Responses to Supplementary questions from the NSW Law and Justice Committee for its Inquiry into the Provisions of the Voluntary Assisted Dying Bill 2021.

Responses provided by Professor David Kissane, Professor and Chair of Palliative Medicine Research, University of Notre Dame Australia, and The Cunningham Centre for Palliative Care Research, St Vincent's' Sydney.

Q1:

In evidence provided to the inquiry hearing on 13th December, Dr. Danielle McMullen, President, Australian Medical Association (NSW) said:

> "We would undertake that the requirement for two separate doctors to both consult with the patient about their reasoning, intent and illness and to discuss with them all options available to them for their care, including voluntary assisted dying... ." (Hansard, page 5)

In evidence to the inquiry hearing on the same day Dr. Cameron McLaren, appearing as a private individual from Victoria said:

> "I underwent the training [Voluntary Assisted Dying training] for two reasons: I did not want a patient for whom I had cared throughout their journey with cancer to have to seek external providers that they chose to pursue this option [Voluntary Assisted Dying]; secondly having been educated in medicine with a strong focus on patient-centred care, I felt that my opinion... ." (Hansard, page 67)

In evidence to the inquiry hearing on the same day Dr. Greg Mewett, Palliative Care Physician, Grampians Regional Palliative Care Team, Ballarat Health Services, Victoria said:

"My final comments would be that I find this [Voluntary Assisted Dying], as a palliative care doctor, patient-centred care... ."

and

"Palliative care is a style of care which, near the end of life, VAD is one type of choice in that care – they are not mutually exclusive." (Hansard, page 69)

In evidence to the inquiry hearing on the same day Associate Professor Charlie Corke, Acting Chair, Voluntary Assisted Dying Board, Victoria said:

> "I note that Dr. McLaren and Dr. Mewett both talked of patient-centred care. Really, the way in which we deliver health care can be considered as patient-centred care or medical-centred care or perhaps as legally-centred care or religious-centred care. There is a whole load of different ways we look at the way we deliver care. But, fundamentally, I think patients are wanting patient-centred care rather than any of those other options."
> (Hansard, page 71)

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"?

Response to Q1

While patient-centred care is generally a desired and politically correct goal of medicine, the theory originated in an effort to overcome paternalistic medical care. Patient-centred care is much more than a proximal goal of responding to a patient's request, desire or need. There is still an obligation for the care to be evidence-based, competent, and of a high standard. Sometimes, what patients think they want (e.g., drugs) is not what they need (e.g., information). A physician who responds to a patient's request for drugs (e.g., unnecessary antibiotics or drugs of addiction) may have a happy patient, yet inappropriate prescribing could hardly be designated patient-centred care. In this sense, Epstein and Street, in commenting on the quality of care for the Institute of Medicine emphasised that "patient-centred care is quality of personal, professional and organizational relationships" (p.100).[1] The behaviour of the physician must remain moral, beneficent and non-maleficent. Thus, a patient who romanticises the physician and asks for sex would not receive patient-centred care should the physician satisfy the patient's sexual needs. An immediate goal might have been met if coitus occurred, but taboos on the physician's behaviour are there to protect the patient's greater wellbeing.

Thus, the committee raises a supplementary question about Drs C. McLaren and G. Mewett describing voluntary assisted dying as patient-centred care. You ask about the implications for the professions of medicine and nursing by describing VAD, as provided for in the *Voluntary Assisted Dying Bill 2021,* as "care" or "patient-centred care"?

I submit that any suggestion that euthanasia or physician-assisted suicide ought to be agreed to in order to meet the patient's proximal desires or perceived needs is naïve, foolhardy, and dangerous to the quality of care delivered to patients in New South Wales. Thus, when a patient is demoralised or depressed because of the hopelessness conveyed to them by their oncologist's deficient communication skills, and they seek relief from this existential suffering through VAD, the compliant oncologist ignores the patient's unstated desire for anti-cancer treatment and hope, agrees that their life is worthless, and that the patient's autonomous wish is sacrosanct, thus assisting them to die in the name of this being patient-centred. This is poor quality clinical management! The introduction of VAD through this legislation will introduce this lower standard of medicine into NSW.

