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RE: Queensland Parliament Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying

The Chair
Health, Communities, Disability Services and Domestic and Family Violence
Prevention Committee
Parliament House
George Street
BRISBANE QLD 4000

Thank you for this opportunity to respond to the above inquiry. We note that this inquiry covers several unrelated matters, namely aged care and palliative care on the one hand, and euthanasia and assisted dying on the other. This submission will briefly address aged care and palliative care, but focus on the topic of voluntary assisted dying, or as we prefer to phrase it, euthanasia and assisted suicide (EPAS). We represent a network of over 700 health professionals including Palliative Care Physicians, Oncologists, Geriatricians, Rehabilitation Specialists, Psychiatrists, General Practitioners and Allied Health Workers who work with and care for people with palliative, aged, mental health needs and disabilities. Please find our responses to the issues for consideration below.

AGED CARE

3. Do the standards of residential aged care, home care and other aged care services provided in Queensland meet clients' and the community's expectations? Can you give examples?

We are aware of patients not receiving their required medication due to the absence of a registered nurse on the staff of residential aged care facilities at the time they are required. It is essential that there be a registered nurse at all times available in aged care facilities to receive their prescribed medication, and any emergency medication (such as pain medication) as required. Furthermore, we are aware of aged care facilities who do not allow palliative care teams onto their premises to see patients, and/or doctors who do not prescribe the treatments recommended by the palliative care team. All of these practices result in inferior care for patients/clients. Staff ratios may also present a problem for adequate care during times of illness. Issues include:

1. Many residents do have not had adequate or appropriate advance care and goals of care planning done at a primary level for individual residents due to lack of expertise/knowledge /time/understanding of how to do so in a just and meaningful way to facilitate appropriate levels of care prior or to avert a un-necessary hospital admissions/re-admission.
2. Reasons for some to many of the admissions/readmissions to hospitals include:
 - Conflicts in dealing with models of care in RACF between frail aged and dying or complex patients with increased palliative need
 - Most nursing done by junior nursing staff as only mode of promotion for senior nurses is through the management ladder
 - Therefore a need for recurrent and ongoing education to all RACF, including RNs, care, staff, GP (medical) and allied health around these patients, and adequate educator role for this to occur with expert input
 - ACFI funding model provides some money for end of life care, but not for more complex or longer-lived palliative care/aged residents, and nursing/carer ratios, especially after hours, cannot provide the medicinal and personal care required for these patients and their relatives along side other residents.
 - There are limited and diminishing numbers of GPs with experience or knowledge of Palliative care (and also poor incentives here through appropriate item numbers) due to the time taken for these patients.
 - There can increased distress from families feeling their loved ones' needs may be better met in hospital, especially in a diverse multicultural or indigenous population who have fears around "not being heard or valued" in a culturally appropriate way
 - There is limited ability/availability of RACF outreach teams to respond to RACF requests for assistance with deteriorating residents also due partly to limited Palliative care experience or lack of integration with Palliative Care services.
 - When Ambulance paramedics are called, they may feel unable to leave residents in place of care due to issues above already outlined, especially after hours.
3. Even for patients known to Palliative Care, lack of more an extensive and integrated resourced model between Aged care and Palliative care, results in breakdown of plans, continuity and responsiveness for these residents.

PALLIATIVE CARE

18. Are palliative care and end-of-life care services meeting the current needs of Queenslanders? Why or why not?

Universal access to palliative care is still not available in Queensland. See comments above about lack of access for people in aged care facilities. Palliative Care Australia has identified other demographics which lead to reduced access to palliative care services; low income, non-urban location, acute care settings and nursing homes, ethnic or indigenous background, very old or very young age, and non-cancer diagnosis. More government

funding is needed to fill the gap. See https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web-1.pdf for findings and information for guidelines of what is needed to deliver adequate palliative care and associated considerations across various care settings.

VOLUNTARY ASSISTED DYING

25. Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?

We strongly recommend against allowing EPAS in Queensland. As healthcare workers, we are aware of much misunderstanding about what is, and what is not, EPAS. We're told that 85% Australians are in favour of a change in the law to allow euthanasia and assisted suicide (based on a poll using a limited and leading question around suffering without alternative approach), but perhaps less well known is that the majority of doctors (those who are expected to actually do the deed) are against euthanasia, and the size of the majority increases as their work is more involved with the dying. All palliative care organisations around the world are against it as is, as well as the Australian Medical Association, and the American College of Physicians and the World Medical Association. These **position statements** and many others are all visible at for your consideration:

<http://www.healthprofessionalssayno.info/resources.html>

So our question is this: Why are we having this debate now, at a time when we have more medical cures than ever before in human history? The timing suggests it is not a failure of *medicine* that has prompted this debate. We believe that this is a societal issue, fear of dying and desire of control over death, which should not be resolved by falsely legitimising the killing of patients by doctors and by claiming the EPAS is a form of healthcare. Moreover, there are many reasons why we oppose the legalisation of EPAS based on the experience in overseas jurisdictions where it is legal. These should make politicians hesitate to introduce laws allowing EPAS into Queensland's Parliament.

Importantly so, despite reported public support for this socio-political agenda, it is rarely discussed that this support is not found this support is weak among groups who express concerns about being pressured to die (i.e. older adults, people with disabilities, people with less education, women, indigenous and racial and ethnic minorities).

