**Submission**
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# INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

**Organisation:** The National Civic Council, The Australian Family Association (NSW), and Anna Krohn

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# Submission to the NSW Legislative Council

# Inquiry into the provisions of the Voluntary Assisted Dying Bill 2021

**Patrick J Byrne**
**National President of the National Civic Council**

**Anna Krohn**
**Researcher in Bioethics**

**Catherine Dodd**
**Australian Family Association, NSW**

**Contacts**

**Patrick J Byrne**
President of the National Civic Council
3-5/1401 Burke Rd, Kew East, Vic 3102.

**Catherine Dodd**
NSW branch Australian Family Association
40 Russell Ave, Faulconbridge, NSW 2776

**Anna Krohn**
Bio-ethics Researcher
4 Chisholm St, Soldiers Hill, Vic 35350

## About the National Civic Council

The **National Civic Council** (the NCC) is a not-for-profit, non-party political organisation which seeks to shape public policy on cultural, family, social, political, economic and international issues of concern to Australia.

## About the Australian Family Association

**The Australian Family Association** (the AFA) is a not-for-profit, voluntary, non-party political organisation concerned with strengthening and support of the natural family. Among its objectives are “to analyse laws and policies for their effect on the family.” In pursuing these objectives, the AFA makes submissions to government inquiries on matters that have an impact on the family.

In pursuance of their aims and objectives both organisations have an interest and hold grave concerns in relation to the important matters raised by the Bill and makes the following comments on behalf of their approximately 40,000 Australian supporters.

## 1. Why Table This Bill this during the Pandemic?

It concerns our members and supporters that during the extremely disruptive, isolating and distressing time of the Covid-19 pandemic that a number of legislatures such as Spain and other Australian states have legalised the practice of euthanasia and medically enabled suicide. It is particularly problematic, that Australia's most populous state is also considering the Voluntary Assisted Dying (2021) (VAD) Bill during this time.

After a period of extended lockdown and disruption, it is extremely difficult for charities, service and community organisations to assemble their dispersed members in order to respond adequately to this important issue. It is especially difficult to compile the degree of suffering and grief experienced in communities and family groups where loved ones have suffered and died during this period while being denied their usual social, spiritual and cultural supports and have been unable to be present together in order to mark all that the dying person has meant to them.[1]

Accompanying this barely mapped community experience, has been a virtual "blizzard" of new legislation which is being pushed "in haste" through many of the parliaments in the Commonwealth- and this "haste" in such a time tends to prevent serious consideration of issues and "deliberative democracy.[2]

Meanwhile, at the coal-face, those working in palliative care have reported new levels of anxiety, fear and dread in their patients, in patients' families and often in clinicians and healthcare workers themselves. Some have described "never-before-known suffering"[3]

The NSW *VAD Bill* 2021 does not appear to take into account the unexpected challenges which patients with terminal and life-limiting conditions are facing in the context of the "new" world created by the pandemic. Not only do our organisations urge the NSW Parliament to replace the abstract and narrow focus involved in legalising so-called VAD in the context of the pandemic, but we also encourage it to consider the "lessons of palliative care" which may assist not only those who are suffering terminal illness and life-limiting conditions- but healthcare more generally as it faces the increased pressure and strain upon healthcare workers and resources.

**We recommend instead that palliative care take the centre stage both in relation to those Australians facing terminal and life-limiting conditions but also more broadly as a way of augmenting strained conventional healthcare**.

