



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Secretary, Select Committee on End of Life Choices in the ACT
Legislative Assembly for the ACT
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Dear Chairperson and members of the Select Committee,

Thank you for the allowing me to make a submission on the important and challenging topic of end of life choices, and please accept my humble apologies for missing the original submission date.

I have sought to make a representation of my views, informed by my personal values as a Canberran, as well as my professional experience as an emergency medicine doctor, serving Canberrans daily on the frontline of the public healthcare system here in the ACT. As someone confronted by death on a regular basis and who strives to compassionately help patients and their families navigate the challenges of life-threatening and life-limiting illnesses, I believe I am well placed to reflect on how we as healthcare personnel support the ill and dying and how the status quo might be served or impaired by certain courses of action.

I am motivated to write in light of the fact that any proposed changes to legislation governing the care of dying people has the potential to have significant impacts on the practice of medicine, and the character of the doctor-patient relationship in the ACT. I write to advocate for my patients, my craft and my colleagues in the healthcare system in the ACT, and to ultimately to convey my opposition to any moves towards the legalisation of euthanasia or physician-assisted suicide in the ACT as deleterious to the wellbeing of our patients by failing to affirm life with all its potentialities, even up to natural death.

Community attitudes coloured by alienation from death and dying

Death is an inevitability of the human condition. However, modern Australians are by and large unfamiliar and uncomfortable with direct encounters with the dead and dying. As longevity has increased through socio-medical advancement, as familial ties have become most fractured and, as health and death has become more “medicalised” and the preserve of hospitals and hospices, directly witnessing and being involved in the care of the dying is an alien experience for most Australians. Fear of the unknown and particularly fear of the loss of independence and autonomy as one’s physical and mental faculties fail, gives rise to distrust of the process of dying. Alienation from being with and witnessing first hand the process of dying as it unfolds for family or friends, and a multitude of dramatic and extreme portrayals of death in media and entertainment, means that many people in the community conflate death with suffering. Many people would sooner conjure images of dramatic hospital scenes and sudden deaths than a slow dignified march towards a long awaited and well prepared for death in the company of loved ones, with ones worldly matters and concerns finalised.

As an emergency doctor I know all too well that some deaths are bound to occur with little warning and in circumstances that are bound to cause suffering and distress for the person dying and those who love them. But I also know that most deaths occur in the context of a long decline in the face of a chronic life-limiting illness or natural withering of age, and that many Canberrans in this position are not simply suffering but in fact “living through the process of death” or “living with dying” and are supported to the best of our ability by dedicated doctors and other healthcare professionals as well as family and friends. Allow me to paint a picture that I feel fits more with these circumstances than the popular trope of a long suffering patient with unmanaged physical symptoms and overwhelming desire to end their suffering actively.

“Living with dying”: how Canberrans exercise choice in their end of life care

Many patients I come across are “living with dying” over an extensive period usually characterised by a slow decline in independence coupled with some symptoms. The average age at time of death in Australia, commonly known as the “life expectancy” is 82.4 years according to 2014 data. By this vintage many Australians have collected a few chronic diseases, most commonly cardiovascular, cerebrovascular or malignant conditions together with some degree of physical and cognitive impairment, and are in a phase of preparedness or at least expectation that the inevitable end to their long journey through life may be nigh. Looking at the top 20 leading causes of death in Australia, all are cancers or chronic conditions associated with a decline typically over at least months if not years, other than respiratory infections (11th most common cause at 1.9%), suicide (12th giving rise to 1.9% of deaths), falls (15th, 1.5%) and cardiac arrhythmias (17th, 1.4%) which are less predictable.

While every patient journey is unique, many of the common chronic illnesses, cancers and to a lesser extent dementia, have predictable natural histories or clinical courses - that is - doctors can foreshadow what are likely to be the constellation of symptoms and complications that characterise a disease as it progresses and as a patient approaches their death with that disease. Cognisant of these, it is incumbent upon the doctors caring for these people to introduce such concepts in a timely manner that allows patients and their families to recognise the process of dying, and exercise choice about their care including when to decline active care and focus primarily on symptoms relief and the alleviation of suffering.