For a clear, thorough and authoritative and objective recent review of evidence in discerning whether euthanasia and physician-assisted suicide are clinically necessary or desirable, we strongly recommend the recently published paper for the International Association of Hospice and Palliative Care, written by Professor Roger Woodruff, oncologist and palliative physician, Victoria. <https://hospicecare.com/policy-and-ethics/ethical-issues/essays-and-articles-on-ethics-in-palliative-care/euthanasia-and-physician-assisted-suicide-are-they-clinically-necessary/>

a. Mistreatment of distressed patients

Research in Canadian palliative care patients has demonstrated that when patients expressed their fears at the end of life it was often misinterpreted by healthcare providers as a request for euthanasia when it was really intended to be a cry for help.(1) When a patient says they wish they were dead, it doesn't necessarily mean they are asking you to kill them. We all have bad days. This research also found that patient desires are known to fluctuate over time, including desires for hastened death and that depression was a common finding (up to 60%) in many.(2) These patients need support, not a referral for EPAS, as recommended in the current VAD training for Victorian doctors.

Palliative care literature shows requests to hasten death are uncommon after referral to specialist palliative care services (1-2%). This number reduces significantly further when problems and symptoms are addressed. It has also been shown that a patient's desire to die is often due to a sense of burden on others and lower family cohesion, and also more likely to persist when managed by a doctor who is not trained psychologically or in palliative care to deal with end of life suffering and sense of hopelessness. (3)

b. Abuses of the law

Australian lawmakers have looked to the Oregon USA model of legislation as a basis for legislation, and many promoters of EPAS have claimed that it has operated without problems for many years. However, the lack of official evidence of problems does not reflect the absence of problems, as the official reporting system does not allow for the reporting of problems.(4) Dr Katrina Hedberg, of the Oregon Department of Human Services, has reported: "We are not given the resources to investigate [assisted-suicide cases] and not only do we not have the resources to do it, but we do not have any legal authority to insert ourselves."(5) Nonetheless, there are many documented examples of abuse. For example:

- Kate Cheney, 85, died of assisted suicide under Oregon's law even though she had early dementia. Her personal physician declined to provide the lethal prescription. Her managed-care provider found another physician to prescribe a lethal dose of drugs. When counseling to determine her capacity was sought, a psychiatrist concluded that she was not eligible for assisted suicide since she was not explicitly seeking it, and her daughter seemed to be coaching her to do so. Nevertheless, Kate Cheney soon received and used the lethal drugs.(6)
- Michael Freeland, age 64, had a 43-year history of acute depression and suicide attempts. Yet, when Freeland and his daughter went to see a doctor about arranging a legal assisted suicide, the physician said he didn't think that a psychiatric consultation was "necessary."(7) Oregon's statistics for the last four years show that only 2% of patients were referred for a psychological evaluation or counseling before receiving their prescriptions for lethal drugs.(8)
- Patrick Matheny received his assisted suicide prescription by Federal Express. He couldn't take the drugs by himself so his brother-in-law helped. Commenting on the Matheny case, Dr. Hedberg of Oregon DHS said that "we do not know exactly how he helped this person swallow, whether it was putting a feed tube down or whatever,

but he was not prosecuted" The state's official annual report on assisted suicide deaths did not take note of this violation of the Oregon law.(9)

- The first known assisted-suicide death under the Oregon law was that of a woman in her mid-eighties who had been battling breast cancer for twenty-two years. Initially, two doctors, including her own physician who believed that her request was due to depression, had refused to prescribe the lethal drugs. Compassion & Choices—then operating under the name Compassion in Dying—became involved in the case and referred the woman to a doctor willing to write the prescription.(10)

c. Mental illness

The incidence of depression in cancer patients has been measured as high as 45%. One study found that up to 80% of depressed patients in palliative care were untreated. (10) Research has also shown that the majority of these cases were missed diagnoses rather than treatment-resistant depression, with treatment effective 6-8 weeks after commencing anti-depressants. (Hart 2012) Desire for hastened death is a symptom of depression. Several studies have shown that treatment of depression increases patient interest in living. In any other group, a request for death would alert a doctor for urgent psychiatric review: why is this group of patients being treated differently? (12)

d. Risks of increasing the suicide rate

The Centre for Rural & Remote Mental Health published a report on Suicide and Suicide prevention in Rural Areas of Australia in 2017.(13) It found that in every state of Australia, the rate of suicide in those who lived outside capital cities is higher than that for residents that live within them, and the rate has risen much higher in rural areas over the period 2011-2015. The rate is much higher amongst Aboriginal and Torres Strait Islander People (11%), and the majority of suicides among this population occur outside of capital cities. A study of male suicides in Queensland found that the appropriateness and effectiveness of health services which rural men are accessing needs to be improved to reduce rural suicide. Legalisation of VAD sends a message to the population that hastening death is a legitimate way to deal with suffering in life. Life in the country is becoming harder for many reasons, and it needs to be considered by the Committee whether legalising VAD will impact suicide rates in Queensland.

In the jurisdictions where EPAS is legal, non-assisted suicide rates have also increased, for example in Oregon USA, it was found that legalising EPAS was associated with an increased rate of total suicides relative to other states and no decrease in non-assisted suicides. The authors concluded: 'This suggests either that PAS does not inhibit (nor acts as an alternative to) non-assisted suicide, or that it acts in this way in some individuals but is associated with an increased inclination to suicide in other individuals.'(14)

Here lies the real agenda:

*In every state in Australia, the rate of suicide among those who live outside the greater capital cities is higher than that for residents that live within them, and the rate has risen much higher in rural areas over the period 2011-2015.....If we are to reduce rural suicides **in the long term**, we need to work out how to address the social determinants of health, using strategies based on knowledge about these determinants as they apply to individual rural locations.**If we are to reduce rural suicides right now** we need to start reducing the gap in access to and use of*

