

**University of Tasmania's Independent Inquiry of the End of Life Choices (Voluntary Assisted Dying) Bill 2020.
Submission of Professor Norelle Lickiss.**

Preamble

It may be worth noting that I first came to Tasmania in 1970 as one of the first academic medical staff of the University of Tasmania medical school and Royal Hobart Hospital, with special interests in cancer medicine and epidemiology, and in geriatric medicine which I introduced into the medical curriculum after visiting centres of excellence in UK. From 1985 I worked as staff physician (and clinical academic and department head) at teaching hospitals in Sydney until 2009 (mainly, but not only in relation to cancer patients), and established the Sydney Institute of Palliative Medicine and within it a specialist training program. I was consultant to WHO (1996) concerning cancer pain relief in China, consultant to the Indonesian and Iranian government (concerning cancer services), Visiting Professor in China, Japan, Taiwan, South Korea and Iran, and lectured also in Harvard medical school and several European Countries, including The Netherlands and Belgium, and in Argentina. I was one of two Western doctors invited to Japan in mid 90s to participate in the formal celebrations of the coming of Western thought to that nation.

However, I must now leave to others the detailed analyses and comparisons called for save to mention that international as well as national eyes are on Tasmania as it grapples with the present complexus. For I write mainly now as a citizen 'stakeholder' of Tasmania (Terms of Reference 5), with frequent contact with the health system often in life threatening situations. This gives a sharpness and clarity to one's perspectives!

I begin this submission by making available my letter of August 2020 to Members of the Parliament of Tasmania – with very minor editorial changes. Thereafter, in the light of the present international and local context, I will put forward considerations of some problems associated with proposals embodied in the Bill, and make suggestions for alternative strategies to achieve the goals desired by our people.

Letter to Members of the Parliament of Tasmania, August 2020

Dear [Hon Member].....

Re Physician Assisted suicide(PAS)/ Voluntary Euthanasia (VE)

COVID has jolted me out of a fairly reclusive life style after decades as a consultant physician and medical educator, with dominant interest in cancer. I have worked clinically mainly in Australia (Hobart first - in the first decade of our medical school, then back to Sydney) and also as educator and consultant internationally (mainly China, Japan, and Iran). I have been privileged to be involved in the care of several thousand seriously ill patients. Since retirement in 2009 from my Sydney positions (and international work) I have lived mainly in Hobart, and have assiduously avoided involvement in the Tasmanian health scene, except for clinical and research meetings and many conversations with doctors who were my students in the 70s and with the doctors and nurses who have cared for me during several life threatening episodes. I am no stranger to ICU or fear.

I am so concerned with present trends in thinking and potential action, and confusion, with regard to the possible legislation about voluntary euthanasia and assisted suicide that I feel the responsibility to stay silent no longer. In this letter I simply try to raise some points which you may want to consider further. There is need for careful focus on substantive issues : this is no time for slogans. COVID-19 has cast a bright light on all our ways of thinking, living , dying, and governing, and what seemed certain and predictable a year ago is no longer so. What has emerged however is the *singular significance of persons and personal relationships within community*. Being born is a social act - we are entering community, and dying is also not an individual but a social affair, as is how we care for each-other. Maybe Tasmania can *lead* this country in person centred care.

1. First of all, do we really want to introduce, here, the taking of the life of our citizens, either by assisting them to suicide or giving a lethal drug? There is civic toleration of deliberate taking of human life in the circumstances of war, or in self-defence. But we have moved on, in my lifetime, from the taking of life of criminals (even if a prisoner *wants* to die) : our society accepts the burden of care (prison) rather than take life - no matter what 'safeguards' anyone wanting to reintroduce capital punishment might devise. It is a seismic shift for a society which abhors even capital punishment to seek to enable the taking of any human life, even and especially by doctors.

2. Second. Doctors, supported by the law, are the guardians of life in society. It is a fact that the vast majority of doctors (the silent majority) do not want to participate in the deliberate ending of the lives of patients either by assisting suicide or giving lethal drugs, and hope the issue stays far away from their practice. It is hard even to get doctors to discuss this possibility -so opposed is it to our deepest traditional ethical instincts. The small group of doctors who see this measure as regrettably very occasionally necessary, and only as a last resort on rare occasions, are to be listened to with respect (and they may be critical in devising a medical reform agenda to improve patient care without change in law). The doctors who are *eager* to for it should be a cause for worry.

Just now doctors (and nurses - but I am a doctor so I focus on doctors) are, in fidelity to tradition, heroically caring for COVID patients , at the risk and sometimes cost of their lives. I think it is totally inappropriate, if not egregious, at this COVID time to be even suggesting that doctors should forsake one of the pillars of tradition, and on occasion deliberately end a patient's life, however much that patient wants this to be done. *This is a red line we should not ask doctors to cross*. Choice (and we all welcome 'choice') *does not define the rightness or morality of an act*. (Every parent knows that - and children have to learn it.) Yet 'choice' is being treated, even in pamphlets dropped in letterboxes, as if it were an end in itself and not a means. But I do not want to try to get philosophical!