Moreover, when Dr Danielle McMullen describes doctors discussing "all options available … for their care, including voluntary assisted dying" (Hansard, page 5 cited in your full question), evidence is offered to you of how this slippage in quality care provision will gradually occur through VAD. Doctors do not have expertise in all options of medical treatment. The oncologist is as deficient in his or her knowledge of mental health care as the psychiatrist is deficient in his or her knowledge of oncological care. The legislation makes a flawed assumption about the quality of information provision by two separate doctors as provided for in the *Voluntary Assisted Dying Bill 2021*. Many doctors offer very inadequate information about what the provision of palliative care entails. Legislators need to be wise about the differential skills of medical practitioners and not assume that doctors can provide appropriate information about palliative medicine.

With respect to Dr G. Mewett's assertion that VAD is "one type of choice" within palliative care (Hansard, page 69 cited in your question), there is growing evidence for the manner in which the delivery of VAD renders palliative care futile,[2] which would damage the prospect of quality palliative care being sustained as a discipline in NSW. Not only is there widespread ignorance in the community about the nature and goals of palliative medicine, but there is a greater stigma attached to this discipline (that is perceived to be about dying) than there is attached to VAD. The art of palliative medicine lies in sustaining some hope in the patient, maintaining quality of life, optimal symptom control and the relief of suffering. Because the aim of palliative care is never to hasten death, it is actually directed towards extending life, which has been confirmed in studies of early referral to

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[1] Epstein RL, Street RL. The values and value of patient-centered care. Ann Fam Med 2011;9:100-103. doi:10.1370/afm.1239

[2] Chambaere K et al, CMAJ 2010. DOI:10.1503/cmaj.091876

palliative care services enhancing quality of life.[3, 4, 5] There is no doubt that palliative care has this ability to enhance quality of life and it does this most powerfully by early recognition of depressed states and the reinstallation of hope and morale. Advocates for VAD like Drs G Mewett, C McLaren and P Nitschke ignore clinical depression, quality of life, and instead celebrate the ending of life. They propose that VAD is a treatment for the pointlessness of life, a complete counterpoint to palliative care and the traditional goals of medicine.

I caution the legislators of the NSW Parliament about introducing VAD as a new treatment or form of medical care. This proposal will irrevocably alter the nature of medicine and, in my opinion, will lower the quality of care provision to seriously ill patients. It will damage the delivery of palliative care. Killing a patient is no more patient-centred care than having sex with a patient is patient-centred care. They both deserve to remain taboo within medical care.

Q2:

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."

Please comment on the presumed capacity provisions (subclause 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?

Response to Q2

Decision-making capacity is a crucial requirement for the safety of society, never more so than when loss of life is the outcome. The MacArthur Competence Assessment Tool is used in studies that formally test for capacity in the setting of depressive illness or psychosis.[6] This tool examines 1) a person's capacity to understand and remember the diagnosis and treatment options; 2) ability to reason about risks and benefits of treatment options; 3) capacity to appreciate their predicament (prognosis) and the consequences of their choice; and 4) ability to communicate or express a choice. Of these four parts, the appreciation test is the most commonly disturbed by depressive and demoralization disorders.[7] It becomes clear that a person's appreciation of the worth and value of their future may be darkened by a negative worldview when depressed or demoralized. When it comes to a decision about continuing life, the highest standard of appraisal is needed to avoid error in this assessment. Studies show that more than 80% of psychotic patients with an illness like

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[3] Temel JS, Greer JA, Muzikansky A, et al: Early palliative care for patients with metastatic non-small cell lung cancer. N Engl J Med 363:733-742, 2010

[4] Temel JS, Greer JA, El-Jawahri A, et al. Effects of Early Integrated Palliative Care in Patients with Lung and GI Cancer: A Randomized Clinical Trial. J Clin Oncol. 2017 Mar 10;35(8):834-841. doi: 10.1200/JCO.2016.70.5046.

[5] Zimmermann C, Swami N, Krzyzanowska M, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. Lancet. 2014 May 17;383(9930):1721-30. doi: 10.1016/S0140-6736(13)62416-2.