*evidence-based medical and psychological treatments for those who are experiencing mental distress: **Centre for Rural and Remote Health NSW** Suicide and Suicide Prevention in Rural Areas of Australia*

e. Risk of coercion

The model of legislation which Australian parliaments are currently examining involved prescription of lethal medical which a patient is expected to consume at home without supervision. It was stated that in Washington State only 10% of those who were given prescriptions ultimately took them. Further as stated before, the experience of psychiatry and palliative care is that desire to die fluctuates and in the majority diminishes with appropriate care, or if someone changed their minds for other reasons, often relational to what is occurring in their personal life. This would indicate that many of those given prescriptions may change their minds and not want to die, but there is no oversight here. How will medication safety and coercion be policed in such cases? See also comments on elder abuse, below.

f. Complications of EPAS

Contrary to proponents' claims, legalizing assisted suicide does not guarantee patients a quick and peaceful death. Previous experience in jurisdictions where EPAS is legal has suggested that complications occur regularly. (15-17)

Consider the case in Oregon USA.

- Speaking at Portland Community College, pro-assisted-suicide lawyer Cynthia Barrett described one botched assisted suicide. "The man was at home. There was no doctor there," she said. "After he took it [the lethal dose], he began to have some physical symptoms. The symptoms were hard for his wife to handle. Well, she called 911." He was taken to a local Portland hospital and revived.(19)
- David Prueitt took his prescribed lethal overdose in the presence of his family and members of the assisted-suicide advocacy group Compassion & Choices (formerly the Hemlock Society). After being unconscious for 65 hours, he awoke. His family leaked the failed assisted suicide to the media. Oregon DHS issued a release saying it "has no authority to investigate individual Death with Dignity cases." (20)

Legislation in Victoria is reputed to be more stringent than above, however, the oversight committee consists of a panel with lack of expertise and scope to review prescriptions given, and if given, the falsification of health records and death certificates allowed to indicate an underlying disease and not the cause or means of death, also eroding the power of the Coroner's office to investigate potential coercion, abuse or complications (not to mention the recording of accurate data for health epidemiology). As in Oregon, Canada, Belgium, and the Netherlands, abuses and complications will remain grossly under reported and unable to be managed.

g. Disability perspective

The late **Stella Young**, comedian, writer and disability activist, wrote on the implications of legalising VAD for people living with disabilities:

‘As a disabled person, I'm accustomed to conversations about quality of life and dignity. Specifically, I'm accustomed to assuring people that my life is worth living. I'm short

statured, a wheelchair user, and I frequently have bone fractures. All the visual cues that make me 'the other' are front and center.

People make all sorts of assumptions about the quality of my life and my levels of independence. They're almost always wrong.

I've lost count of the number of times I've been told, "I just don't think I could live like you," or "I wouldn't have the courage in your situation," or, my favourite one to overhear (and I've overheard it more than once), "You'd just bloody top yourself, wouldn't you?". What we as a society think we know about what it means to live as a disabled person comes from cultural representations of disability seen through a nondisabled lens. And we, as people with disability, rarely get to tell our own stories.

Also, social attitudes towards disabled people come from a medical profession that takes a deficit view of disability. This is my major concern with legalising assisted death; that it will give doctors more control over our lives. As a disabled person who has had a lot to do with the medical profession, I can tell you that this is the space in which I've experienced some of the very worst disability prejudice and discrimination. Doctors might know about our biology, but it doesn't mean they know about our lives.

Media reports on assisted dying feed these misconceptions. ABC News reported on the case of Barbara Harling, a Queensland woman with motor neurone disease who said that she would consider moving states when a Voluntary Assisted Dying Bill had passed. Harling is quoted as saying: "Well, let's put it this way. I can use my left hand; my right hand is just about useless. If I can't use my left hand to wipe my bottom, then I can do nothing else for myself. That means someone has to do everything for me. I couldn't bear to live like that."

The thing is, a lot of people do live like that. I know many, many people who depend on personal assistants for all of their daily living tasks, some of them requiring 24 hour care. Having to rely on someone else to wipe your bum may not be something anyone aspires to, but I'm quite sure it's never killed anyone.

Perhaps our discomfort with this kind of thing is why we don't hear the counter view in reports about assisted dying. Often we hear supporters of euthanasia and assisted suicide talk about wanting to avoid the pain and often, we hear stories like Barbara Harling's, which are more about wanting to avoid a loss of autonomy and independence.' (21)

We also refer you to testament given at the time of public enquiry into VAD Legislation in Victoria. See **disability advocates Sam Connor, Kelly Cox and Liz Carr** at this link discuss their experiences and views: <http://www.healthprofessionalsayno.info/links.html>

h. Risks to Indigenous Australians

The Committee will be aware that there is a life expectancy gap between Aboriginal and non-Aboriginal Australians throughout Australia, including Queensland. People in the state are dying of preventable diseases and injuries in their 50s, 40s, and even 30s. Considering that we as a country are dedicated to closing this embarrassing life expectancy gap between Aboriginal Australians and other Australians, introducing euthanasia would be very contradictory and frankly immoral.

If VAD were to be legalised, then care would need to be taken to ensure that some of the most marginalised residents of the state, who have some of the worst health outcomes,

should understand what exactly the legislation is about. There is no word for euthanasia in Aboriginal languages.

