Submission
No 66

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

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Date Received: 22 November 2021

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22 November 2021

Ms Tina Higgins
Director - Committees
Standing Committee on Law and Justice
Parliament of New South Wales
Macquarie Street
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Dear Ms Higgins,

Submission to the Inquiry into the provisions of the Voluntary Assisted Dying Bill 2021

Thank you for the opportunity to make a submission to the Inquiry. The basis of this submission is a speech that I had the privilege of presenting as part of a Parliamentary Webinar '*Palliative Care in Rural, Regional and Remote NSW: Where we are, where we should be and the implications of Voluntary Assisted Dying (VAD) Legislation'* on Wednesday 17 November 2021.

I qualified as a medical doctor 21 years ago, and have worked in the speciality of Palliative Medicine for 19 years. I moved from the United Kingdom to Broken Hill, Far West NSW, Australia, where I have lived and worked for the last 9 years. I am the first and only Specialist Palliative Care Physician employed full time by the Far West Local Health District (LHD). I serve the 30,000 people that live rurally and remotely in Far West New South Wales, a geographical area of 195,000km^2 that makes up the western one third of our State and boarders the three states of Queensland, South Australia and Victoria. I am also the elected co-chair of the NSW Health Agency for Clinical Innovation (ACI) End of Life and Palliative Care Executive Network.

This submission is made in my personal capacity and therefore the opinions expressed in it are purely my own; I am not presenting on behalf of or representing the views of the Far West LHD, NSW Health or the ACI.

I am passionate about providing high-quality patient-centred palliative and end of life care in all care settings for the rural and remote community within which I lives and calls home. I work closely with and supports my medical, nursing and clinical colleagues in hospitals, health facilities, primary care and residential aged care across Far West NSW to do the same. As the only Specialist Palliative Care Physician working in rural and remote NSW, I am a strong advocate for the healthcare needs of rural and remote Australians. I desire to see everyone that lives in rural and remote NSW have equitable access to high quality holistic palliative care at home and in their own community, to allow them to live as well as they can for as long as they can, to achieve their goals and, as their disease progresses, to die a natural death in the place where they wish to be. Therefore, **I cannot support the legalisation of physician-assisted suicide and euthanasia in NSW.**

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness. Palliative care addresses suffering and enhances quality of life. Palliative care is not just for those in the last weeks and days of life, but occurs from diagnosis through to death, and supports families in their bereavement. Central to the provision of best practice palliative care is the meticulous assessment, prevention, early identification, treatment and support of the physical, psychological, emotional, spiritual, cultural and social needs of patients and their families. To do this, patients need access to appropriately trained and skilled, multi-disciplinary palliative care clinicians. People who are dying, and their families, require care and support 24 hours a day, 7 days a week; this is pivotal to ensuring patients and their carers are supported with their palliative and end of life care needs.

This is what I am trained to do - practice safe, high quality, evidence based palliative medicine. And this is what I do every day – I walk alongside and support those who are dying, their families, carers and communities. When I meet with patients and their families, I assess their needs. I consider what may be causing or underlying their physical symptoms, and where necessary I arrange investigations, blood tests or scans. I use the many different tools in my tool box to problem solve, to treat with intent and to relieve their symptoms - this may be pain, nausea, a dry mouth or constipation. Sometimes I use medications, or sometimes refer them for interventions such as nerve blocks, radiotherapy or chemotherapy for cancer related pain. Sometimes I refer them to our physiotherapist or occupational therapist, if the use of various aids or equipment will help relieve their symptoms. I then do the same for their psychological, emotional, spiritual, cultural and social needs. We use everyone available to us – doctors, nurses, physiotherapists, occupational therapists, speech pathologists, dieticians, social workers, psychologists, counsellors, Aboriginal health workers, chaplains and volunteers - to assist in providing care and support and addressing the patients and their family's needs.

I also explore what my patient's concerns, worries, anxieties or fears may be. I listen to understand their circumstances; I elicit what their goals are; we talk about death and we talk about dying, and ultimately what is important to them and their families as they face the end of their lives.

The palliative care team and I walk alongside our patients and their families. We plan in anticipation for what we know will likely happen as their disease progresses, and we are available to meet their needs as and when necessary.

