

Submission to parliamentary
committee:

Joint select committee on end of life
choices – Western Australia

by

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I am a Palliative Care Specialist practising exclusively in the area of palliative medicine in Western Australian hospitals. I am fully accredited and medical board certified. The following submission represents my personal opinions, comments and reflections, gathered over more than 15 years of clinical practice. I am not representing the views of any organisation or professional body with whom I am affiliated.

My career, my vocation is dedicated to the medical care of people at the end stage of their lives.

Terms of Reference:

a) Assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illness:

What does a Palliative Care doctor do?

The doctors who specialise in end of life care are called *Palliative Care Physicians*. Palliative Care is a relatively recent development in medical care (1960's). Most people know very little about palliative care and most doctors misunderstand the role of palliative care. This is a crucial point.

In order for patients to see a palliative care specialist, a referral is required from another doctor (eg: their GP, oncologist, neurologist). There are two systemic shortcomings here. The first is supply of Palliative Medicine Physicians. The second is referral practices to palliative care.

There is inequality in palliative care provision in the nation and in WA. Palliative Care Australia recommends an ideal ratio of 1 full-time palliative care physician to every 100,000 of population. In WA, 2016 census (www.abs.gov.au) reports a population of 2.47 Million. Perth has a population of 1.9 Million and we only have around 12 full-time Palliative Medicine Specialists (but we need 19). These statistics do not take rural and regional areas or the aging population into account. Some country areas (Wheat-belt and Mid-west) will have no palliative care physician by next year due to retirement. Other rural and regional areas will continue to have less than once a month visits due to funding shortfalls. Even Fremantle, Bentley, Armadale, Peel and Joondalup Health Campuses do not have on-site Palliative Medicine Specialists.

Most people have never heard of palliative care, and most doctors think palliative care doctors only get involved with patients when they are about to die (1-2 weeks). Therefore, referrals to palliative care specialists do not occur early or often enough. Yet, palliative care specialists are experts in caring for people with chronic/incurable illness who are suffering. In Rosenwax et al's paper (Palliative Medicine 2006; 20: 439-445) looking at access to specialist palliative care in WA, only 68% of cancer patients and 8% of non-cancer patients (eg dementia, heart, lung, kidney failure) in their final 12 months of life saw a palliative care specialist.

In my practice, we are the most capable of all doctors to care for patients in their last months of life. Furthermore, we are the most qualified to talk about prognosis and realistic expectations in these final months.

Patient-centred care:

Research evidence on healthcare communication states emphatically that doctors do not communicate well. This includes communication about:

1. Prognosis

2. Treatment options including palliative care (doctors often do not mention treatment that *they themselves don't* provide but another specialist might – ie they only offer treatment they provide)
3. Effect of treatment on Quality of life

Therefore, many patients with chronic/incurable disease receive a lot of medical treatment believing that they will “get better”. This is often not the case. They might live longer (life prolongation) but often have poor quality of life.

Patient-centred care has been talked about in medicine for decades but doctors still do not know how to put this into routine practice. In the August 2017 editorial printed in the high impact, peer-reviewed, medical journal JAMA, the author discusses the use of evidence-based tools to improve patient decision making around treatment (JAMA. 2017;318(7):617-618. doi:10.1001/jama.2017.10168).

We are a long way from achieving the goal of effective patient-centred care. When was the last time a doctor asked you about your lifestyle, quality of life, hopes, priorities and expectations before offering medications or surgery for your medical problem?

Only when we can communicate clearly, honestly and accurately about treatment choices can we truly help patients to make the right choices and avoid unnecessary overtreatment that prolongs suffering. Only when all patients have access and receive the best medical/surgical care appropriate to them as individuals, can we consider that we have tried our best. Only at this stage, can we consider euthanasia or physician assisted suicide as an option.

We urgently need to prioritise communication skills training for doctors in shared-decision making and change health system accreditation processes and procedures to mandate excellence in delivery of patient-centred care.

b) Review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas Jurisdictions

I do NOT believe that changes are necessary to the current framework of legislation in Western Australia for people who approach the end of life as a consequence of medical illness.

The Acts Amendment (Consent to Medical Treatment) Act 2008, Part 4

This refers to the amended Criminal Code. This protects the medical practitioner from criminal prosecution in the event of withholding or withdrawing medical or surgical treatments which are considered futile. This does not constitute an act of euthanasia or physician assisted suicide. In practice, these amendments have given medical practitioners the confidence to act in accordance with patient wishes regarding *treatment limits*. The importance of this must be emphasised.

Medical practitioners are obsessed with curing disease and correcting pathological conditions. In the context of acute and curable disease, society should feel safe and confident that one will receive the best and most appropriate treatments to enable a swift return to their normal (or in medical terms “baseline”) health and function. However, in the context of chronic and incurable disease (eg. most solid organ cancers, chronic heart, lung, liver, and kidney diseases, dementia) the health system and clinicians struggle to cope. The paradigm of “curing and fixing” cannot be applied here as cure is impossible. However, it is common to see doctors trying to apply to same paradigm of acute/curable disease to chronic/incurable disease. The result is life prolongation. In many cases, patients with chronic/incurable disease, will welcome life prolongation. However, patients in their final months of life may consider life prolongation very burdensome. For example, a patient with heart disease who is in the final 12 months of their life will have several admissions to emergency departments and hospital wards for treatment of breathlessness.