Not only do many Aboriginal Queenslanders have very poor health outcomes, but many also have limited comprehension of English. As health care professionals, we often have great difficulties in communicating with Aboriginal patients, despite our best efforts, and have seen Aboriginal patients receiving sub-optimal care due to language barriers. Our patients with terminal and non-terminal illnesses often find their conditions unbearable because we frequently have great difficulty in explaining the complexities of conditions and their treatment to patients whose first or even second language is not English; Aboriginal interpreters exist, but the demand for them far exceeds their supply. Therefore, introducing the possibility of a doctor being able to kill a patient will further confuse patients and the trust between patient and doctor will be even harder to build and maintain. This will further dampen efforts to close the gap in life expectancy between Aboriginal and non-Aboriginal Australians.

If VAD were legalised, then the great efforts that we now expend in persuading our patients to accept treatment in order to alleviate their suffering and prolong their lives could be redirected to educate them about the benefits of asking for an early death instead of accepting expensive medical care, especially in a setting of rising health care expenditure. Indeed, over the years, we have evidence for this from colleagues working in the Northern Territory of Aboriginal patients being fearful of palliative care, or even of intramuscular injections, because of the legalisation of euthanasia in the Northern Territory almost two decades ago.

"...I do not think it is an exaggeration to say we are in times of terror for our country...I have worked doing locums in Alice and Darwin and going to remote Aboriginal communities with the Palliative Care Service Top End. For Aboriginal and Torres Strait Islander people, if legislation goes through in the Territory, (probable domino effect from Victoria), people will understandably be more afraid than ever of accessing what they call 'white fella medicine', especially Palliative Care. And so many are dying so young." Dr Helen-Anne Manion OAM, Palliative Care Physician and Director Co-founder *DYING AT HOME PROGRAM*.

We trust that you would agree that it is wrong that these vulnerable and marginalised Aboriginal Queenslanders who are already dying too young should be enabled to die even younger. Instead, resources are desperately needed to educate them about preventing and managing, the diseases they are dying from prematurely.

As spoken by indigenous **Senator Patrick Dodson** during considerations for the Rights of the Territories Bill, *"Regardless of how you feel about the topic itself, can we be certain that we can craft a regime that will actually provide adequate protections to people, particularly those in the most vulnerable of circumstances?"*

For the sake of the health and well-being of marginalised Queenslanders with poor health outcomes, especially Aboriginal Queenslanders, we suggest resources be directed to enabling Aboriginal Queenslanders with poor health status to live longer and healthier lives, including the provision of adequate health education and treatment that might reduce the

unbearable hopeless suffering that increasing numbers of Aboriginal Queenslanders are enduring.

i. Euthanasia is not medical care

We reject the notion that EPAS constitutes a form of medical care. Doctors are taught to care for the vulnerable and not to intentionally shorten life. By introducing EPAS as a procedure which is carried out by doctors in healthcare institutions, it is given a veneer of medical legitimacy which it does not deserve. If the Australian public insist on this practice being legalised, we suggest it be removed from the healthcare setting and not contaminate the environment of care and compassion which should be found there. The fact that the Victorian working party charged with implementation of that state's EPAS legislation will have to train doctors demonstrates clearly that it is not within the doctor's skill set. Like capital punishment in the USA, others should be trained for a practice in conflicts with medical ethical guidelines that have existed for millennia. The power imbalance of the therapeutic relationship cannot be underestimated, as discussed and evidenced earlier in this paper, in forming the views and actions of patients. Those involved in the care of those at the end of their lives, the vulnerable and marginalised should not be involved as agents or facilitators of a non-therapeutic socio-legal phenomena.

“Neither palliative care nor medicine can eradicate total suffering; similarly, politicians and lawyers do not have such power. There may be an illusion of a medical solution to alleviate suffering, but the real answers lie in how we connect and support each other as a society, as health care providers, and as professionals entrusted to care for people who are dying and their families.” A/Prof Leeroy William, Palliative Medicine Physician, Eastern Health, Victoria. <https://onlinelibrary.wiley.com/doi/abs/10.5694/mja17.01217>

Nor should it be implied that EPAS/VAD is part of palliative care or expected to be an extension of palliative care. There are many who already do not seek palliative care for their needs due to media and general misconceptions or misinformation around what constitutes palliative care and its implications. By even implying that EPAS/VAD is part of palliative care would create further misunderstanding and fear of those truly vulnerable and in need of care. Lastly, in a multicultural society with migrants from areas of injustice, persecution, war, torture and power imbalances, fear of the actions of those with authority within medical and healthcare systems cannot be underestimated, preventing those with palliative needs to come forward for assistance.

Such legislation for ***the argument for autonomy of a few to be managed within healthcare actually infringes upon the autonomy of those vulnerable in ambiguous health care and legal systems***, and this infringement extends to those with disabilities and mental illness, as well as the aged.

j. Harm to physicians

In jurisdictions where EPAS is legal, physicians who carry out assisted suicide have reported a negative impact from the act. In an American study, of 38 oncologists who reported participating in EPAS, nearly a quarter regretted their actions, and another 16% reported

that the emotional burden of performing EPAS adversely affected their medical practice. Doctors were not trained for this task and have not asked for this role. If VAD is legalised, doctors should have nothing to do with it, so the role of healer is not confused. Shortly after legislative introduction in Ontario, over 200 doctors who initially had supported the enactment of legislation in Canada have removed themselves from the “Medical Assistance In Dying” Register, due to the effect of their experience into the reality of what their actions involved. There is a great and stark incongruence here in the role of the physician in the therapeutic relationship.