[6] Grisso T, Appelbaum PS, Hill-Fotouhi C. (1997). The MacCAT-T: a clinical tool to assess patients' capacities to make treatment decisions. Psychiatric Services, 48(11):1415-9. DOI: 10.1176/ps.48.11.1415

[7] Kissane DW. (2004). The contribution of demoralization to end-of-life decision making. *The Hastings Center Report,* 34(4):21-31.

Schizophrenia lose their decision-making capacity; when a unipolar depression is present, only 31% have been confirmed to lose capacity.[8] These are studies of psychiatric patients and they have not been undertaken in the palliative care setting. A recent meta-analysis, however, compared studies of incapacity in psychiatric and medical settings, concluding that the average proportion of patients with incapacity was 45% (95% confidence interval, 39-51%) with no difference between psychiatric and medical settings.[9] These authors concluded "Clinicians should be more alert to the possibility that their patients may lack decision-making capacity. Assessment of capacity should be frequent using the appropriate legal frameworks to act in the best interest of patients."

If up to half of the patients with depression or demoralization can lack capacity at some stage during their palliative care illness, and many of these patients have their depression pass unrecognised or undiagnosed, we begin to see a significant subgroup who are indeed very vulnerable, who may not appreciate what their future may hold, and who need protection. As Mills argued, the duty of legislators is foremost to prevent harm to others in society. Sanctioning medically assisted dying will not achieve this.

Many studies have revealed high rates of depression being missed by oncologists and other medical specialists, who focus on the disease at hand and fail to competently treat the whole person. For instance, in 2014, a major Scottish study of 21,000 cancer patients revealed that 73% of depressed patients were not in receipt of treatment.[10] In my practice, I find many patients whose depression has existed for several months and been missed by their specialist before a referral was made.

Euthanasia advocates recommend that legislators adopt the principle of "presumed capacity" in Acts supportive of medically assisted dying. Such an approach ignores the evidence presented here that depression is commonly missed in our society and that about half of those patients who are depressed will lack decision-making capacity with respect to euthanasia or physician-assisted suicide. Acts that legislate for "presumed capacity" fail to have adequate safeguards to recognise those subjects who have become suicidal and wish to end their life for reasons of mental illness.

Q3

In evidence provided to the inquiry hearing on 8th December, Ms Penny Hackett, President, Dying With Dignity NSW said:

> "The key feature of this law is choice. It is voluntary and no-one is compelled to be involved. Those who oppose VAD laws are not required to use them or to participate in the process." (Hansard, page 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?

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[8] Owen GS, Richardson G, David AS, Szmukler G, Hayward P, Hotopf M. (2008). Mental capacity to make decisions on treatment in people admitted to psychiatric hospitals: cross sectional study. BMJ, 30;337:a448. doi: 10.1136/bmj.39580.546597.BE

[9] Lepping P, Stanly T, Turner J. (2015). Systematic review on the prevalence of lack of capacity in medical and psychiatric settings. Clin Med (Lond). 15(4):337-43. doi: 10.7861/clinmedicine.15-4-337.

[10] Walker J, Holm Hansen C, Martin P, et al. Prevalence, associations and adequacy of treatment of major depression in 21,151 cancer outpatients: a cross-sectional analysis of routinely collected clinical data. *Lancet Psychiatry* 2014; published online Aug 28

Response to Q3

Our community uses the word “choice” as the act of selecting between two or more possibilities. Use of this word appears simplistic for health care decision-making. Medical ethics prefers the concept of informed consent, which recognises the complexity involved with medical treatment decisions, and has an established set of principles to guide whether informed consent is autonomously provided.

A more sophisticated concept is that of “agency”, where “Agency is the internal capability of persons to exercise self-governance in the competent control of their life and with the freedom to exercise personal choice. From the perspective of agency, autonomous agents are those who initiate their actions exercising their power to do so; they act by self-governing.” (p. 556).[11] In the psychiatrist’s assessment, agency is examined by exploring judgement capacity, insight, and cognition, while excluding altered perceptions, delusions and overvalued ideas that mar reality.

