales.

Physicians assessed as “unimpaired” 64% of those who, according to the MacCAT-T assessment had impaired Reasoning; 70% who had impaired Appreciation; 61% who had impaired Understanding and 100% of those who had impaired Choice.

This lack of ability of physicians who are actually caring for terminally ill cancer patients with a prognosis of less than six months to live to accurately assess their patients’ decision-making capacity is likely to be exceeded in flawed assessments of decision-making capacity by other doctors – who do not necessarily have an established relationship with the person – making an assessment of decision making capacity in relation to a request for assisted suicide.

It will be practitioners such as this who will be making these assessments under the Bill, leaving these patients at risk of wrongful death due to a false presumption that the person has decision-making capacity, when studies such as this indicate that this is a very risky presumption to make.

3. Can you please comment on what the actual meaning of the word “choice” is, as generally understood by the population at large and in the specific context of medico-health decision making?

“Choice” depends on fully informed consent and genuine decision-making capacity and voluntariness. Even for those who think that a person’s choice to request prescription and supply of a lethal poison for the purpose of suicide or to ask a medical practitioner to directly end their life by administration of a lethal poison should be given effect to, this Bill – as set out in detail in our submission – fails to ensure that such requests are genuinely fully informed, voluntary and made with capacity.

In our Submission we addressed the issue of the prevalence of elder abuse and its implications for this Bill:

... doctors miss the signs of elder abuse and coercion. The Bill will not prevent an elderly person being bullied or subtly persuaded to ask for their life to be ended – for someone else’s convenience or gain.

*Elder abuse, including from adult children with “**inheritance impatience**” is a growing problem in Australia. This makes legalising assisting suicide unsafe for the elderly.*

A [parliamentary report on Elder Abuse in New South Wales](#) also referenced the failure of professionals to identify undue influence and so unwittingly facilitate elder abuse.¹

Dr Henry Marsh, a British neurosurgeon and proponent of legalising assisted suicide and euthanasia, has acknowledged the possibility of coercion and elder abuse leading to wrongful deaths under such a law but he simply doesn’t care:

[“Even if a few grannies get bullied into \[suicide\], isn’t that the price worth paying for all the people who could die with dignity?”](#)²

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<https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/6063/Report%252044%2520-%2520Elder%2520abuse%2520in%2520New%2520South%2520Wales.pdf>

² <https://www.medscape.com/viewarticle/879187>

A recently released report on elder abuse in Australia³ has confirmed the concerns raised in our submission.

Relevantly, this report found that:

*The estimate for the prevalence of elder abuse among community dwelling people aged 65 and older in Australia is **14.8%**, based on findings from the SOP. This estimate is based on experiences reported in the past year in the survey. The most common form of abuse is psychological abuse (11.7%). Neglect is the next most common abuse subtype at 2.9%. For the other subtypes, prevalence rates are 2.1% for financial abuse, 1.8% for physical abuse and 1% for sexual abuse. (page 2)*

Each of these abuse types is relevant for assessing the safety of a Bill that allows a lethal poison to be prescribed and supplied to an elderly person. Proponents of the Bill who dismiss the risk of elder abuse in this context are naïve or disingenuous or simply so focused on demanding their “right to die” that they ignore this risk.

Adult children were most likely to commit financial, physical, and psychological abuse. Sons were almost twice as likely as daughters to commit financial abuse. Adult children were on par with intimate partners as perpetrators of neglect. Intimate partners also featured commonly as perpetrators of physical, psychological, and sexual abuse.

perpetrators were reported to have ... and financial problems (nearly one in five). The most common problems associated with financial abuse were financial problems.

Inheritance impatience was a characteristic of 19.1% of abusers in Queensland in 2018/19. (Citing: Elder Abuse Prevention Unit (EAPU) (2019). Year in review. Brisbane: UnitingCare. Page 31,

[https://www.eapu.com.au/uploads/research_resources/\[web%20circular%20device%20cover\]Elder%20Abuse%20Prevention%20Unit%20\(2\).pdf](https://www.eapu.com.au/uploads/research_resources/[web%20circular%20device%20cover]Elder%20Abuse%20Prevention%20Unit%20(2).pdf))

(page 2)

Elderly people prescribed and supplied with a lethal poison may be at risk from adult children and intimate partners perpetrating financial, physical and psychological abuse – including seeking to hasten the death of the person for financial benefit; bullying or nagging the person to ingest the poison; physically forcing the person to ingest the poison.

The Bill provides no protections whatsoever once the lethal poison is prescribed and supplied.

people with poorer health were more likely than those with better health to report experiencing elder abuse. Having a disability was associated with a higher likelihood

³ Qu, L. et al. *National Elder Abuse Prevalence Study: Final Report*, Dec 2021, <https://aifs.gov.au/publications/national-elder-abuse-prevalence-study-final-report>

of experiencing elder abuse. Low social support and lack of social contact were associated with a higher likelihood of experiencing elder abuse (page 2)

*There is **a correlation between all abuse subtypes and low social support** (including social isolation and loneliness). (page 61)*

A low sense of social support is the highest risk factor for physical abuse (30.4%) and the second highest risk factor for financial abuse (29.8%). (page 66)

There is also a correlation between isolation and loneliness and requests for euthanasia. For example, the Sixth annual report for Quebec reported that for April 2020-March 2021, 24% of people gave as a reason for wishing to have their life ended by a lethal injection experiencing “isolation or loneliness”.

*Where older people sought professional help, they were more likely to turn to the helping professions, medical professionals such as GPs and nurses ... Notably, of those older people who reported taking action, **substantial minorities considered these actions were ineffective. Responses indicating actions were ineffective were highest for financial abuse (over one third)** (page 3)*

When GPs were told by patients about elder abuse, including financial abuse, in many cases the GPs took no effective action and the abuse continued. Under this Bill the abuse may involve causing the death of the person for financial gain or other motives.

This confirms the concern that there is no guarantee that either of the assessing practitioners under this Bill will adequately identify or respond to the presence of, or the risk of, financial, psychological or physical abuse playing a role in a person’s request for a lethal poison to end their life or the actual ingestion of such a poison if prescribed and supplied for self-administration.

As pointed out in our submission, “*The section of [the mandatory training in Victoria for participating medical practitioners] dealing with assessing voluntariness, including the absence of coercion takes just over 5 minutes to complete including a 2 minute 20 second video and slides which take a further 2 minutes 50 seconds to read.*”

Given what this latest report on elder abuse confirms about its prevalence and the failure of professionals including GPs and other health professionals to adequately identify and respond to it there are no grounds for assuming that the provisions of this Bill are adequate to prevent wrongful deaths by elder abuse by pressure to request or ingest a lethal poison.

Simply chanting “choice” as a mantra does not address this real and substantive risk.

- 4. In regard to the evidence referred to above in question 3 and the issue of “choice”, what would be the real and actual implications for citizens who, while potentially meeting eligibility and other requirements of the *Voluntary Assisted Dying Bill 2021*, are not able to have provided to them high quality, readily available palliative care, particularly with respect to those residing in rural, regional and remote NSW?**

We understand that Clause 4 (1) (i) of the Bill was amended in the Legislative Assembly to include in the entitlements of regional residents a right to “*the same level of access to high quality care and treatment, including palliative care and treatment, as a person who lives in a metropolitan region*”.

If this principle is to be taken seriously then, even if the Bill were to pass, it should not come into effect until real equity in access to *“high quality care and treatment, including palliative care and treatment”* between regional and metropolitan residents in NSW has been achieved.

To do otherwise would indicate a failure to give due weight to this principle.