For a variety of reasons, at the time of diagnosis often doctors fail to be frank and fearless about this side of the story of our care: patient decline and death. Many of us probably see it as an admission of our own fallibility and the limitations of our craft at a time when we think patients only want positive results, hopeful messages and to focus on healing. In rapidly progressive diseases such as neurodegenerative disorders or advanced cancers, doctors are perhaps more likely to be realistic about circumspect goals and may include palliative care concepts or specialist referral early in the treatment of these problems, but for other slower conditions like heart disease, COPD, strokes and dementia, this may not happen until years have elapsed and death seems more imminent.

In the final stages of their lives, older people, those with cancer and other chronic life-limiting conditions find themselves encountering doctors more frequently, either by nature of GP and hospital presentations for acute illnesses, or intensified need for chronic disease management or oncological care as diseases progress. It is often in this phase of increasing illness that most doctors start to broach the concept of palliative care.

I feel that this is the point at which most people start to exercise their end of life choices. It is incumbent on the clinician to recognise that their patient is declining as part of what will ultimately be a life-limiting condition, and in so doing granting patients the opportunity to make known their wishes on a variety of subjects, their so called “goals of care.” This can be made known in documents such as an “Advanced Care Directive” that establishes not only Resuscitation Orders and limitations to interventions offered during acute illnesses, but also objectives around death including patient preferences about when to withdraw active treatment, preferred location for end of life care and final days, cultural and spiritual requirements and goals surrounding death and dying including “bucket lists” and the like. It is a useful exercise and under-utilised at present although uptake is increasing. This allows doctors like me to understand a patient and their families premeditated wishes around death, particularly those of us caring for people during acute illnesses where patients might not be able to advocate for themselves. In much the same way that modern mothers, as consumers of the healthcare system prepare a “birth plan” of their preferences around labour and birth, I hope that one day advanced care directives and establishing wishes for care leading up to death will be just as common and accepted.

Once a doctor has broken open the subject of decline and demise, and particularly the nature of the symptoms that a patient is or will experience as part of that, they can discuss the medical management of these symptoms and/or the withdrawal of other active managements such as chemotherapy or surgery which by their side effects or other mechanisms may contribute to suffering, or no longer remain a priority. This withdrawal of certain active treatments and a reorientation of care towards primarily controlling physical symptoms is what constitutes the beginning of a “palliative phase” of care for most people and clinicians.

I am of the opinion that, for want of appearing negative, too many doctors are failing to introduce palliative care early on as a concept in the management of chronic, life-limiting diseases, and only preserving it as an explanation of that care which is provided to someone facing imminent, inevitable death when other measures are futile. It need not happen when death is imminent but rather ought to be an option which patients can exercise at any point of their choosing once the diagnosis of a life-limiting condition is known.

Physical symptom management leading up to death is the most commonly understood aspect of palliative care, but often happens in the unwittingly in the process of chronic disease care conducted by many different medical professionals. Where symptom control is complicated or constitutes the sole focus of an episode of inpatient care in hospital or care in the community it is often overseen by medical specialists in palliative care. What is less spoken of but equally, if not more important in the face of slow decline, is the psychological, emotional and spiritual care of people as they reconcile with their own mortality and are forced to face much uncertainty. It is this holistic approach to care that patients need as they “live with dying” and that is also part of the care provided by dedicated palliative care services here in the ACT. Not everyone who is dying necessarily needs palliative care by specialist physicians, but everyone dying progressively ought to have palliative care of one form or another to transition them into hopefully a peaceful death, as much as possible in circumstances of their choosing or which were entered into with some preparedness and acceptance. I am happy to say that in my career as a junior doctor and even today in emergency medicine I have often provided palliative care, not always to those who are imminently dying, but always with compassion and always in a patient-centred focus.

Palliative care in the ACT: access block and gaps in continuity of care

It is the business of every doctor in the ACT to provide palliative care in one form or another, and it is consistent with the best traditions of our craft. I feel it is best captured by this aphorism from Dr E. Livingston Trudeau when he said that in medicine we are called to “To cure sometimes, to relieve often, to comfort always.” For our part, doctors need to be more mindful of giving our patients and their families the facts about their illness and inevitable death, and opportunities to exercise their autonomy with respect to accepting or declining active care, transitioning to a palliative phase focusing on symptom control, and establishing their desires around the circumstances of their death.