Autonomy is the personal exercise of self-governance, choices and control over aspects of human life that the laws of society permit the individual to govern. Respect for the autonomy of individuals requires health practitioners to establish the patient’s decision-making capacity to give informed consent to specific treatments offered.[11] Decisional capacity is examined by physicians’ assessments in five component areas: understanding, appreciation, reasoning, choice, and values.[12] Thus, competence to consent to treatment is ordinarily assessed not only by hearing an expression of choice, but also by clarifying the understanding of medical information, checking the person’s appreciation of the personal relevance of this information, and the intactness of logical reasoning. However, when persons frame their prognosis pessimistically and out of proportion to the perception of their health providers, this disordered relationship to their future could impair their appreciation of the personal relevance of their medical information. This can occur in states of depression and demoralization, which may disrupt the coherence of personal preferences by changing them, in the process diminishing the agency of the person.

The identification of the minimal conditions of autonomy requires distinguishing between autonomy-conferring reasoning and autonomy-undermining reasoning in this decision-making capacity. While the state of intoxication with alcohol or other substances is one obvious way to diminish agency, states of depression, demoralization, existential distress and family dysfunction all carry the capacity to diminish agency. The legal frameworks designed to protect a person’s autonomy should establish not only adequate decisional capacity but also prove positively the person’s ability to act with unaffected and undamaged agency. Without true agency, there can be no genuine autonomy.

Q4

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

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[11] Mendz GL, Kissane DW. Agency, Autonomy and Euthanasia. The Journal of Law, Medicine & Ethics, 48 (2020): 555-564. https://doi.org/10.1177/1073110520958881

[12] T. Grisso et al., “The MacCAT-T: A Clinical Tool to Assess Patients’ Capacities to Make Treatment Decisions,” Psychiatric Services 48, no. 11 (1997): 1415-1419.

quality, readily available palliative care, particularly with respect to those residing in rural, regional and remote NSW?

Response to Q4

The provision of palliative care in our society brings the speciality that is recognised as expert in the alleviation of suffering and the optimal treatment of symptoms, be they physical, psychological, existential, social or spiritual in nature. Access to palliative care is considered a basic human right. It ensures delivery of the highest standard of competent medical care to those terminally ill and dying. It is an authentic alternative to voluntary assisted dying and, when provided, many patients who are in a state of despair and have begun to contemplate suicide or a desire to hasten their death will re-engage with life and the wish to live once their suffering is ameliorated and their quality of life enhanced once again.

Legislators ought to ensure statewide access to palliative care before entertaining the provision of a lesser approach in permitting physician-assisted suicide or euthanasia. See the submissions of Palliative Care Australia and the Australian and New Zealand Society of Palliative Medicine for details on the shortfall of funding and provision of palliative care in rural, regional and remote parts of New South Wales. There are major deficits that legislators have an obligation to address.

Q5

In the Victorian *Voluntary Assisted Dying Act 2017* there is a strict prohibition on the subject of Voluntary Assisted Dying being initiated with a patient (clause 8). An equivalent strict prohibition provision is not contained in the New South Wales *Voluntary Assisted Dying Bill 2021*. If a piece of legislation is to proceed from the New South Wales Parliament regarding Voluntary Assisted Dying, should it include a strict prohibition provision similar to clause 8 of the Victorian *Voluntary Assisted Dying Act 2017*?

Response to Q5

Patients who are close to their dying are at one of the vulnerable moments of their lives. If a doctor suggests VAD to them as a reasonable treatment option for them to consider, the doctor conveys a sense of hopelessness and even more so, the futility and pointlessness of any remaining life. This is a highly influential message to convey to a vulnerable patient because of the many implicit associations that might occur to that patient. Thoughts like, “I will suffer, there is no more that can be done to help me, no quality or value remains, it is time I said goodbye” are typical of what the average patient could consider. There is no appreciation of the preciousness of human life. The inevitability of the doctor’s message is the hopeless and helpless predicament that the patient may appear to be in.

Psychiatry has long understood that when the clinician thinks that the patient might as well suicide, the risk of the patient doing so is extreme. Such a predicament conveys a subtle, unspoken message which is often transmitted non-verbally, yet picked up by the patient with great clarity. This is known as the science of countertransference, what the therapist conveys back to the patient without needing words. The axiom in psychiatry is that if a clinician finds him or herself thinking that a person might be better off dead, they ought to admit the patient to hospital, ensure their safety, obtain a second opinion, and take very active steps to preserve the patient’s life. We can learn from such principles about the care of the actively suicidal patient who is mentally unwell. Indeed, not every doctor or nurse is effective in conveying hope. Many clinicians lose hope and give up as they struggle to deliver optimal care.