k. Inadequate Palliative Care

The most recent data from the Australian Institute of Health and Welfare states that in 2016, there was an insufficient 226 specialist palliative medicine physicians across all Australia. We are gravely concerned about the potentially dangerous impact this legislation would have, undermining the medical profession and devaluing palliative care. Palliative care must be resourced as a priority and provision made for all Queenslanders to experience a positive end of life. Those living with terminal illness require some of the greatest levels of support. Should we not be investing our efforts into enhancing and innovating palliative care to ensure it? We believe that until all Queenslanders have access to palliative care, it is immoral to even consider legalizing EPAS. We refer again to the Palliative Care Australia Workforce Strategy, mentioned above.

l. Elder abuse

Elder abuse is a recognised problem in Queensland, as evidenced by the advertising of the Elder Abuse Helpline on the Queensland Government website. (20) The NSW Government released a report on Elder Abuse in 2016. The Committee found evidence that elder abuse is a significant and growing problem in our community. Financial abuse emerged during the inquiry as a substantial problem demanding urgent action on the part of government. The report refers to claims that the law as it stands provides insufficient safeguards against financial abuse, that it does not treat many forms of financial abuse as criminal, and indeed, that the law itself is significant enabler of abuse. A need for increased awareness of financial abuse was noted. See the **Report into Elder Abuse** here:

<https://www.parliament.nsw.gov.au/lcdocs/inquiries/2387/Report%2044%20-%20Elder%20abuse%20in%20New%20South%20Wales.pdf> & <https://www.parliament.nsw.gov.au/lcdocs/inquiries/2387/summary%20of%20recommendations.pdf>

In June 2017, the Australian Government Attorney-General's Department launched the Australian Law Reform Commission's (ALRC) report on elder abuse: **Elder Abuse – A National Legal Response**: <http://www.attorneygeneral.gov.au/Media/Pages/National-Plan-to-address-elder-abuse.aspx>

It also found that elderly persons are victims of financial fraud. It recommended that a national register of enduring powers of attorney be established to prevent greedy children from using the document as a "license to steal" from their elderly parents.

The paper notes that “the potential for pressure and coercion in setting up the instruments” [the powers of attorney appointing children to act on their parent’s behalf] and that “early inheritance syndrome” is on the rise. “With Australians living longer than ever before, the ALRC inquiry heard many examples of children who were impatient to get their hands on their parents’ money and tried to claim their inheritance before they were entitled to it.”

While the exact prevalence of elder abuse is not established in Queensland, the ALRC reported that “at the international level, the WHO (2015) recently reported that estimated prevalence rates of elder abuse in high- or middle-income countries ranged from 2% to 14% ... and that the perpetrators are likely to be related to the victim...[and] one study suggests that neglect could be as high as 20% among women in the older age group (Australian Longitudinal Study on Women’s Health, 2014). Older women are significantly more likely to be victims than older men, and most abuse is inter-generational (i.e., involving abuse of parents by adult children), with sons likely to be perpetrators at a greater extent than daughters.” The report is accessible here: https://www.alrc.gov.au/sites/default/files/pdfs/publications/elder_abuse_131_final_report_31_may_2017.pdf

What has this got to do with euthanasia? A portrayal of the mixed motives of family support of euthanasia was the topic of the winning short film in this year’s Tropfest Festival; ‘The Mother Situation’ <http://mobile.abc.net.au/news/2017-02-12/tropfest-matt-daytakes-top-honours-forthe-mother-situation/8263168?pfmredir=sm> This also exemplifies concerns around inadequacy of safeguards one a means to be killed is issued vulnerable individuals who may change their views over time, as is a common experience.

26. How should VAD be defined in Queensland? What should the definition include or exclude?

There are many scenarios in the end-of-life situation which are ethically challenging. These include the cessation of life-supporting therapy, symptom control which may reduce the consciousness of the patient, and limitation of nutrition and hydration. Each deserves to be considered individually in ethical terms, as different facts need to be considered for each practice. We believe, therefore, a narrow definition of euthanasia and assisted suicide should be used, so it is not confused in practice or in ethical terms, with other end-of-life decision-making issues. We oppose the use of the definition ‘voluntary assisted dying’ for several reasons. Firstly, the term ‘voluntary’ in this instance suggests that ‘involuntary’ and/or ‘nonvoluntary’ assisted dying exists. However, such acts with intention to kill would normally constitute murder, and should be named as such. As suggested in the Issues Paper, the tactics of those promoting laws allowing EPAS have tried to suppress use of the term ‘suicide’ in an attempt to increase support for this practice, rather than to clarify its meaning. In such debates, changing recognised terms such as euthanasia and physician assisted suicide or using other terms in advocacy for “voluntary assisted dying” laws, including “medical assistance in dying”, is evasive and renders the reality of such acts and their application unclear and confusing, particularly for the general public’s and members’

of parliament interpretation. They also imply the person who is being killed is actively dying, which they are not. Further they create misunderstanding of what constitutes good and best practice end of life care in the dying, as practiced by palliative care. We believe that any terminology that reduces transparency or creates illusion or confusion in debate is to be avoided; a practice where one is given the means to kill oneself is, therefore, more accurately termed as a form of 'suicide' than 'dying', which is much broader in meaning.

Killing of patients by another, such as a doctor, would be murder or manslaughter if no legal provision were available to allow them to avoid prosecution. For decades such provisions across the world have been termed 'euthanasia' and we see no need to change this terminology. 'Medical aid in dying' as used in Quebec is an attempt to give the act legitimacy by conflating it with other medical procedures. 'Medical assistance in dying' is similar. We need to keep our definitions clear so we all know what we're talking about. The term euthanasia comes from the Greek – it means 'good death'. However, this is not particularly helpful as both sides claim the advantage of bringing about a good death, and indeed, the question of what constitutes a good death is at the heart of the euthanasia debate.