We know that only 50% people who are living in NSW with a life limiting diagnosis are able to access the palliative care support that they need. We also know that for Australians living in regional, rural and remote NSW, this number is significantly less than this 50%. [1]

Providing palliative care in a rural and remote LHD that covers the western one third of NSW presents a number of challenges but also a number of benefits. Some of these challenges lead to highly variable access to and quality of palliative care. For example:

- Some patients benefit from dedicated specialist services; others rely on care provided by GPs, community nurses and residential aged care staff
- Some patients can be admitted to a specialist hospice unit; others only have the option of dying in their local acute hospital if not at home
- Some patients can access 24/7 palliative care support; others can only contact their clinicians during working hours
- Some patients are able to receive as much home care, day and night, as they require (usually funded privately or via the National Disability Insurance Scheme(NDIS)); other patients and their families are lucky if they get a couple of hours help a week
- Some family members can access carer support, counselling and bereavement support; others are left with no access to social or emotional support or counselling either during their relatives illness or after they have died

But the benefits of providing palliative care in rural and remote NSW are immense. We provide a sense of community, familiarity and continuity, with clinicians often going above and beyond for patients and their families in their small communities.

Our local service provides palliative care to our patients in whatever place they wish to be cared for – in hospital, multi-purpose facility, aged care facility, disability group home, their own home and for Aboriginal people, back on Country. Many of our patients are geographically isolated from health services, often by hundreds of kilometres, many without GPs or in-patient beds based in the town they live, so palliative care services need to be accessible and flexible to go to them.

Successful partnerships with other health providers such as General Practitioners (GPs) with an interest in palliative care, the Royal Flying Doctor Service (RFDS), Aboriginal health services, aged care facilities, disability services and home care services are fundamental to being able to support patients to be cared for and to die in their preferred place.

The philosophy of our service is wherever the patient is, we will go. But we have to be resourced adequately, with medically, nursing, and allied health including bereavement support, to be able to do that. Our service started over 30 years ago, with a single Registered Nurse. I joined the team as the only doctor 9 years ago, and we have slowly been growing a comprehensive multi-disciplinary service since then.

I would like to present two deidentified patient stories as an examples of what can be done for a palliative care patients in remote NSW when the appropriate palliative care model of care and resources are in place.

These two stories demonstrate that people in remote areas can access quality palliative care with the right staffing skill mix, the right model of care and the right funding. For us, it is about being able to give people a choice where we can, and ensuring that in which ever care setting they are located, they will receive good palliative and end of life care, and that their loved ones are offered bereavement support after death. However, we need to ensure equitable, sustainable and high quality provision of palliative care across the whole population and across all care settings, particularly ensuring access to suitably trained medical practitioners, nursing and allied health staff, with high level clinical and communication skills.

For the 50% patients who die in the Far West LHD that are known to our Specialist Palliative Care Service, we are consistently provide high quality palliative care that supports and enable 98% of patients to be cared for and to die in their preferred place.[2]

But is that choice true choice? We don't have a specialist hospice or dedicated palliative care beds staff by specialist nurses in any of our Far West LHD facilities. Therefore, if a person doesn't want to or is unable to be cared for at home, the only option is dying in the local hospital, which may be hundreds of kilometres away from their home and community, as it was for patient X. This is the same for many of the regional and rural LHDs within our State.

Our Specialist Palliative Service provides 24/7 on-call nursing support, but I am the only medical specialist that supports our nurses and I do that 24/7 singlehandedly. Our team is often seen as the 'gold standard' amongst our rural and remote peers, but this comes at a personal cost where the only option is to work beyond our contracted and paid hours for our patients and our communities. Across our State, there are many LHDs that don't have 24/7 palliative care services, either nursing or medical. There are some LHDs that only have access to part time or fly in fly out doctors; the nurses in these LHDs do an incredible job, but the message is that the provision of palliative care is limited, inequitable and unsustainable across our State, particularly in regional, rural and remote NSW.

But it's not just clinical services. There are is limited access to home care and social support services for patients and their carers, which increases the sense of burden in patients and fatigue in carers, particularly those wishing to be cared for and to die at home. Again, the inequality in availability of these services is intensified in rural and remote NSW.

And then what of the 50% patients living with life-limiting illnesses that die in our District and our State that aren't referred to or have access to specialist palliative care services or die without receiving any form of palliative care?