When a doctor suggests euthanasia or physician-assisted suicide as a management option to a patient, the attitude is one of paternalism and power, wherein the clinician makes a value judgement about the worth or lack of worth of another person, dismisses their life as futile, and offers to end their life like an animal. The outcome is extraordinary in degree, the power imbalance is extreme, the risk to the patient is severe, and the damage to trust and integrity of the medical profession profound.

There are many stories from Belgium of doctors first of all prescribing a medication for pain, and then asking the patient if they would like to make a booking for euthanasia. Legislators ought not be blind to the bias of euthanasia advocates who suggest that all treatment options be placed on the table.

The Victorian *Voluntary Assisted Dying Act 2017* included a strict prohibition on the subject of Voluntary Assisted Dying being initiated by a clinician (clause 8) to protect the patient from such unwitting and dangerous behaviour from health care practitioners. The danger is real, as I hope my commentary above illustrates. I strongly recommend the inclusion of such a prohibition if NSW legislators propose to proceed with a New South Wales *Voluntary Assisted Dying Bill 2021.*

Q6

The Victorian *Voluntary Assisted Dying Act 2017* has, with respect to minimum requirements for co-ordinating medical practitioners and consulting medical practitioners, a requirement for the involvement of a medical specialist and an individual with relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed (clause 10). Equivalent provisions are not contained in the New South Wales *Voluntary Assisted Dying Bill 2021*. If a piece of legislation is to proceed from the New South Wales Parliament regarding Voluntary Assisted Dying, should it include provisions similar to clause 10 of the Victorian *Voluntary Assisted Dying Act 2017*?

Extract of clause 10 Victorian Act: Minimum requirements for co-ordinating medical practitioners and consulting medical practitioners

(1) Each co-ordinating medical practitioner and consulting medical practitioner must—

(a) hold a fellowship with a specialist medical college; or

(b) be a vocationally registered general practitioner.

(2) Either the co-ordinating medical practitioner or each consulting medical practitioner must have practised as a registered medical practitioner for at least 5 years after completing a fellowship with a specialist medical college or vocational registration (as the case requires).

(3) Either the co-ordinating medical practitioner or each consulting medical practitioner must have relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed.

Response to Q6

The need for relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed became very apparent to me in reviewing the patients who made use of the Northern Territory's *ROTI (Rights of the Terminally Ill) Act 1995*. The classic example in Darwin was the patient who suffered from Mycosis Fungoides (a form of lymphoma) and whose haematologist treating her condition indicated that her prognosis was of the order of nine months. A second medical specialist also certified that she was not yet terminal and did not meet the requirements of the Act. An orthopaedic surgeon ended up certifying that she was terminal, although he lacked expertise in the treatment of lymphoma. Now the regulations associated with the *ROTI Legislation 1995* required that "this (consulting) practitioner hold a qualification in a medical specialty related to the terminal illness, recognised by fellowship of a specialist college in Australia" (p.1098). [13] The coroner was required under the ROTI Act to review the medical records of each patient making use of the Act and ensure that the legislation was appropriately followed. The coroner made no statement nor took any actions about several breaches under this Act.

Unless relevant expertise is required by the Act, clinicians who are social advocates for euthanasia (such as Dr P. Nitschke in the era of the *ROTI Legislation 1995* in Darwin) will readily certify that patients meet the requirements of the Act, when in fact they may not. This need for expertise is one of the most important safeguards for any euthanasia act to avoid vulnerable depressed patients accessing the act to commit suicide.

As the practice of medicine grows steadily in complexity, the majority of general practitioners in our society lack expertise in treating illness as such as cancer and need to refer to specialists for the patient to access informed expertise. Patients expect such referral. Legislators ought provide safeguards, in my opinion, in legislation giving doctors the right to euthanise patients to ensure that appropriate specialist expertise about the nature of any illness and its prognosis is present before approval be given for such a practice that results in the loss of life.

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[13] Kissane DW, Street A, Nitschke P. (1998) Seven deaths in Darwin: studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. Lancet, 352: 1097-1102.