3.Third. It is a normal part of life to want to influence if not control not only what happens to us, as far as we can, as well as how we respond to what happens. It is part of human responsibility. It is normal at a certain stage of life, to want to die - to have a sense that the time has come: this sense, in a well informed and well cared for patient, is not necessarily a sign of depression, and we bystanders (as well as doctors) need to understand this. We need to help doctors know how we feel about this, and who we trust to advise doctors trying to make difficult decisions about continuing potentially life-saving or life sustaining

treatment, or ceasing it, and instead, concentrating on care directed at comfort and dignity. *All of this may and should be occurring within the present legal framework (in confidential conversations with our privacy not invaded by bureaucratic procedures).* This freedom is simply not understood by many of our citizens and even a few doctors. We must improve this understanding ! And obviously good 'comfort' care should be available to all (and is not, yet). Neglect is another issue entirely.

4.Fourth. It is accepted that the proposed legislation is for the benefit of the patients who desire not only to die but specifically to be assisted to suicide or to receive a lethal drug. But, whilst the *legislation does not in fact increase the freedom of the patient*, save to encourage the necessary talk, and make a *request*, not merely to die, but to be put to death by a doctor, the legislation dramatically affects doctors (and medical education). Our people simply do not realise this : all the 'talk' is about ensuring that the patient's suffering is relieved (by ending life) - and they do not realise that *the core of this legislation is the involvement of doctors*. We citizens have an obligation to minimise suffering, but not at the price of unnecessarily eroding medical practice and distressing doctors by even asking them to deliberately end the lives of patients. The realisation of the truth of the matter is a shock even for well informed citizens .

Furthermore, it is stressed in all the 'talk' that the legislation is for the benefit of *patient*, and not for the carers, family, economy, administrators, and so on. Not even for bystanders who cannot bear to see a loved one suffer or in grief, cannot bear to think of it all (issues we all understand). But stop here.. How is the legislation to be evaluated when those it is supposed to benefit have passed on and cannot offer comment?

5. Fifth. *It is a myth that all is going well after the 2019 Legislation in Victoria!* A highly respected senior consultant physician in Melbourne, Prof Odette Spruijt, until recently on staff of Peter MacCallum Hospital, is in the process of preparing a short piece concerning the doctors' experience has given me permission to share the cogent observations in the draft (attached), being currently revised at the same time as this doctor is on the frontline of the Melbourne COVID scene. The revision may be published soon in Medical Journal of Australia - Insight . *Her words in the draft deserve very careful (if painful) reading.*

6.Sixth. It is easy for any of us, but especially those of us no longer either caring for families or in the work force, to feel keenly the burden we are for society. Some in our society are particularly vulnerable, and could very readily agree to a subtle suggestion pointing towards assisted suicide or euthanasia. We have responsibility for the most vulnerable, and the most powerless among us - if we fail in this, our community (if not our government) has surely lost its soul.

The rule of law not only supports us but guides us. You, as a legislator, may be facing the most onerous decision of your parliamentary life. Parliament also *leads* us to form a better society, as well as supports us. This is life and death legislation, involving enormous social risk - hence the efforts for 'safeguards'. *The central question is whether doctors should be asked to be part of the deliberate ending of human life.*

Since sketching this letter I have been asked to express an opinion on the safeguards embodied in proposed legislation; my response is simple, and analogous to my response if the proposed legislation were to reintroduce capital punishment, namely that safeguards however elegant are irrelevant for the central question remains: Should doctors deliberately end the life of a patient by assisting that patient to commit suicide or administering lethal medicine? My response remains 'no!' - we 21C persons and doctors must continue to seek valid ways to reduce distress and increase the well being of each other and society, even in the deepest difficulties and darkness. COVID-19 may be teaching us more about all that!

But there are problems out here and we can do better. There is *whole reform agenda* needed in my view - including nursing home reform, improvements in some aspects of medical practice, public education about 'advance directives' etc, but that is another matter : but you may be able to help both in formulation of issues to be addressed and in implementation.

Due respect should be paid to those parliamentarians who have worked so hard to put together the proposed legislation, convinced that the only way to benefit some patients wanting to die is for doctors to facilitate their suicide (PAS) or use drugs to deliberately cause their death (VE). However it is my respectful suggestion that you should either change direction towards Reform, or *at the very least*, delay any consideration of legislative change (with the probability of distressing our frontline doctors and nurses and eroding medical practice - as is already occurring in Melbourne) until after this COVID time. It may be politically difficult but I think that the vast majority of the people will support you if you make it clear that you are changing direction out of respect for the doctors (and nurses) who are, in Victoria even as I write, risking their lives.

If anything I have written in this difficult letter (or much that I have omitted) seems worthy of further conversation, I would be pleased to talk quietly, preferably in person if you could spare the time. I will not make any public comment nor be available to media. I trust the Parliament to act rightly, and have tried to contribute constructively to your deliberation.

Sincerely and with profound respect,
Norelle Lickiss etc

Attachment to the Letter: Informal comments by Professor Odette Spruijt FRACP concerning Melbourne .

".....Advocates for euthanasia and assisted suicide have used the results of the first 12 months of Victoria's Euthanasia/Assisted Suicide (E/AS) laws, to argue for removal of safeguards of the initial act. Again, true to form, the narrative provided is one of unrelieved suffering unless more people are able to access this option more easily. Also, true to form, a narrative of 'if not assisted dying/euthanasia, then devastating deaths are the only alternative', is put forward.

As a palliative care specialist of over 25 years of practice, mostly in Victoria, I have found the institution of the Victorian law to have a devastating effect on my practice of palliative

medicine. I have witnessed the devastating impact of this law on the cohesion of teams, on the relationships within clinical units, and as a cause of deep moral distress among many of my palliative care colleagues, for whom this law, and this accompanying narrative, is anathema to the very core of our sense of what it is to be a doctor.