We support the recommendations of this healthcare team that as a community:

> *We explore alternative ways of providing care under such pressure and discuss three areas of learning from resource-limited settings:*
>
> *(1) integration of palliative medicine into everyday practice,*
>
> *(2) simplification of biomedical management plus multidisciplinary teamwork; and*

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[1] See for example: O'Connor, M. and Wilson, B. (2021), Managing bereavement when a family member dies in an aged care home: the impact of COVID-19. Med J Aust, 214: 333-333.e1. https://doi.org/10.5694/mja2.51003

[2] Fins, Joseph J. "Is deliberative democracy possible during a pandemic? Reflections of a bioethicist." Journal of Theoretical and Philosophical Psychology (2021). 41(4), 216–225. https://doi.org/10.1037/teo0000191

[3] Maxxine Rattner (2021) COVID-19: Encountering Never-Before-Known Suffering, Journal of Social Work in End-of-Life & Palliative Care, 17:2-3, 104-107, DOI: 10.1080/15524256.2021.1881692

*(3) effective use of volunteers.*[4]

This echoes the work of the World Health Organisation (WHO) which prepared a guiding document entitled 'Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises."

### 1.2 In the Long Shadow of Covid 19

Our member organisations are also concerned by the disturbing implications of "long-covid" evident in patients who have survived and recovered from the acute phases of the infection but are presenting with neurological, nervous system and mental health issues.[5]

The Spanish Influenza offers some insight on society-wide mental health issues after that pandemic. In 2010 Sven-Erik Mamelund studied asylum hospitalisations in Norway, which was not a World War I combatant. He found that the number of first-time hospitalized patients with mental disorders attributed to influenza increased by an average annual factor of 7.2 in the six years following the pandemic.[6]

This VAD Bill comes at a time when the Covid19 pandemic is creating strain upon the mental health of many Australians, not just as a result of restrictions on social contact with workplace, friends and relatives, but from effects of the disease itself. Covid19 is a vascular disease that is leaving more people with long-covid condition than are dying from the disease.

The largest study so far by University College London (UCL) identified 200 symptoms affecting ten organ systems in people with long covid, at higher levels than in people who were fully recovered. Some of the signs of long covid are conditions which might be considered "life limiting" and coupled with an extended period of depression or other mental illness could contribute to an upswing in "suicidal" thoughts and requests.

Doctors at Johns Hopkins Medicine report that the most common lasting symptoms include fatigue and loss of breath, heart problems, kidney damage and diabetes. In addition

- *Neurological problems:* Neurologist Arun Venkatesan, MD, PhD, says: "Some individuals develop medium to long-term symptoms following: infection, including brain fog, fatigue, headaches and dizziness. The cause of these symptoms is unclear but is an active area of investigation."
- *Autonomic nervous-system problems*: Postural orthostatic tachycardia syndrome (POTS), is a condition that affects blood circulation. Tae Chung, MD, who specialises in physical medicine and rehabilitation, says: "POTS can leave survivors with other neurologic symptoms, including continuing headache, fatigue, brain fog, difficulties in thinking or concentrating, and insomnia."

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[4] Knights D, Knights F, Lawrie IUpside down solutions: palliative care and COVID-19BMJ Supportive & Palliative Care Published Online First: 17 July 2020. doi: 10.1136/bmjspcare-2020-002385

[5] Long Covid: What is it and what are the symptoms? BBC News, 17 September, 2021. https://www.bbc.com/news/health-57833394

[6] The Spanish Flu Pandemic and Mental Health: A Historical Perspective, May 29, 2020 Greg Eghigian, PhD, *Psychiatric Times,* Vol 37, Issue 5, Volume 37, Issue 5.

https://www.psychiatrictimes.com/view/spanish-flu-pandemic-and-mental-health-historical-perspective

Even in patients without POTS, persistent insomnia, or "covid-somnia" is an increasingly common complaint among covid19 survivors.

- *Mental health issues*: After surviving covid19, some people are left with lingering anxiety, depression and other mental-health issues. Physical changes such as pain and weakness can be complicated by long periods of isolation, stress from job loss and financial difficulties, and grief from the deaths of loved ones and the loss of good health.[7]

**The timing of the NSW VAD Bill does not take into account the implications for healthcare, healthcare professionals and patients caused by Covid 19-time; nor does it, with its simplistic structure of "first" and "final" requests for VAD, do more than scratch the surface of complex mental health issues which may at first prompt requests for shortened life and VAD.**

### 1.3 The sub-epidemic of suspicion.

There is one additional factor which the NSW Parliament would be wise to consider. In addition to the considerable short and long-term destabilization of Australian communities presented by the coronavirus (and by government measures designed to mitigate it), there is emerging in some sectors of society a distrust of conventional medical solutions and even of scientific evidence itself.

