



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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Committee Secretary
Committee on End of Life Choices
ACT Legislative Assembly
GPO Box 1020, Canberra 2600

Manuka 2603

Dear EOLC Committee Secretary,

Re: Euthanasia and Assisted Suicide

Having been a medical practitioner since 1976, and working in Anaesthesia since 1978, and also in Intensive Care since 1984 (being a Fellow of the ANZ College of Anaesthetists and of the College of Intensive Care Medicine), and having practised in Canberra since 1991, I wish to make a submission to your Committee opposing euthanasia and assisted suicide.

While I realise certain forms of suffering may not be able to be relieved by medicine, suffering of an existential kind for example, much can be done to improve the quality of life of those who are terminally ill through accessing good Palliative Care. Accompanying a person towards their death in a sensitive and compassionate way is a skill that takes time to develop, and is a labour-intensive exercise, but one which is rewarded, in those who take on this work, by the peace that usually comes to the patient and their family as a result.

Facing death requires courage and acceptance. Old age, even if not afflicted with any specific disease, is frequently associated with declining physical and perhaps mental abilities which can increase the burden a person may present to family and friends, to society and to themselves.

While it might be thought that granting specific patients of sound mind, nearing the end of life, the ability to end their lives without any risk of legal sanction is a reasonable, practical, desirable and compassionate thing to do, there are potentially many negative social consequences that may result from taking such a step.

It may be possible for those not responsible for administering the drugs used to achieve this outcome to distance themselves both from the result, and from the decision to move in this direction, and indeed, to advocate this course in a committed way. It may not be so easy for the medical practitioner involved in prescribing and administering the drugs used for euthanasia to distance themselves from this responsibility. While some of my medical colleagues have a 'crusading' approach to this topic, believing they have a duty to minimise the duration of problematic suffering by ending the patient's life expeditiously, many members of the medical profession are opposed to euthanasia (50% against, 38% for, 12% undecided in a detailed AMA survey of members in published in 2016).

Having seen many patients die over my working life, some in the operating theatre, some in Intensive Care, and in hospital wards, having experienced the deaths of near relatives, friends and colleagues, some of which have occurred at home, and having had a close in-law take their own life at my then Sydney home many years ago, I can confidently say that the deaths that caused the greatest distress to families were those involving suicide. I also know of cases in Intensive Care where patients expressed a wish to die while sick, but recovered well subsequently, and were later glad to be still alive! And I know of cases in Intensive Care where some ICU specialists advocated ceasing treatment, (other specialists wishing to persevere), only to find the patient returned to good health. (Prognosis - particularly a bleak view of prognosis - can be in the eye of the beholder!)

Having said this, however, it may be worth observing that, at times, patients, their families and their doctors may be overly ambitious in what they believe medicine can achieve. Where a proposed regime of treatment appears to have a very low chance of success, when the patient is already afflicted with serious illness, and the treatment seems fraught with serious complications, it is not inappropriate to elect to forego these treatments and choose supportive care only, realising that though death may be the result, the patient's remaining life will probably be less burdensome and more peaceful than if alternate courses were pursued.

Most pain can be fairly well managed without resort to drugs which in kind and dosage seriously disturb mentation, (though in extreme circumstances, these may be necessary for adequate pain relief). Some distressing illnesses, eg those associated with degenerative neurological diseases, Alzheimer's disease for example, are not so easy to treat or prevent (at present). However, a compassionate accompaniment of the patient and their family, with sufficient relief of skilled staff to prevent carer stress, does much to alleviate even these disturbing circumstances.

The previous mention of suicide also raises a problematic issue: Given that much effort in the area of mental health is targeted at suicide prevention, where does the boundary between 'acceptable' and 'unacceptable' suicide lie? Is it up to the patient to decide? If so, where would a patient's 'rational' and 'voluntary' choice of suicide sit, (assuming the patient genuinely believed that life itself caused them 'unendurable' suffering), if new legislation were to permit assisted suicide when expectancy was less than 12 months? Is 'intractable depression' an example of a terminal illness?

Prognostications about life expectancy can be very pliable - many patients admitted to Intensive Care have less than twelve months to live (maybe less than days to live) without treatment, and numbers have less than twelve months to live with it, yet might still make a quality recovery, (and be appreciative of it), after a short sojourn in ICU.

Illness itself is often associated with a feeling of being the passive recipient not only of the disease, but of all that goes with its diagnosis and treatment (or its neglect). The patient does genuinely suffer in many ways. I say this as someone who in the last four years has had a serious infection in one foot, (which threatened the viability of that leg, and hence threatened me with serious disability), three serious skin cancers excised, (one of which required a second more extensive operation), blood clots in my lungs following two long plane flights, an episode of pneumonia and, only several months ago, a life threatening bowel obstruction requiring emergency surgery. In my latest illness, I was very aware of the care my colleagues who performed my surgery provided me, and the concern my other colleagues (medical and nursing) showed me. I was, in effect, surrounded by love, manifested not only in visits and words of sympathy and encouragement, but in constructive and purposeful clinical action. I recovered fortunately, though in different health systems, or with more tardy diagnosis and treatment, this same illness could have proved fatal. Other illnesses may not be amenable to curative treatment, but despite this, the patient can still be assisted by health professionals, friends and relatives in such a way that they realise they are still supported, loved and valued, even in their declining state. If a decision is taken to actively end a person's life, this seems a strange way to express love, particularly if those taking this decision believe no form of existence follows death. Love, true love, is a creative activity, not a destructive one.