I am very aware that many doctors have reconciled the law, on the basis of patient choice and I am also very aware that palliative care is not a panacea for all suffering. That would be a ridiculous claim. Especially since the majority of people who access euthanasia and assisted suicide world-wide do so not for the relief of physical suffering but rather for the relief of existential suffering, fear, loneliness and concern about causing burden to those they love. Such suffering is not within the realm of medical practice alone to alleviate, but calls for an examination of what we as a society understand as a life worth honouring and living.

During this COVID-19 pandemic, many have celebrated the creative ways in which communities have worked together to support the elderly, the vulnerable and those who are most impacted by many of the consequences of physical distancing. We have recognised more deeply the importance of community caring. This is the spirit that can transform the suffering of many people approaching the end of life, facing isolation, loss and grief, dependence on others and physical frailty. That is the time when our mettle as a society is most needed, our insistence on reasserting the value of each person, no matter what their physical state might be. To regard those who are at the end of life as if they come within a different category of human, that the sanctions on deliberate ending of life that we (so far) accept in other stages of life no longer apply, is to fundamentally change our value system at its core. It is not enough to talk about patient choice as if autonomy means only me. Autonomy is also relative, we are relational beings, we depend on each other, and what we do affects each other. Again, the pandemic has emphasised this very clearly, that our actions responsible or otherwise, affects those around us tangibly, for better or worse.

While I try to avoid the slippery slope terminology, I see so much evidence of this in the attitudinal creep associated with the implementation of euthanasia/assisted suicide, that I find it hard to not adopt this metaphor. The slippery slope refers to the normalisation of these practices as much as to numbers of people who are assisted to die. I have seen this in the hospital in which I work, as those of us who express objection to E/AS are challenged as uncaring, dogmatic, and confrontational, as our views are not respected and our rights as conscientious objectors are not protected. I have seen it in the documentation of 'consider VAD if appropriate' in a clinical note on a patient who survived a suicide attempt, albeit written by a junior inexperienced doctor, but echoing the growing sentiment of normalisation and acceptance of this 'practice' for the relief of suffering. I experience it in my new hesitation to invite open discussion about end of life care wishes, for fear that this will be interpreted as an invitation to discuss E/AS, with which I cannot engage. Previously, this discussion took place in a secure space of 'even if I (patient) wished for this, I know you cannot do it and will do all you can to help relieve my suffering' whereas now, there is uncertainty as to what I am saying or meaning and what the patient is saying. The elephant in the room is now enormous. I feel deep distress when I see junior doctors respond to patient's expressions of a wish to die by beginning the VAD process, as is now our hospital policy. No longer the mental health review, no longer the palliative care pathway, now the

simplistic acceptance that a wish to die in a person with life threatening illness can be taken at face value, and acted upon. if we follow the Age article's narrative, our duty is to grant this wish as quickly and as expeditiously as possible preferably without question or exploration of the factors leading to this request.

Palliative care doctors are generally very reflective practitioners who are determined to avoid imposing their values on their patients, who aim to be good listeners and to validate the patient experience and wishes. The quality of communication, the intersubjective dynamic, is very specific to that particular interaction. This is one of the main reasons that I fear E/AS. How can I be sure that my exhaustion, my anxiety, my discouragement, my fear of my own mortality, is not influencing the patient in their decision-making. Just as I examine these relational dimensions of my practice, so I wonder about the intersubjective dynamic between consenting and consulting clinicians and the patients they see. How do they ensure that they are not influencing or being adversely influenced by the interaction.

This E/AS system in Victoria and elsewhere has been set up as if this relational dynamic does not have any bearing on the outcome of the consultation, that the doctor can be impartial and the patient (who may likely be at one of their most vulnerable and fragile times of life) can also be impartial and unaffected by the doctor. If that is indeed the dynamic, then why bother with the medical consultation at all, dispense with it altogether and let people take their lives unimpeded by so-called safeguards. It is after all, not a medical encounter if the doctor is there only to complete required paperwork.

In my more cynical moments, I wonder if involving doctors in these processes is merely to bring a veneer of respectability to the taking of human life by E/AS. Doctors and health professionals continue to be held in great respect by society, as witnessed during the COVID-19 pandemic, where their efforts to save lives and be with people who were dying from this virus, often at great personal cost. This trust underpins the practice of medicine and the professional relationship. What will be the impact of E/AS on this trust.

The limits and safeguards so often emphasised by our health minister and E/AS lawmakers on instituting this law will continue to be eroded in the way this Age article has done. More examples will be cited of people who die sadly and 'outside' the comfort of assisted dying laws, more arguments raised for further extension of access to E/AS, with further slide down the slope of recalibration of our humanity."

(Comments of Professor Spruijt used with permission).

Events since August 2020 of high relevance to the social context of this submission.