**The bid to legalise the medicalised causation of death within the elderly and other at-risk populations (even admitting that 2021 Bill attempts to safeguard patient agency) risks feeding this fire of distrust and suspicion further.[8]**

## 2. Muddying of the Forensics of Action and Language

Our organisational network is concerned that medical information be clear, unambiguous and is presented in a way that is culturally accessible. This is particularly important in relation to major, irreversible and life-defining decisions which ought to engage the deepest principles and values about human life, the human lifespan and human dignity in both the patients affected by suffering and declining ability and in their carers, whether familial or professional.

It is therefore particularly troubling that the present draft of the NSW 2021 VAD Bill, under the cover of its euphemistic title of "voluntary assisted dying" attempts to normalise practices which do not so much "assist" as cause the death of a person by medical means and with the collaboration of willing healthcare professionals.

What is being legalised is intentional and direct medical facilitation of the death of a patient whether by that person's own hand, or with the assistance of a health practitioner or in some cases (where the patient indicates that they plan to self-administer a lethal dose) with the direct involvement of a very broadly (and in our opinion poorly) defined adult "contact" person.

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[7] COVID 'Long Haulers': Long-Term Effects of COVID-19, Tae Chung, M.D. et. al., Johns Hopkins Medicine, 1 April, 2021. https://www.hopkinsmedicine.org/health/conditions-and-diseases/coronavirus/covid-long-haulers-long-term-effects-of-covid19

[8] Majdi M Sabahelzain,Kenneth Hartigan-Go,Heidi J Larson,The politics of Covid-19 vaccine confidence, Current Opinion in Immunology, 71, (92-96), (2021). https://doi.org/10.1016/j.coi.2021.06.007

It is curious that nowhere in the legislation is there an admission that this process is, at the very least, "assisted suicide". Indeed the Bill regulates the veiling of the cause of death in the publication of the death certificate.[9]

It may be that this measure is an attempt to protect the "dignity" of the person seeking VAD. This may also be because there is widespread community support for "suicide prevention" programs. However, it seems that "covering up" the history and reality of a person's "choices" does not preserve dignity of the person. Nor does the VAD Bill's renaming of a "toxic dose" or "lethal substance" in many places within the Bill as "a voluntary assisted dying substance" aid either clarity or dignity.

Harvey Max Chochinov has pointed out a distinctly person-centred and "dignity-conserving-care" outlook is the goal of contemporary palliative care. One element in preserving such personal dignity is to ensure that a suffering person is given the chance to "pass on" the true account of their own life and the value of their decisions. Indeed as Chochinov points out, the more the patient, family and healthcare team are able to address the "dignity-conserving-care" package the more imaginative and caring options are discovered:

> *When the preservation of dignity becomes the clear goal of palliation, care options expand well beyond the symptom management paradigm and encompass the physical, psychological, social, spiritual, and existential aspects of the patient's terminal experience.*[10]

## 3. Voluntary Assisted Death is not compatible with Palliative Care.

Clause 10 of the VAD Bill presents itself as a safeguard for patients seeking VAD. It states that a healthcare professional must not initiate a discussion about VAD "unless" it is in the context of "also" informing the patient about treatment options. In other words, this provision allows a practitioner to "slip" VAD into discussion about a range of ostensibly "like" options available to a competent but otherwise terminally ill patient.

While the Bill's attempt to encourage the disclosure of treatment options is commendable, there are profound ethical and practical differences between the discipline of palliative care and the deliberate medical induction of patient death.