There isn't a week that goes by when a patient or their family member doesn't ask me about assisted suicide or euthanasia. When this occurs, I take the time to explore what is behind that request. For patients, it is usually due to fear of what may happen, fear of loss of control, fear of symptoms, fear of being a burden. For families, it is usually their distress and pain at watching their loved one dying and the grief that accompanies death.

Our role as palliative care clinicians is to identify and meet patient's needs and address their fears - to be willing talk about things that other clinicians don't want or aren't able to; to not be afraid of talking about death and dying, offering truth and honesty, and offering our specialist skills, expertise and availability. To be willing to walk alongside our patients and their families. When supported by our palliative care service, these requests are replaced by met needs, relief of distress and often expression of gratitude.

I will never forget a young patient asking me for euthanasia – he was a gentleman in his 30's with metastatic kidney cancer, whose wife was 6 months pregnant. I spent time with him and his wife; I heard his concerns and fears, I managed his symptom, and I treated his underlying depression. He subsequently embraced palliative chemotherapy and gained a new lease of life. He expressed extreme gratitude that euthanasia wasn't available, because he knew that if it had been, he wouldn't have been alive to see his son born and create precious memories for his wife. I'm sure every palliative care clinician will be able to tell you multiple similar stories.

This individual patient story is supported by research evidence. Whist acknowledging the statistics that public opinion supports VAD when presented with the theoretical possibility of terminal illness, research has demonstrated that patients' attitudes to treatment changes dramatically when they are faced with the hard reality of a terminal cancer diagnosis and death. When compared with a matched control group of members of the general public, oncology patients were willing to accept intensive treatment with considerable side-effects for a minimal worthwhile benefit of 1% cure.[3] When 'the public' becomes 'a patient' and has to confront the hard reality of disease rather than the purely theoretical possibility of illness, they are likely to accept any treatment that offers some possible benefit and hope, however slight. Patients are also willing to endure considerable adverse effects for a minute chance of possible benefit of either cure or symptom improvement.

From families, I hear relatives express their observation of the extreme pain and suffering they believe their loved one is experiencing, which drives their requests for euthanasia and subsequent support for VAD from bereaved families. However, my independent and objective clinical assessment is that the patient is settled, comfortable and has good symptom control whilst it is the grieving relative who translates their own emotional distress and pain onto the patient, which colours the 'suffering' they see in their loved one. On a relevant aside, there is a reason that the Medical Board of Australia (MBA) Code of Conduct for Doctors states that doctors should '*avoid providing medical care to anyone with whom you have a close personal relationship*.' The code acknowledges that '*providing care to close friends, those you work with and family members is inappropriate because of the lack of objectivity,… and risks to the patient and doctor*'.[4] It is this same loss of objective perspective that we observe clouds the opinion of relatives as they transfer their own emotional distress, pain and suffering onto what they (incorrectly) see their dying family member experience.

In addition, the distress that precipitates these requests from relatives would not be relieved by the VAD legislation. For example, request often come from relatives of patients who are unconscious in the last days or hours of life, or those who have lost their memory and have declining physical function due to dementia; patients in both situations would be excluded from the VAD legislation as the patient no longer has cognitive capacity to make healthcare decisions for themselves.

There is an inevitable emotional pain that comes with disease, loss of physical and cognitive function, loss of independence, dying and death – for as Queen Elizabeth II said, *'it [grief] is the price that we pay for love'*. The emotional distress of grief will never be relieved by VAD, rather we need to ensure equitable access to trained and resourced services that are able to provide emotional support and grief counselling to carers, relatives and families during the patient's illness as well as in the pre-bereavement and bereavement phases.

But it's not just patients that change their opinion. A few years ago, I had a junior doctor spend a year training with me. She was a stanch advocate of VAD, that was until she spending time working with us. She said that, even as trained doctor, her opinion had formed from a place from fear, ignorance and misinformation. We taught her how to complete impeccable holistic palliative care assessments, taught her how to manage symptoms with intent, and we grew her confidence in having difficult conversations with dying patients and their relatives. She developed high level palliative care clinical and communication skills that completely turned her opinion regarding VAD on its head.