Several events which have occurred since August 2020 have significantly influenced my thinking, notably:

a) Continuing public discussion and representations in the media expressing the increasingly strident concerns of individuals to achieve certain personal goals, and their conviction that legalisation of PAS/VE would be the only strategy to achieve these goals - and the seriously unbalanced local media (with demonstrated reluctance to publish proffered material not in accord with the popular support for the legislation under discussion)

b) Debates in both House of the Tasmanian Parliament in which the sincere concern of Parliamentarians for some aspects of the welfare of the people was made manifest, at considerable personal cost;

c) The evolving COVID situation – a drastic spike in Victoria, the worsening parlous situation in Europe, USA, and the resurgence in our Asian neighbours, notably Singapore (where a Tasmanian graduate is the leading medical authority) , and in Indonesia where there is a huge mortality among doctors, and the continuing threat of a second wave in various parts of Australia (notably, currently, Sydney), and even in Tasmania. *In the course of this pandemic, we have depended on not only the competence but the integrity of the doctors advising the various governments: the integrity of the medical profession matters.*

d) The publication of several major Reports highlighting deficiencies in Australia in care of the aged and disabled, and the frequency of domestic violence, elder abuse and suicide. These features of the social context in Tasmania are of continuing concern, with continuing vulnerability as a common thread - all this despite Tasmania being recognised as a privileged and precious place in which to live

e) Continuing disturbing evidence of the adverse consequences to the medical profession as well as citizens in other jurisdictions which are familiar to Tasmanians of the legalisation of what is (unfortunately) termed 'assisted dying'. International information is now readily available concerned demonstrated harm, even though the most publicity tends to come from proponents of the legislative changes enabling PAS and VE.

Some aspects of the international context

The aiding and abetting of suicide or the deliberate termination of the life of another human being save in self- defence or war, have hitherto been capital crimes , and the carrying out of such activities by doctors is doubly abhorrent. The social risks associated with decriminalisation or legalisation of what have been hitherto capital crimes have been long recognised by the wise. Serious problems were foreshadowed, in decades of discussion, whenever requests for voluntary euthanasia became audible, even if not strident, as now (and the reason for this evolution requires major analysis - a pressing academic challenge).

Notable examples familiar to many in Australia (apart from our own debates of the last 50 years) were the deliberations of the landmark House of Lords Inquiry of 1994 : chaired by Lord Walton. The Select Committee on Medical Ethics, though sympathetic to some arguments in favour of VE, recommended against a change in law, because of the social risks foreseen. The Committee noted that ' the rejection of euthanasia as an option for the individual, *in the interest of our wider social good*, entails a compelling social responsibility to care adequately for those who are elderly, dying or disabled.' (my emphasis) They recognised keenly the social risks of the proposed legislative change.

Harm to the medical profession is of high social significance. Such is occurring even in countries lauded as paragons and models for the Tasmanian Legislation. Concerning information is increasing. Anecdotes abound , but a major recent review of significant original research mainly the Netherlands and USA demonstrated this clearly that

participating in PAS or VE can have a significant emotional impact on participating clinicians (Kelly et al,2019)

Harms resulting from the Oregon Legislation of 1994 (also familiar to many Australians) were already apparent within a few years ; they were outlined by leading authorities (Foley K and Hinden H,2002). Legislators in Oregon, in facilitating physician assisted suicide, deliberately excluded the administration of lethal drugs by doctors, for fear of damage to the medical profession, but the prevailing arrangements have eroded the integrity of medical practice and "patients are unprotected while believing they have a new right" (p 174).

The Canadian situation as carefully depicted recently by Professor Herx and colleagues (Herx L, Cottle M, Scott J, 2020) is particularly concerning: they portray '*significant and dangerous consequences*'. The adverse consequences noted within four years of the legislation include: 'the widening and loosening of already ambiguous eligibility criteria, the lack of adequate and appropriate safeguards, the erosion of conscience protection for health care professionals, and the failure of adequate oversight, review and prosecution for non-compliance with the legislation". But these words in the introductory paragraph do not reflect the impacts of the facts subsequently documented. Just one example : 'A significant number of reports have documented cases in which individuals have been told by health care professionals to consider euthanasia as an "answer" to a poor quality of life or lack of health care resources to meet their needs' - and this is occurring with disabled people 'Euthanasia providers are now making recommendations to add drugs (e.g., potassium chloride) to the existing drug regimen which will cause rapid cessation of cardiac activity and reduce the potential for ischaemic damage to organs to be transplanted'. There are guidelines for preparing children (by examining instruments etc) for the euthanasia death of a loved one. Opposition is strong from citizens in the disabled community, mental health professionals, palliative care clinicians, and public policy leaders. But clearly the genie is out of the bottle.

What emerges is a portrait of a society which Tasmanian people, doctors and legislators would shun. These highly credentialled and respected Canadian authors 'urge the World Medical association and colleagues around the world to look beyond the simplistic media reports and to monitor developments in Canada carefully and wisely before making any changes to their own country's legal framework for medical practice'. We in Tasmania must take heed of the Canadian experience.

There is serious international concern about trends in both practice and thought, the pressure being brought upon doctors, and the critical importance of recognition of the moral basis of, and the role of conscience in all medical practice: 'Refusing to act wrongfully. is foundational for the individual and society, contributes substantially to social stability and is the necessary but not sufficient condition for perfective freedom of conscience. It is essential for ethical medical practice because it protects personal and professional integrity and can be the ultimate safeguard for patients (Murphy S, Coelho R, Violette P et al, 2020) .

But it is important to stress that what is published is a tiny fraction of what is thought and felt throughout the world and throughout time : The Hippocratic Oath was

quite clear that it is not fitting for doctors to put patients to death. And except in truly exceptional circumstances, and in the tragic times when there has been moral collapse of the medical profession (as did occur in my life time) doctors have refrained from transgressing this deep traditional moral principle - a true red line which the Tasmanian Bill seeks to cross. The evidence internationally is clear on this: this is a known irreversible crossing, a crossing of the Rubicon.