In clause 28, there is the requirement that the so-called "co-ordinating" physician (that is a professional who is perhaps distinct or even disjunct from the patient's regular or "treating"[11] health professional) has agreed to access a patient's "clear" request for VAD has no "conscientious" or practical objections to proceed (within a matter of "business days) to take on the role of assessing the patient's eligibility and to agree to "co-ordinating" VAD for that patient.

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[9] The explanatory notes for the Bill declare in Division 4: *The Division specifies that a person who dies as a result of the administration of a prescribed substance in accordance with the proposed Act does not die by suicide.*

[10] Chochinov, Harvey Max. "Dignity-Conserving Care—A New Model for Palliative Care." JAMA 287, no. 17 (2002): 2253. doi:10.1001/JAMA.287.17.2253.

[11] Defined as such in the Bill no. 28 (j).

We note that the Bill does not require the "request" to be persistent, but this first request begins the "process" towards a final request and process of approvals. The Bill attempts put in place the role of a witness, a second "health care practitioner" (the consulting practitioner), a Board and a raft of paper-work. However, in essence, it appears that this complicated bureaucratic process rests on a total of two (i.e. the first and final request) by a patient. The Bill does not demonstrate how subtle changes in communication and care may influence both requests for VAD or the interpretation of these such requests. As national peak body Palliative Care Australia points out:

> *Currently, the majority of health professionals in Australian have not undergone formal training in communication skills, advance care planning conversations or effective strategies to respond to the needs of people with a life-limiting illness, their family and carers.*[12]

Clause 18 defines the eligibility of the so-called "co-ordinating" VAD practitioner includes the requirement that the agent is a healthcare professional who has a general registration of over 10 years, or is registered in a "specialisation" (though which specialisation is undefined) and has undergone "approved training" (such training is also unspecified).

By agreeing to consider and co-operate in the patient's request for VAD (whether or not this path is brought to completion) the "co-ordinating practitioner"[13] must, according to clause 24, also inform patients what their:

a) *palliative care and treatment options available (are), and*

b) *should discuss the palliative care and treatment options with the person's medical practitioner.*

Given the degree of specialisation across the healthcare professions and the nature of patient-practitioner professional relationships, this section is very misguided and unclear.

**What provisions in the Bill guarantee that the "co-ordinating" physician has either the expertise, knowledge or inclination to provide a specific patient with up-to-date, appropriate or accurate information about what the Bill describes as "standard" care let alone personally delivered palliative care? Furthermore what guarantee is there that the "co-ordinating" healthcare professional, has any respect for, or motivation to respect, an objective discussion about palliative care?**

Unfortunately, recent Australian research has shown that discussion around end-of-life care can confuse palliative care with a blunt cessation of treatment with minimal symptom control. The research found that some associated the concept of hospice with medical inaction, poor existential state and grim decline.[14]

**Palliative care relies on personal, tailor-made, on-going and often subtly changing practices which are responsive to the patient's culture, family and philosophical values and is delivered**

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[12] Palliative Care Australia. https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2015/08/20160823-Euthanasia-and-Physician-Assisted-Suicide-Final.pdf (accessed 20th November, 2021).

[13] Clause 24 defines "coordinating practitioner" simply as "medical professional who accepts the patient's" first request.

[14] Collins, A., McLachlan, S. A., & Philip, J. (2017). Initial perceptions of palliative care: An exploratory qualitative study of patients with advanced cancer and their family caregivers. *Palliative Medicine*, 31, 825-832.