Using heart failure as an example, the current medical paradigm for treatment of heart failure is “fluid restriction” and aggressive diuretic therapy. Initially, patients with improve and return to their “baseline” health. However, as the heart continues to fail,

they will not be able to return to baseline health and become increasingly disabled by fatigue and breathlessness. Finally, they will be completely confined to a chair or bed. Most patients will experience several cycles of breathlessness – admission to hospital for aggressive treatment – discharge home – breathlessness, admission to hospital etc. This will occur until patients spend prolonged periods in hospital and minimal time at home. This is often the trigger for doctors to consider palliative care – often because they cannot get these patients “out of hospital” (and public hospital bed pressures rise). Sadly, doctors are often so entrenched in the paradigm of “fixing” pathology that they are unwittingly committing patients (and their families) to prolonged physical and emotional suffering.

As doctors, there is increasing awareness that the paradigm of treating chronic/incurable disease requires a different approach. Medical treatments that prolong life without gains to quality of life will eventually be inappropriate in all patients with chronic/incurable disease and the correct treatment will be the provision of palliative care/comfort care. The amendments to *The Criminal Code* will allow doctors to practise in the most appropriate way without fear of criminal prosecution.

The Acts Amendment (Consent to Medical Treatment) Act 2008, Part 2

This refers to the amended Guardianship and Administration Act 1990. This introduced into the Western Australian legal framework useful changes to medical decision making in the context of cognitive impairment due to illness. Provisions such as the “Advance Health Directive” and “Enduring Power of Guardianship” significantly adds clarity to the process of health decision making as people with chronic/incurable diseases approach the end of life. As discussed in the previous paragraphs, patients with chronic/incurable disease will experience deteriorating function and quality of life as the disease progresses. This is inevitable. The amendments to the Guardianship and Administration Act 1990 enable patients and their elected health advocates to make treatment decisions that must be respected by health practitioners. Ideally, these documented treatment decisions will be exercised when patients or their advocates consider life prolonging medical treatments (for example, this includes antibiotics, dialysis, artificial feeding (tube or drip), artificial ventilation, CPR, surgery) are no longer wanted. Patients should find this extremely empowering.

Patients and their family should feel confident that doctors will always cure disease when they can, prolong life when cure is not achievable, and provide comfort when life prolonging treatment is no longer wanted. The current framework of legislation provides adequately for this. For a minority of people (In Netherlands, euthanasia accounts for less than 3.6% of all deaths) who believe that immediate death is the only option for them, we need to be focussing on our healthcare systems and improving delivery of compassionate and effective health care.

I do NOT support new legislation to introduce euthanasia or physician assisted suicide (also known as “medical assistance in dying”). The effect of such legislation will be societal confusion and erosion of confidence in doctors. Doctors should not be given legal permission to kill their patients. I acknowledge and support position statements on euthanasia and physician assisted suicide published by:

Australian and New Zealand Society of Palliative Medicine

(<http://www.anzspm.org.au/c/anzspm?a=sendfile&ft=p&fid=1491523669&sid=>)

Palliative Care Australia (<http://palliativecare.org.au/download/2448/>)

c) Consider what type of legislative change may be required, including an examination of federal laws that may impact such legislation

No legislative changes to include euthanasia or assisted suicide are required

d) Examine the role of Advanced Health Directives (AHD) Enduring Power of Authority (EPA) Enduring Power of Guardianship (EPG) laws and the implication for individuals covered by these instruments in any proposed legislation

Applied appropriately, advanced health directive's and current legal frameworks around guardianship will enable patients with chronic/incurable disease to exercise their preferences for or against medical treatment that will prolong life, but bring poor quality of life.

In my professional treatment of patients receiving care in the last few months of life, it is apparent that many patients are ill-informed of important issues such as prognosis or medical treatment options available to them. Most patients receive the default medical or surgical treatment that temporarily corrects the immediate medical problem but does not change their deteriorating quality of life. This results in excessive exposure to medical and surgical intervention. For patients such as these, the correct medical management should focus on treatment options that improve quality-of-life and reduce suffering. This should be the option clearly offered to patients so that they may choose the most appropriate option.

Advanced health directive's and nominated health advocates (through Guardianship legislation) should further identify patients who desire comfort and palliative care rather than life-prolonging therapy when they present to doctors in emergency departments.

By this mechanism, the current legal frameworks uphold patient choice and autonomy without unnecessary compromise to "at risk" groups (including the social minorities, disabled, minors and the frail elderly) associated with the proposed euthanasia and assisted suicide legislation.

Improvements to communication systems and processes should be considered a priority in any proposed legislative framework changes. A registry that allows health practitioners to easily access individuals' advanced health directive's will certainly improve appropriate delivery of care for patients wishing to limit unwanted medical or

surgical intervention.