Doctors in Tasmania, have, on the whole have focussed on patient care and simply refrained from public (or much private) discussion, apart from the very few truly and sincerely eager for these legislative changes: as I noted in my August Letter to Parliamentarians, those few doctors must be respected and their views sought about what improvements in care should be urgently striven for in Tasmania, now. *But it would be irresponsible not to take note of the information available, notably that on Canada : we must not take any steps which could let Tasmania slide into an analogous situation.*

Passive silent resistance by Tasmanian doctors is not to be underestimated. It is possible that the serious flaws in the Bill could be, at least in part, consequences of the fact that most - or all - doctors opposed to the Bill deliberately refrained from assisting conscientious parliamentarians to 'improve' an instrument which these doctors regarded as a hazard to good medical practice, and therefore, the good of our people.

Personal comments on these matters.

1. *The goals being sought (urgently) by the people and voiced in regular 'letters to the editor', media 'bites'; and articulated for the most part by Members of Parliament , and alluded to in early sections of the Bill, are in my view not contentious and indeed laudable.*

These include :

- a) to be listened to and 'heard when one is very ill, especially with a probably fatal illness;
- b) be free to determine the goals of care when facing serious possibly or probably fatal illness;
- c) either give or withhold consent to adequately explained and understood medical measures even those aimed at prolonging or sustaining life;
- d) to influence as far as possible the shape of the last phase of one's life, with due regard for the needs of others;
- e) to have suffering associated with illness prevented or minimised, and to be relieved as far as possible of distress caused primarily by the symptoms of disease or its treatment, notably but not only pain;
- f) to die, as well as live, with as much dignity as possible, and be respected no matter how afflicted;

g) to be free of duress from any quarter when making all such serious decisions, and to have the support of trustworthy persons who ideally understand one's personal priorities and values, and acts only out of motives of beneficence.

h) to have the care one needs with due regard to the limits of community resources and the needs of others. (*NB Home care packages should be immediately available once moderate or high level needs are identified*); obstacles must be addressed.

i) to have no intrusion of *privacy* - leaving undisturbed a trusted doctor-patient relationship in the last decisions and phase, even moments of life . (knowing then the role of doctor as *comforter* - sharing strength, not causing death) (The recording for bureaucratic/procedural purposes of the shape of my distress or the estimated severity of my suffering would be a gross violation of privacy, far more significant than those feared to occur with the electronic health record or the COVID app !)

It needs to be recognised that all of these goals are achievable *with no change in legalisation*, IF :

a) The whole scope of the current law were adequately understood and applied by our citizens and by all clinicians, notably all doctors with clinical responsibilities. (There is room for formal legal analysis of the existing relevant Tasmanian law and wide publication of an adequate description. University of Tasmania Law School might assist in this project).

b) Appropriate medical attention and appropriate care were always available to all our citizens in all locations, including all public and private hospitals and residential aged care facilities (nursing homes especially), and at home;

c) Every doctor (based in community, residential aged care facilities, or hospitals) with clinical responsibility for patients with serious illnesses, notably if incurable and progressing and probably eventually fatal, should ideally have, readily available at all times, medical consultants (such as palliative medicine specialists) with special expertise in complex clinical decision-making, symptom relief and in other relevant aspects of care, and clinics staffed by such experts to which to refer patients and their families, as well as essential home and nursing home consultations, for continuing clinical assistance (in a partnership model) maybe over several years or many months, not just at a time of (at least partly) preventable crisis.

None of these conditions, outlined above, prevail throughout Tasmania, as far as I know. There is (at least) anecdotal evidence of serious deficiencies as well as some relevant Reports. Attempts have been made to remedy some of these deficiencies, but they appear underutilised. For example, the Goals of Care document developed by Professor Michael Ashby and extensively used in public hospitals should be available in every health related facility, including clinics and all practice locations (private as well as public) and familiar in homes.

Suggestions concerning alternative strategies to achieve desired personal goals before adopting a regressive 'last resort'.

Either decriminalisation or legalisation of what are currently capital crimes (namely the aiding suicide or the deliberate taking of human life save in self defence or war) is surely a *last resort*, a regressive (not progressive) solution to *poorly delineated problems*.

What are the problems to be addressed by the proposed legislation ?

To my knowledge there are NO systematic and comprehensive (involving both public and private patients and institutions) relevant population-based or institution based Tasmanian data or even comprehensive (public and private) service- based concerning the frequency of failures to relieve pain, the incidence of unrelieved suffering, and so on. Or if they exist they are not widely known in the public arena. Instead, grossly distressing anecdotes and unfortunate experiences of loved ones or friends, have been the basis of the development of measures (embodied in the Bill) carrying high social risk.

The distressing, constantly repeated anecdotes which have featured in the media and parliamentary debates (and led to interstate comment) each justify urgent forensic analysis to establish accountability ; if substantiated (and hopefully they will not be substantiated) they indicate deficient clinical practice - so seriously deficient that, if responsibility is proven, health professionals responsible associated for such outcomes, or health administrators who tolerated them should be sanctioned, and certainly no more drastic practices like assisting patients to take their own life (properly called suicide) or permitting doctors to give lethal injections should be even contemplated in Tasmania.

The shape of the social risk associated with the proposed legislation?