**through an engagement with the changing physical, psychological, cultural and spiritual needs of the patient. It is not something that is achieved by the sort of bureaucratic "tick" boxes and form filling that is insisted upon in this VAD Bill.**

As the Australian Psychological Society (APS) insists:

> *Palliative care is the most well-developed approach to care for those with a life-limiting illness. It is multidisciplinary and provides holistic support to people with terminal illnesses, for their families throughout the illness and for family and carers following bereavement. Traditionally palliative care services did not include psychologists but with the increased evidence-based interventions psychologists are now core to the delivery of best practice end-of-life care.*[15]*.*

The New South Wales' peak body for palliative care, while refraining from taking an official position upon the legal sanctions surrounding euthanasia or medically assisted suicide states:

> *voluntary assisted dying is not part of palliative care practice. We believe that: If palliative care health professionals or organisations choose to offer and provide voluntary assisted dying for their patients with life-limiting illness, this is a practice separate from palliative care.*[16]

**Our organisations are deeply concerned that palliative care be positively and equitably promoted throughout urban, regional and remote areas of this large country. Since palliative requires a concerted exertion of social, economic and professional "capital", there is a real danger that euthanasia and voluntary "assisted dying" will appeal to some suffering patients, and that the public and institutional resourcing of palliative care will languish, as has happened in US states like Oregon after assisted suicide was legalised.**

## 4. Confusing the practical and ethical nature of healthcare relationships

Palliative Care NSW insists that:

> *All people working in palliative care should be treated respectfully and demonstrate professional behaviour towards colleagues and co-workers regardless of their views on voluntary assisted dying and the decision to exercise their right to conscientiously object or conscientiously participate in any aspect of voluntary assisted dying.*

Somewhat bizarrely clause 28 (j) envisages a situation in which a patient, who begins the path to state-sanctioned VAD with the patient's "co-ordinating" VAD practitioner, can also be receiving treatment or care from other "treating" practitioners whose goals and aims may be at odds or even in contradiction to VAD.

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[15] What psychologists should know about voluntary assisted dying | APS (psychology.org.au)

[16] Position-Statement-VAD-Palliative-Care-NSW.pdf (palliativecarensw.org.au)

The Bill rather weakly "encourages" the VAD-seeking patient to inform the other practitioners providing care with the information about the request for VAD. The Bill places the onus upon the suffering patient and yet threatens the "other" (presumably non-VAD collaborating) treating practitioners if they "withdraw" care from that patient.

Perhaps even more puzzling, is the fact that the NSW VAD Bill does not require that the two authorised medical practitioners to be specialised in the disease or condition with which the patient is afflicted, nor indeed are they required to had a long-term relationship with that patient. They are able but not required to consult with the regular "treating practitioner." They are able but not required to seek psychological or cognitive assessment of the patient.

The co-ordinating practitioner and in some cases a witness or contact person need only to presume by some means that the patient is still determined to take the VAD path. It is not clear what skills or expertise this particular practitioner has in determining existential, social, temporal or other factors may be influencing the patient's request, especially if this is via a "gesture."

Since there is a superficial "tick box" approach to giving reasons or "justification" for the VAD decision, the two practitioners are not required to assess the patient's freedom from a range of cognitive and social pressures or disabilities.

Our organisational networks are therefore not reassured that the purported safeguards in the VAD Bill do protect the most vulnerable. It appears that the Bill rather privileges those who are most able to express their wishes and to pursue these through to the regrettable and lethal end.

There are many other concerns our organisations have with the NSW VAD Bill 2021, including:

- The difficulty of determining accurately whether a patient's diagnosis of 6-12 month life expectancy is a sufficient qualification for VAD;
- The insufficient understanding of the ethical position of a practitioner or institution which conscientiously and clearly opposes the practice of VAD, with the insistence that for instance a nursing home collaborate in the transfer, facilitation, toleration of a VAD decision;
- The Bill does not appear to be cognizant of the many other "carers" and workers in contact with patients who may also find the decision for VAD will cause them moral, professional and spiritual distress and dilemma;
- The potential confusion and conflict between different healthcare practitioners, especially given that this Bill lists a confusing multiplication of "practitioners" under different titles, e.g. "co-ordinating" "relevant" "treating" or in some places simply "the medical practitioner."

This Bill should be rejected for being contrary to providing good medical care for the most vulnerable of NSW citizens.