We would all like to see people in our communities dying with dignity and without suffering. The question is, how do we go about achieving this?

First of all, we need to be clear on what euthanasia is not a medical treatment. Euthanasia is sometimes confused with cessation of treatment which aims to prolong life. In life-threatening illness, treatment initially aimed at cure may become futile (no longer working), or so burdensome (such as due to distressing side-effects) that any benefit from the treatment is no longer worthwhile. At this point the treatment may be no longer prolonging life so much as prolonging the process of dying. At this time a decision may be made to stop, or not to start, such a treatment. This practice is not euthanasia because the intention is not to kill the patient, but to allow the underlying disease to take its course. Full supportive care will remain in place so the patient is kept comfortable and family supported through this time.

In the same way, taking someone off life support is not euthanasia. It's not flicking the switch that kills the patient, it's the underlying disease that does it, that's why they were on life support in the first place.

We are aware of media reports that claim that palliative care services starve patients to death. This is a simple misunderstanding of the changes in physiology that occur at the end of life, the anorexia-cachexia syndrome, where patients not only lose their appetite, but will not put on weight regardless of what they eat.

Another situation which is often confused with euthanasia is adequate symptom control in the terminally ill. Very occasionally in the terminal stages of disease the distressing nature of a patient's symptoms may require the careful sedation of the patient, while seeking to preserve their dignity. It is not euthanasia because the intention is not to kill the patient, but to alleviate their distressing symptoms.

Some people would call this practice of symptom control *passive* euthanasia because of a myth in the community that use of morphine shortens the life of the patient. They argue that if we already practice *that* type of euthanasia, there is no reason not to practice the *other* type of euthanasia, using lethal injection, which they call *active* euthanasia. You see the problem in this terminology. We therefore suggest that the terms ‘active’ and ‘passive’ euthanasia be avoided.

Philosophers have spent a lot of time talking about the principle of double effect in order to justify analgesia use at the end of life, but it really isn’t necessary. It’s all based on a myth – that morphine kills the patient. This myth been around for years, and we don’t seem to be able to squash it. It makes people scared to use what is an excellent treatment for pain. But in fact **morphine in therapeutic doses does not shorten life**. Indeed, it may actually prolong it. An Australian study (21) showed increased survival of palliative care patients on high doses of morphine, likely due to a less stressful and better symptomatically controlled dying process for those individuals.

Stopping futile and burdensome treatment and maintaining adequate symptom control are good medical practices at the end of life and should be encouraged in clinically appropriate situations. They should not be confused with practises aimed at killing patients.

We define *euthanasia* as ‘An act where a doctor intentionally ends the life of a person by the administration of drugs, at that person’s voluntary and competent request, for reasons of compassion’. The key points to note are that it is an intentional act by a doctor, motivated by compassion. It is a decision made voluntarily by the patient, with no coercion involved, and they are mentally competent at the time. We prefer to keep the definition narrow, so we can evaluate each end of life scenario individually.

We define *physician assisted suicide* as ‘The situation where a doctor intentionally helps a person to commit suicide by providing drugs for self-administration, at that person’s voluntary and competent request’. The doctor is thus distanced from the act, but morally it is no different to euthanasia as the motivation, intention and outcome are the same – therefore in this submission, the terms are used interchangeably.

We commend these definitions to the committee.

<https://gimmun.gimptuj.si/2017/files/Euthanasia.pdf> - WHO definitions

On the issue of defining **choices around dying**, it is interesting to note that *The Parliament of Victoria Inquiry into End of Life Choices*, made **forty-nine (49) recommendations** toward the adequate care of those approaching the end of their lives. The recommendations included addressing societal stressors, resource and health system issues, the greater need for Palliative Care provision and respite, as well as inadequacies around support of vulnerable individuals and their families/carers. **We find it incongruous that is in this State the last of the recommendations was being addressed first**. Until the other 48 recommendations are addressed adequately, those seeking euthanasia or physician assisted suicide, may actually be so because they may feel they have limited or **no other choice** presented to them. Presenting legislation for euthanasia and physician assisted suicide as one of choice also misleads the public and those who govern around the role of healthcare

for the dying and the social agendas needing to be addressed to provide appropriate dignified care.

27. If you are a health practitioner, what are your views on having a scheme in Queensland to allow VAD?

As outlined above, we oppose the introduction of VAD in Queensland. If laws allowing EPAS were to be approved, we strongly suggest that it have nothing to do with the practice of medicine. This is not a novel idea. Euthanasia is practised in Switzerland by non-physicians. Capital punishment, a process similar to euthanasia, is practised in USA by non-physicians. This will allow the practice of killing patients to be separated from medical practice, which since ancient times has contained ethical prohibitions against harming patients, and for which doctors are not trained. The government could set up clinics with staff trained to assess clients and hand out drugs without the complication of involving the medical fraternity.

Particularly in view of the fact that laws for EPAS are being promoted as a right to autonomy, or the right to decide the timing and manner of one's death, it is recommended that medical practitioners be separated from EPAS. Individual doctors would of course be eligible to train as VAD practitioners if they wish, but not within the framework of healthcare.

Safety issues are still paramount even in these settings, especially in terms of coercion, depression, agendas involved in decision making and provision of best practice care.

28. If there is to be a VAD scheme, what features should it have?

As outlined above, we oppose the introduction of VAD in Queensland and do not believe it is possible to construct legislation which would adequately protect our patients. If VAD is legalised it should be separated from healthcare and not involve doctors. Please refer to the recommended recently published paper for the International Association of Hospice and Palliative Care, written by Professor Roger Woodruff, oncologist and palliative physician, Victoria, for this most up-to-date, expert, authoritative and comprehensive review on this exact topic area: <https://hospicecare.com/policy-and-ethics/ethical-issues/essays-and-articles-on-ethics-in-palliative-care/euthanasia-and-physician-assisted-suicide-are-they-clinically-necessary/> No system will have features able to mitigate risk. Safeguards are only an illusion of such, as evidence has proven time and again.