This misinformation is widespread amongst patients, relatives, public, MPs and journalists. I've often heard it said that the medications we (doctors) prescribe in the last days of life are used to '*put people out of their misery*', and that we give morphine to dying people to effectively shorted their life. I've even heard a NSW MP publically say that '*voluntary assisted dying happens everyday [in our public hospitals], we just don't call it that, we call it pain management.... People are essentially given central nervous system depressants [by nurses and doctors] until they stop breathing*.'

These misconceptions are far from the truth. The first promise that I swore in the Hippocratic Oath when I graduated as a doctor was to '*first, do no harm*'; I was trained to care and support life, not kill and intentionally shorten it. The World Health Organisation definition of Palliative Care includes it '*affirming life and regarding dying as a normal process*', which '*intends to neither hasten nor postpone death*'.[5] In accordance with international best practice guidelines, the discipline of Palliative Medicine does not include the practices of euthanasia or physician-assisted suicide.[6]

The truth regarding the medications used by palliative care clinicians in the last days and hours of life is:

a) medications are only used to treat and relieve symptoms to ensure people do not die in pain, in distress or with unresolved symptoms; they are not given intentionally or unintentionally to shorten life or hasten death.

b) the route of medication administration (often by subcutaneous injection) is used because patients are dying and so are no longer able to safely or effectively take to take oral medications.

c) the medication doses that are prescribed and administered are gradually and accurately titrated to treat the symptoms as they occur. When titrated appropriately, they do not cause central nervous system depression and they do not cause people to stop breathing. The unconsciousness and changes in breathing that occur are a natural part of the dying process and are not as a consequence of or side effect of medications. These physiological features of dying occur, with or without medications, because the person is in the last days, hours and minutes of their life. Some people die comfortably without any medications; in these scenarios, these physiological features of dying are observed. Some people develop symptoms that are commonly seen in the dying - pain, restlessness, nausea, vomiting, breathlessness and/or secretions – and when they occur, without the use of medications, the physiological process of will be unsettled, uncomfortable and symptomatic. The reason we use medications is to relieve these symptoms and reduce distress for patients and their loved ones that are present, which allows them to die comfortably and peacefully.

Contrary to popular belief and fear, there is strong evidence that people significantly live longer with good palliative care and when there symptoms are well controlled with medications, including opioid analgesia (such as morphine) and anxiolytics (such as benzodiazepines).[7,8] As a Specialist Palliative Care Doctor, I spend a lot of time educating patients, their families and their loved ones, and correcting these misinformed beliefs regarding medications. I believe that it is also important to correct the false allegation made by the NSW MP quoted above - voluntary assisted dying does NOT occur every day in NSW hospitals; giving medications (either voluntarily with the patients consent or involuntarily without their consent) to intentionally end a person's life is currently illegal and is against the clinical code of practice of all doctors or nurses, and anyone participating in such practice risks their registration and prosecution. However, good palliative care by highly trained and skilled clinicians does occur every day throughout our hospitals. Good pain and symptom management is NOT VAD by another name.

The research evidence that the early introduction of palliative care leads to significant improvements in quality of life, mood, contrary to popular opinion, longer survival and prognosis.[7,8] However, we know that the current provision of and access to palliative care is limited, inequitable and unsustainable across our State, particularly in regional, rural and remote NSW.

Palliative Care is a privileged journey we share with our patients and families. We only get one chance to get it right for that individual patient and their family.

I cannot support the voluntary assisted dying legalisation. VAD seeks to alleviate the trials associated with life-limiting illness with a handful lethal drugs and a premature death. On the contrary, palliative care seeks to walk alongside patients and their relatives, to relieve pain and other symptoms, to provide holistic multi-professional support, and to offering people hope and quality of life. Therefore, **I believe that we have a unique opportunity to impact every single NSW resident by positively investing**

in equitable and sustainable palliative care services, and ensuring that we develop comprehensive, highly trained, 24/7 access to in-patient, specialist hospice and community palliative care services in every city, town and community across our State. I believe that this is possible for everyone, not just the current fortunate 50%, and that our service has demonstrated what it is achievable even for those that live in the remotest corner of NSW.

If invited to by the NSW Parliament's Standing Committee on Law and Justice, I would be prepared to appear at a public hearing and speak to this submission.

Yours sincerely,

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Far West LHD

References
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