The social risk, expressed in the frequent mention of 'safeguards' in the parliamentary speeches and in a Bill of 170 pages, is very great:

I comment briefly on some aspects of the evident social risk.

i) There is risk to the vulnerable, to undervalue the self, of subtle pressure to participate, and even what is sometimes called 'wrongful death'. Certain social circumstances, notably economic scarcity, abusive relationships, marginality, cognitive deficit, mental illness, frailty, disability, social isolation, communication difficulties, illiteracy, lack of care and even abandonment all heighten risk.

Economic scarcity (societal or personal) as relevant?

In 1920, exactly 100 years ago, an eminent lawyer and eminent psychiatrist published a book indicating the intolerability, in bad economic times, of sustaining the burden of such as the frail aged, and other non productive citizens (Binding K and Hoche A, 1920) This idea took root - some human beings should not be allowed to continue living for the economic burden is too great. A shift in societal (including medical) attitude towards the frail took hold and was regarded as the root cause of the mid century travesties manifest at the Nuremberg trials at which Leo Alexander was observer):

The beginnings at first were merely a subtle shift in emphasis in the basic attitude of the physicians. It started with the acceptance of the attitude, that there is such a thing as a life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the

ideologically unwanted, the racially unwanted and finally all non-Germans. But it is important to realise the infinitely small wedged – in lever from which this entire trend of mind received its impetus was the attitude toward the non-rehabilitatable sick.”(Alexander L, 1949)

So a shift in attitude on the part of physicians or society at large(or the media) to the frail, those approaching death, those who are a burden to others... the 'non- rehabilitatable sick', could be like a canary in a mine, a warning of danger. *We must learn from the past! Now.*

But it is not only society which may undergo a shift in attitude but also the vulnerable themselves. The current debates have had already effects - a doctor has noted that frail patients in hospital in Tasmania are already apologising for taking up beds. The culture in which one is embedded can have serious influence on perspectives one develops and on decisions one makes ; the vulnerable may well absorb very quickly the idea they (we) are not only a burden with no continuing value to society, but also a burden which our society can no longer carry.

There is an important nuance here. In this context it could be is a short step to feel pressured to choose death, not as a consequence of a sense of completion but as an economic service to society. Such a choice may be noble and free but does not necessitate the institution of the procedure defined by the Bill - but may call for agreement to withhold consent from potentially life prolonging treatments /procedures and to accept good appropriate care - a decision which does not call for the moral compromise of the attending doctor, and which is perfectly possible within the existing legal framework. Neither letters to the editor nor Parliamentary speeches have dwelt on the concept of altruistic suicide - for the sake of the welfare of others. Such sentiments are commonly expressed, quietly. Indeed such thoughts may particularly come to the minds of those of us who were nurtured in youth by stories of brave persons like Captain Oates who travelled with Scott in the Antarctic, and went out into the snow to cease to be a drain on his companions ('I may be away for a long time'), and therefore the concept needs at least mention in a State so involved with the Antarctic. It is worth stressing that a commitment to altruistic suicide, or expression of desire to die 'soon' and/or not 'go on too long', which is not uncommon for a trusted doctor or nurse to hear, do not equate with a request for either physician assisted suicide or euthanasia but for further conversation, and maybe significant changes in treatment and care to accord with such a request. This is not sleight of hand but good medical practice.

We, the elderly are conscious that we are burdensome. But the remedies for that may be better decision-making - by us citizens as well as doctors - to ensure that resources are used for those who can most benefit. This is a concept (related to triage) which has been emphasised in the distribution of ventilators in COVID care - to those who can benefit most, not those, maybe in greatest need but with little chance of survival : ethics in a new key. It is especially important in times of economic scarcity and must be appreciated wisely.

ii) The risk of harm to the integrity of the medical profession is extreme.

There has not been adequate realisation, on the part of the citizens, or parliamentarians, of the threat to the integrity of the medical profession (on which some

aspects of the welfare of our people much depends). Most citizens who, if questioned, are in favour of "assisted dying" are not conscious of what they are in fact asking of doctors - and when this is pointed out they are taken aback. The doctor called on to assist, the proposed partner in the procedure, is faced with a request which goes against one of the core moral traditions of medicine - not to take life. The threat of damage and distress not only to the doctor concerned but to the medical profession as a whole in Tasmania has not been sufficiently realised by our citizens and maybe not even by our politicians. There is room for true compassion here - our doctors should not even be asked to participate in these procedures. The danger of taking away the moral content of the act of terminating a patient's life, as if it were simply another clinical option, is frightening.

As it is in the Bill, there is provision to *train* doctors to participate. They are to be trained to deliberately cause death whereas many years of medical education and experience have developed their competence to treat patients even with risky measures if called for (even, for example, making patients unconscious and carrying out operations), without causing death - imagine asking an anaesthetist to make sure that an anaesthetised patient does not wake up! They are to be trained to differentiate persons whose dying as a result of self harm, say an overdose, is to be prevented by the application of superb clinical skills (a common demand in large emergency departments) and some patients whose taking of a lethal drug and therefore dying is to be not prevented but facilitated. It is hard to believe that our citizens or politicians have thought this through. What is now criminal behaviour is to be normalised as good medical practice! Our people regard doctors very highly, just slightly lower in regard than nurses : we care about the doctors. It has not been made clear that the proposed procedures put doctors at so much risk of distress and harm, and risk the integrity of the medical profession on which our welfare so deeply depends.