29. Are there aspects of VAD schemes in other jurisdictions that should, or should not, form part of any potential VAD scheme for Queensland, and why?

It is the experience in other jurisdictions, as outlined above, that make us believe that it is not possible to construct legislation which would adequately protect our patients. If VAD is

legalised it should be separated from healthcare and not involve doctors. We have given references and links and outlined this in other sections of our submission. See above.

30. Who should be eligible to access VAD and who should be excluded?

See rationale and arguments and rationale presented in other sections.

31. Should the scheme be limited to those aged 18 and over? If so, why? If not, why not?

As outlined above, we oppose the introduction of VAD in Queensland and do not believe it is possible to construct legislation which would adequately protect our patients. In particular we do not believe that adolescents cannot have the experience to develop the breadth of intellectual, psychosocial and spiritual development required to deal with the existential questions from life to which suffering and dying belong. There is a large variability in the development between individuals. There are no standard routes to develop from child to adult and there is no fixed developmental speed, and there are also male and female differences in this. The minimal developmental levels reflecting full capacity to judge the situation and the full weight of the request for, and consequences of, euthanasia are rarely if ever reached during the teenage years. Further, we know from adolescent and young adult psychology studies action in this group may be driven by peer influence and impulse. The qualities provide great concerns in the face of legislation even for those up to the age of 25.

Furthermore, it is evident that the influence from those surrounding children and adolescents is strong and cannot be neglected. When faced with difficult medical decisions, minors will inevitably be dependent on the strong and evident authority of their parents, thereby diminishing their own autonomy in the decision-making process. Influence can exist through unspoken signals of pain and distress. Minors will try to take responsibility and look for methods to alleviate the suffering in his surroundings for which he is the cause. The opportunity to request euthanasia may be perceived by a minor in this situation as a chance, or even an obligation, to relieve this suffering. It is impossible to assess these influences in an objective way and to weight them at the time when a minor requests euthanasia.(22)

This group is also particularly vulnerable to suicide from mental illness, and particularly so in regional and indigenous populations, and in particular so in men. Again psychological and mental health strategies, and earlier detection and management of illnesses and their psychosocial context are what need to be addressed here.

32. Under what circumstances should a person be eligible to access VAD? Could it be for example, but not limited to, the diagnosis of a terminal illness, pain and suffering that a person considers unbearable or another reason?

As outlined above, we oppose the introduction of VAD in Queensland and do not believe it is possible to construct legislation that would adequately protect our patients. International experience proves that safeguards do not prevent scope-creep, suicidal practices or abuses. We have grave concerns around re-defining criminal law, the definition of suffering, safe

guard provision and postulated regulation. Overseas experience has demonstrated repeatedly that original changes to the law have been gradually extended or changed, that regulation and reporting is often inadequate, and that definitions of concepts including “suffering”, are so arbitrary, that there can be no significant evidence to demonstrate that safe-guards would work or be able to be used without bias. Specific concerns include the issues of extension of legal re-definition of what activity is decriminalised, consent, medical practice and process complexities. As such practices represent a seismic shift in how a society views individual lives, the potential harms and impacts to patients, carers/families and clinicians are also great.

Resultant will be the extension of injustices and how our society views what life is worth living. In the 2016 New Zealand Parliamentary Commission into legislative introduction in that country, **Simon O’Connor**, the Chairman of the Health Select Committee reported, *“It is very difficult to see how there could be sufficient safeguards to actually protect vulnerable people in New Zealand. And that’s been the experience overseas as well, it probably comes down to the simple question of ‘how many errors would Parliament be willing to accept in this space?’”*

33. What features should be included in a process to allow a person to legally access VAD?

As outlined above, we oppose the introduction of VAD in Queensland and do not believe it is possible to construct legislation which would adequately protect our patients.

34. What safeguards would be required to protect vulnerable people from being coerced into accessing such a scheme, and why?

We believe it is the obligation of government to protect its most vulnerable citizens. As outlined above, we oppose the introduction of VAD in Queensland because we do not believe it is possible to construct legislation that would adequately protect our patients. Please see arguments above, and the comments of the Chairman of the New Zealand Health Select Committee above.

35. Should people be provided access to counselling services if they are considering VAD? If so, should such counselling be compulsory? Why?

As outlined above, we oppose the introduction of VAD in Queensland and do not believe it is possible to construct legislation that would adequately protect our patients. These patients should instead be referred to best practice referral pathways and appropriate healthcare professionals able to assist and accompany them in their care.

36. How could a VAD scheme be designed to minimise the suffering and distress of a person and their loved ones?

Palliative care, appropriate care and service provision for the elderly, those with disabilities and earlier detection and support of those with depression and marginalised social needs, and assistance for carers, **not VAD**, are the best way to minimise the suffering and distress

of our citizens. In the context of VAD laws, considering such legislation as a way of relieving the suffering and distress of loved ones suggests the needs of family and not the patient may be considered as justification of use of such a law (as it is in some forms of euthanasia legislation in The Netherlands) and is to be deplored.