From a systems perspective as a doctor at the threshold between the community and the hospital, I find that there are many patients coming to hospital from the community having had inadequate palliative care provision in the community owing to:

- Difficulty making appointments with their GPs or attending due to immobility/illness
- GPs who feel ill prepared to unilaterally provide complex palliative care or advanced symptom relief in the community thus requiring palliation to occur in hospital
- Delays once referred for patients to be seen by specialist palliative care services for home based care due to small size of the service
- Waiting lists for Clare Holland house due to lack of beds or physicians to care for patients

Addressing these gaps through funding GP education, more dedicated palliative care inpatient beds, and creating a much larger and more robust home-based palliative care service will improve the availability of quality palliative care for Canberrans, increase the visibility of palliative care both within the healthcare system and broader society and allow more people to “live with dying” and ultimately die with dignified, individualised care.

Physician assisted suicide and the medical practitioner

In the final week of my studies as a doctor, I undertook an oath known as the Declaration of Geneva which is the modern revision of the Hippocratic Oath. The opening line of this states: “I solemnly pledge to consecrate my life to the service of humanity.” It goes on to say, “I will maintain the utmost respect for human life.” To my reckoning the prospect of undertaking any measure that ends the life of a patient, even at their request, will never be the purview of a medical doctor, and runs contrary to our responsibility to respect human life.

There is no denying that people who advocate for euthanasia care deeply about vulnerable, dying people. But as I’ve stated above, many people in our society fear death and dying because of fear of the unknown, fear of physical and existential suffering, fear of losing independence, fear of being burdensome to care givers. To quote the President of the Australian Medical Association Michael Gannon, to legalise euthanasia would “be a victory for fear over hope, and would in no way enhance the provision of quality end-of-life care.” I feel that doing everything we can as a society, a polity and a government to enable all people to understand death and to face it with dignity, courage, support and good care would see a serious shift away from the current levels of support shown in surveys about euthanasia. More importantly it would see a serious shift away from fear around the topic of death to a more nuanced appreciation of it as an inevitable period of life as rich in opportunities for growth, for love, for sharing moments and resolving anxieties and conflicts as any other part of life.

To legalise euthanasia would reinforce the idea that exists in some quarters of society that human life is dispensable when inconvenient or uncomfortable. As stated above, when most of the people who are “living with dying” are older and dying slowly of chronic diseases, legalising euthanasia will see our aged population at risk of being (further) dehumanised, their experiences devalued in light of their disabilities and imminent death. In a new society where life is discardable and certain forms of death are optional, labelling some deaths and preceding circumstances as more preferable than others will lead to situations where these value judgements are applied, uninvited, to the lives of others. In some jurisdictions where euthanasia has been legalised, it has been extended to those with dementia, a condition of chronic cognitive impairment, and to children, both situations wherein a person could not be exercising autonomy when they lack competency but instead have those decisions made on their behalf. This flies in the face of that much vaunted value underpinning the euthanasia movement: exercise of autonomy and control. I sincerely hope any proposed legislation surrounding euthanasia will protect these vulnerable groups by making them ineligible for legal euthanasia.

Should I ever be called upon as a doctor to administer euthanasia it will be my intention to decline to do so as contrary to my convictions for the reasons stated above, and I hope that any drafted legislation will protect me in that exercise of my autonomy and free will. Furthermore I hope any legislation will not compel me to be a party to physician assisted suicide through obligatory referral to euthanasia providers, and will protect me in my exercise of free speech to counsel my patients against such a course of action.

My conviction is that even at its weakest, most difficult and in its final moments, human lives and human deaths have incredible potential to demonstrate resilience and courage, to inspire hope, to experience and show love, to teach and to allow people to grow. It is for this reason that I have dedicated my career and indeed consecrated my life to the service of humanity through medicine, such that in saving or prolonging lives I might enable those in my care and those around them to enjoy more such moments, and ultimately enjoy a dignified death for which they and loved ones have had an opportunity to prepare. I believe that euthanasia as a system and a means to cut short a human life, albeit with a stated aim of alleviating suffering, ultimately devalues some other lives and other forms of death in the process.

My hope is that more could be done in the ACT to affirm lives of our midst which are lived in the face of chronic disease and death, and to dispel fears about dying and instead embrace the process of dying as a period rich in experiences. My hope is that by investing much needed resources into palliative care, the ACT Government would go a long way to improving the care and experiences of those “living with dying” and those around them as they approach an inevitable demise which we all must face one day. My hope is that we can create such a death-positive society that euthanasia is not contemplated, because of the quality of life we achieve for people as they approach the end of the journey.

Sincerely yours,

Dr Matt Bray MBBS

Emergency Medicine Registrar