There is indeed risk even of *moral injury* to doctors responsible for patient care, with all that entails, and to colleagues who work with them. Those of us who have worked beside doctors trained in a context where euthanasia is long accepted and normalised as part of the clinical armamentarium know well the shock of meeting doctors who have no sense of the moral significance of this act - they are morally wounded. And surely we do not want this mentality to be introduced into the Tasmanian health care service or community, or imbibed by impressionable medical students and junior doctors-in-training. Furthermore, It also may be said that doctors whose morality is defined by law maybe a danger to society. There is much more to be said concerning morality and medicine particularly in relation to the matters under discussion, but the World Medical Association journal, notably in recent issues, has offered much to ponder.

It is noteworthy that there has been a weakening of institutions which are the traditional guides to morality, but Parliament may remain one of the key bastions. In the instance of capital punishment - where community attitudes may well be favourable to the reinstatement of it if appropriately framed questions were asked - it is parliament which has stood firm, despite the huge material costs of this stance ; the soul of Australia may have been saved by such courage. This example may be relevant to the present situation where *Parliament may be called to stand firm on a matter of moral principle (doctors do not deliberately take the lives of patients) despite a groundswell of community sentiment urging*

otherwise. The soul of Tasmania could be at stake ; we, as a society, can be judged by how we care for the most needy and powerless.

There is another dimension which should stop Tasmanians asking this of doctors: should COVID break out even here, the doctors and nurses will be called on to be true to another core moral tradition - to be prepared to die for one's patients. This is happening, even on our doorstep - literally hundreds of heroic doctors (as well as heroic nurses) have died in Indonesia, caring for COVID patients. Every month the worldwide situation is worsening. Do our people really want our doctors to forsake their core traditions? and to be profoundly distressed because of this?

Are there alternative strategies to this 'last resort' to achieve the goals our citizens are seeking?

The legalisation of physician assisted suicide and euthanasia is truly a last resort, almost a sign of defeat. Surely this 'last resort' (a truly final solution) has no place where there are other alternatives which could be supported and fostered or at least seriously tried.. And there are other strategies worth urgent consideration to achieve the goals wished for by our citizens.

Each of these strategies will require very significant resources including strong support from the medical profession throughout Tasmania, committed and competent personnel, wise committee oversight, and popular support, hopefully including supporters of the Bill even as it is.

I have foreshadowed some directions for strategy development on the basis of information available to me, largely that on the public record and also anecdotes from my friends and acquaintances. Some suggestions are as follows :

1 Rapid improvements in the medical care readily available in nursing homes throughout Tasmania (with due regard to complexity of reasons for the current problems).

In the Netherlands, at least around a decade or so ago, nursing home medicine was a specialty I visited an impressive teaching facility for that specialty in Rotterdam. It is to be noted that palliative medicine as a clinical speciality, as in UK and within the Royal Australasian College of Physicians, was not present, at least at that time, in The Netherlands. In Australasia (and UK), specialist training in palliative medicine, as in haematology etc, involves several years of arduous specialist clinical training after passing barrier examinations and fulfilling other requirements. The fact that specialists in palliative medicine are available, though scarce, in Australasia does not negate the potential value of also developing nursing home medicine as a recognised speciality. Despite currents of opinion which would lessen the tendency to aggregate the frail elderly, a demand for high quality nursing home medicine is likely to increase rapidly, and the recent debates concerning this Bill could provide an impetus to a role Tasmania could play.

For the University of Tasmania could give a lead in this matter. This University (within the Wicking Institute) carefully developed an excellent, internationally respected academic program in Dementia Care culminating in a bachelor's program. Is it possible that

an analogous academic program could be carefully developed in nursing home medicine? The building blocks are already in place.

2. Upskilling of doctors throughout Tasmania in what may be called 'Late Phase Medicine" , relevant at any age.

Such a program of continuing education would incorporate elements of general internal medicine (notably concerning chronic and complex disease - including diabetes, renal failure, cardiac failure, degenerative neurological conditions, etc), some aspects of psychiatry, geriatric medicine, palliative medicine, ethics , and so on with emphasis on clinical decision-making in relation to patients with complex, chronic, probably fatal illness, and in the relief of major symptoms (all in whole-of-life perspective), and appropriate care, particularly domiciliary care. (NB *Home care packages for every one of those aged citizens with recognised high level care needs wishing to stay at home should be made available immediately as the necessary infrastructure for the renewed medical care here envisaged.*)

This would involve a major and well funded new program of continuing clinical education, involving not only seminars, clinical meetings, and some online learning, but also some provision for clinical attachments, clinical projects, and maybe some certification of achievements.(Personal experience in some elements of such education in several contexts has been that doctors are highly appreciative.)

The demanding complexity and cost of the program needs to be recognised: assistance with acknowledged expert specialised educators from outside the State may be essential. The University of Tasmania, might have oversight of such an innovative program in conjunction with the clinical Colleges, AMA, and the Department of Health: a Grand Coalition committed to significant and measurable outcomes.

Such upskilling of doctors would not obviate the need for specialist consultants to assist all doctors. Indeed as knowledge and awareness of the possibilities of excellence are enhanced, the recognition of the need for occasional focussed assistance may increase.

Dignity and suffering are complex aspects of the human condition (Malpas and Lickiss,2007 and 2012) and there are limits to what even the best medical practice can achieve. But Tasmania should strive for excellence in truly person centred medical practice and health care and our doctors and our administrators supporting them may take pride in the striving.

3 Correction of some anomalies in the availability of specialist palliative care services to supplement the care being given in all in institutions and situations.