In many facets of life we accept (sometimes even take on) suffering, studying for exams, encountering work stresses, caring for sick children or partners, losing a job, or running for and shouldering political office, for example. We usually recognise the need for courage and perseverance in the face of the adversity that may occur in such circumstances, perhaps partly because we hope something may be gained through enduring these hardships (though this is not always clear). The problems nearer life's end, however, do seem (and may be) the last we need to cope with, so why not shorten them?

This is a question asked by many now it seems, urged on by foreign example and a wide variety of adverse personal experiences. Objections are frequently raised by people of religious faith, and denied by people of none. However, those with religious faith may not be sure what actually awaits them in person once they die, nor can those of no religious conviction be confident in their 'certainty of oblivion' at death either. What seems certain, however, is that nothing (much) is lost by being committed to endure life to its end, accepting whatever support may be on hand. After all, if existence holds nothing more than what we experience now, foregoing an opportunity to die early at worst prolongs one's quantum of suffering by some (potentially avoidable) margin. If however, a different form of existence awaits us once our body dies, and the mode of this subsequent existence depends somehow on the way we lived and died, and how we supported others through this process, then it may be of the greatest importance that we take no unnecessary risks with ourselves or with others in the way we act as life draws to a close. Hence, it is not indifference to the person that urges caution about euthanasia, but concern for them. And if indeed, suffering, if it cannot be wholly relieved till death supervenes, has a redemptive aspect to it, then not only the patient, but also those suffering with them, participate in an activity of value in enduring it and being supportive throughout it.

There are also other senses in which an accelerated end to a person's life may do them a disservice - there may be matters of a personal nature a patient hopes to resolve before dying that foreshortening their lives may prevent. These issues may be of a particularly intimate kind and their confrontation may develop in unforeseeable ways as a person's life draws to a close. Addressing this concern is incompatible with pre-emptively ending a person's life.

Dying is also not something that cannot be done by a surrogate - it is an activity or process that, while onlookers can observe and participate in, can only be undertaken or experienced by the person themselves. Hence it would seem others should not interfere with this highly personal activity, except in such a way as to support the person going through it, neither actively accelerating nor retarding the process for their own personal reasons, regardless of how foreign or distressing the experience may be from their own standpoint. Life should not be taken from a person, but yielded by the person.

Medicine has always been on the side of cure if possible, and keeping the patient comfortable if not. Doctors have traditionally accompanied their patients during this final part of their lives providing whatever assistance seems required short of deliberately hastening their deaths. As an anaesthetist, I act as the 'Pain Consultant', once a fortnight to once a month in the university tertiary referral hospital where I work (Canberra Hospital). During the 'Pain Round', my colleagues and I not infrequently see patients from the oncology service (and, at times, other services) who are dying, and in need of some modification of their pain-relieving regimen. The Pain Service is consulted in particularly problematic cases, where the primary medical care team wants further advice. I have never once, in over 20 years or so of being involved with this service, seen a patient who could not be adequately managed by some modification of their drug regime and thus rendered sufficiently comfortable, yet without resort to intentional lethal drug dosing. Much of the demand for euthanasia seems to come from people who have seen relatives or friends suffer badly, without adequate support, near the end of their lives. (Some demand may come from those who experience chronic pain syndromes, while otherwise healthy, and fear an uncontrollable amplification of pain should they develop a terminal illness). These personal experiences can be very formative and compelling, yet my own experience suggests instances of unmanageable pain near life's end are entirely avoidable, provided a conscientious medical attention is available 24/7, and provided good nursing care is on hand. Seeing euthanasia as the solution to problematic cases amounts to a denial of the possibility of relief through access to better pain management techniques, and supportive palliative care.

Legalising euthanasia changes the medical role allowing doctors to actively end patients' lives. Once this avenue is open, however selectively, anyone who enters the 'eligible criteria' zone will know that they can have their lives ended any time they wish. This has the potential to attenuate

their fortitude and their willingness to continue living. Though it may be claimed that choosing to die would remain an entirely voluntary matter under any proposed change in the law, were such an option available to everyone who met certain criteria, though some may, prior to a serious illness, have opposed euthanasia, the mere availability of this option might sway them to change their mind as their illness advances, not only as their own suffering might increase as their disease progresses, but as they see the increasing distress and fatigue their friends and relatives suffer consequent upon their illness. Hence, a changed legal climate may induce an increased demand for this service. Recalling earlier comments about the approach to one's own death potentially determining what happens subsequently, such an effect may be extremely detrimental!

Politicians have a duty not just to themselves and their constituents, (and to others to whom they may have made a promise to campaign for legislative change), but also to future generations in the legislation they endorse. Euthanasia, once introduced, may be expected to change the commitment of the medical profession, to sap the courage of at least some members of society, and to excuse governments, families and friends of terminally ill patients (or those with advanced degenerative conditions) from being troubled too long by their illnesses. These are likely the most obvious negative consequences of any change in the law. Shakespeare has Hamlet recommend that 'we bear those ills we have than fly to others that we know not of!' I strongly advise against any change in the current law.

Changes in the law should not be driven by those whose negative experiences of relatives dying have induced in them a thoroughly negative attitude to the circumstances surrounding death, nor by a dread of dying such experiences might induce in others. Much can be (and is already being) done to make this process peaceful and gentle. The energy engendered by negative experiences of death is best harnessed to improve the supportive care of those we love whose lives are drawing to a close, not to expedite their end.

Yours Faithfully,

Paul Burt MB, BS, FANZCA, FFICM February 22 2018