From **Michael Ferguson**, the Tasmanian Health Minister, on the 23rd of May 2017, *"I ask those promoting this bill to be truly frank and honest in their descriptions, and for those listening to the debate today, if or when you hear those euphemisms, you need to remind yourself that the real words, however distasteful they are, are mercy killing and assisted suicide by a doctor..... Such a bill lacks adequate safeguards.....A prime responsibility of a parliament is to pass laws that are for the good of the common people. When considered from a social perspective the parliament creates laws to protect the vulnerable people in our society. I wish a parliament could end suffering for anyone, for everyone, by passing a law. That is a fantasy, an impossible and false hope, albeit a compassionate aspiration, but a totally tragic building of false hope."*

37. Should medical practitioners be allowed to hold a conscientious objection against VAD ? If so, why? If not, why not?

If VAD is legalised it should be separated from healthcare and not involve doctors. Medicine is an inescapably ethical practice and patients do not have the right to overrule the autonomy of the medical practitioner to act in accordance to their own beliefs or professional and expert understanding of best practice medicine. It is not in the interests of Queensland society to have medical practitioners who are comfortable to treat their patients in ways they personally believe are wrong. It is also an abnormal situation to expect a doctor who provides or understands what constitutes best evidenced practice for such patients, to have to conscientiously object to not refer for euthanasia and assisted-suicide practices, which have no good evidence in safety, where there cannot exist adequate oversight of coercion, and where there is gross under-reporting of complications, as well as unaddressed needs.

For those with a greater professional and ethical understanding of what is being presented here, it is an absurdity to expect someone to refer or counsel their patient toward such a dangerous and inadequate poor substitute social practice, in the name of "autonomy". Respect of autonomy is one of the four moral principles in healthcare and medicine, and needs to be balanced against the others (beneficence, non-maleficence & justice) in relation the effects of the autonomous action and not be positioned above common welfare. Assertion of one's autonomy in itself is not a basis for a healthcare intervention, especially in the face of a socio-legal agenda, not due to the failure of health care or medicine.

38.If practitioners hold a conscientious objection to VAD, should they be legally required to refer a patient to a practitioner that they know does not hold a conscientious objection or to a service provider that offer such a service? If so, why? If not, why not?

If VAD is legalised it should be separated from healthcare and not involve doctors.

Some of our members would construe referral of a patient for VAD as being complicit in facilitating VAD and therefore against their conscience. We do not believe that the patient has a right to force a medical practitioner to act against their conscience. Furthermore, it is not in the interests of the Queensland public to encourage medical practitioners to act against their conscience when it comes to patient care. The Medical Board of Australia recognises the right of medical practitioners to decline to personally provide or participate in care to which they morally object (Good Medical Practice 2.4.7).(24)

Further, such laws or change to code of conduct would create a further silencing of legitimate debate around the controversial topic area in society in medicine, and pose a further risk to the vulnerable in our society. It should be noted that over 30 jurisdictions around the world have rescinded or rejected proposed legalisation within the last 4 years, and that such practices are only actually legal in a very small number of jurisdictions. Of importance it should be noted in the last month a major Bill in Mexico expected to be introduced was defeated due to the legitimate arguments of those disabilities groups and psychiatrists around safety concerns, mental health issues and the effect of public perception of what life may be then be considered worth living.

Our question to the Queensland Government is; Why would the Queensland Government want such a controversial and inherently unsafe legislation to exist for its citizens, and then even consider coercion of doctors and healthcare to accept it with absolute co-operation at this time, and in the process deviate attention away from what is truly required and evidenced to be so for its citizens' in need, instead?

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Mr Bob Nelson, B Social Science MA, Psychologist, NSW
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Dr Rachel Chalmers, MBBS FRACP, Nephrologist, NSW
Dr Melissa Lee, B Dental Surgery, Dental Practitioner, NSW
Ms Joan Lane, RN, Nurse, NSW
Dr Andrie Tanuwidjaja, B Dental Surgery, Dental Practitioner, NSW
Dr Kristy Choi, B Dental Surgery, Dentist, NSW
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Dr Catherine Faehrmann, MBBS FRANZCP, Medical Practitioner, NSW
Ms Stephanie Herrenberg, Registered Nurse, Nurse, NSW
Ms Evelyn Bernado, Hospital Scientist, Scientist, NSW
Dr Ann Tokura, MBBS, General Practitioner, NSW
Dr Catherine Lennon, MBBS FRACGP IBCLC, General Practitioner, NSW
Ms Elizabeth McCarthy, Registered Nurse, Nurse, NSW
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Ms Katherine Higgins, Registered Nurse, Clinical Nurse Educator, NSW

Mr Paul Donkin, Chemist, Chemist, NSW
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Ms Deirdre Hulton, Registered Nurse, Nurse, NSW
Dr Roberta Leary, MBBS Hons, Medical Practitioner, NSW
Ms Lillian Augoustinos, Bachelor of Social Work, Social Worker, NSW
Ms Judith Sultana, Registered Nurse, Nurse, NSW
Ms Ruth Stoodley, Exercise Physiologist, Physiologist, NSW
Ms Bev Littlefair, Registered Nurse, Nurse, NSW
Ms Julie Dulay, Registered Nurse, Nurse, NSW
Ms Mary Manan, Registered Nurse, Nurse, NSW
Ms Jehan Manan, Assistant in Nursing, Nurse, NSW
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Dr Myra Tan, MD, Medical Practitioner, NSW
Ms Teresa Thompson,, Physiotherapist, NSW
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Dr Marguerite Harb, MBBS, Medical Practitioner, NSW
Dr Anthony Zandes, MBBS, Intern Doctor, NSW
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Mr Michael Mchugh, Registered Nurse, Nurse, NSW
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Ms Tania Sequeira, RN, Nurse, NSW
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