In particular it may be necessary to enhance and subsidise the availability of palliative medicine consultants, palliative nursing consultants, appropriate clinics, and even in some locations appropriately staffed palliative care units in the private sector. It is necessary to ensure that no economic disincentives are at play to reduce a ready access to needy patients and their families to consultative services, clinics and when essential, inpatient units staffed by nurses specifically trained in palliative nursing. There is a tendency in Tasmania to equate the need for palliative care with proximity to death. It is important to note the relevance of the concepts enunciated by Robert Twycross, an

internationally recognised authority (Twycross, 2020), that palliative care should be available, not on the basis of prognosis, but on need, notably major and difficult symptoms or gross distress. *Palliative care is not about dying but about living better despite having some pathological condition.* (Research and teaching by Robert Twycross at Oxford was the source of what expertise and knowledge I could bring back to the cancer services at the Royal Hobart Hospital in 70s.)

There is an imperative for the matching of the patient's needs with suitably competent clinicians who may or may not be palliative medicine specialists ; some doctors specialising in other fields, such as nephrology, haematology, family medicine and so on, also have specialist training in contemporary palliative medicine, and this trend to double training is very beneficial for patients and broadens the possibilities for specialist assistance. Some patients may have intermittent contact with relevant specialists or clinics, embodying palliative medicine expertise, for months or years, in parallel with other treatment modalities. These matters are relevant to attempts to improve the care of needy patients throughout the course of a serious illness, not just in a terminal crisis. (But it also to be recognised that enhancement in the availability of high quality palliative care in all locations, however desirable and ethically essential, is not in itself an adequate response to the surge for PAS or VE - but it would be a good beginning.)

The related problem of an apparent lack of training in Tasmania in specialist level palliative nursing (a recognised specialty elsewhere) needs to be urgently addressed. Again, the University of Tasmania may be of assistance in exploring this matter.

4. Recognition and expansion of the concept of the 'Hospital Without Walls' as a means of preventing or minimising distress associated with disease or its treatment.

Admission to hospital is recognised to be hazardous: infections may be encountered, sleep deprivation is common, routines abandoned, supportive or treasured personal relationships jeopardised, and so on: the experience can cause severe morbidity and distress and indeed demoralisation. The challenge is then to make available to patients the advantages of hospital expertise and facilities, but in such a manner that the disadvantages are minimised.

One response is the ' Hospital in the Home', now a well established component of the concept 'Hospital Without Walls' elsewhere, and being gradually introduced into Tasmania. Some patients require hospital level treatment to enable recovery from an episode of disease, for example pneumonia, or an exacerbation of a chronic condition (such as chronic lung disease, or cardiac failure). There may be need for investigations such as blood tests ,IV infusions or drugs such as antibiotics, need to recalibrate drugs and other measures, but the patient may not need to be admitted to an onsite hospital bed, and be supervised by hospital staff at home. Precise assessment and selection of patients is key: experienced clinicians are essential. The advantages are significant to the patient, family/carers, and general practitioners - and to budget holders.

5. Systematic collection of data throughout Tasmania re major symptoms being experienced by patients in all hospitals and nursing homes, with recognition that lack of control of a

major symptom, and extreme distress is a medical emergency, and to be treated as such by the equivalent of practices set up to deal with other medical emergencies.

The collection of such data should be motivated by a recognition that the finding of error (like finding a case of COVID) is a pathway to success not a sign of failure. A system based on this ethos was built up in the 90s within a busy Palliative Care Service at Royal Prince Alfred Hospital : it proved to be highly efficient, treasured by staff, and of significant value as a means to quality improvement (Glare PA, Lickiss JN. 1992).

6. Urgent public education concerning all the possibilities for self determination embodied in the present legal framework concerning medical practice.

Our citizens recognise the importance of Wills concerning (mainly) disposal of property, but may lack understanding of the significance of Advance Directives/Advance Care Planning/nomination of Responsible Person or Enduring Power of Attorney all to assist conscientious doctors to make difficult decisions most in accord with one's wishes. Such procedures have limited but significant value IF correctly used, but the conversations associated with them are very valuable indeed. The Parliamentary Debates have served to reduce the taboo about discussions concerning dying and this is of benefit and sets the stage for far more widespread understanding and application of the various means available. There is scope for major efforts in publicising and making available these procedures .

Advance Directives and the name of the Responsible Person or Enduring Guardian (the terminology varies between States - the one to whom the doctor should most note to assist in a difficult decision if the patient is incompetent) should be more prominent not only in the public mind but in every place where health care is offered. Day patients, even admitted for risky procedures requiring a general anaesthetic, do not apparently get asked usually for such information - a remediable anomaly.

Each of these suggested alternative strategies would be demanding, would require leadership (indeed a 'champion' - there is much at stake), an administrative infrastructure and resources, including some specialist assistance from outside Tasmania to supplement local experts and effort (I could nominate such experts if this would be of assistance). There is scope for modification and improvement of each. It is my conviction that each of these strategies at least justifies careful scrutiny, considerable investment, and trial, in whole or in part, as an alternative to proceeding now to the proposed legislation - a seismic shift fraught with huge personal and social risk.

In conclusion.

I have written as a citizen 'stakeholder' and put forward my personal assessment of problems and possibilities in the face of the challenge posed by a popular movement postulating drastic solutions which I consider both unwise and unnecessary. The march of medicine in our time may have left some personal goods far in its wake - and we need time to close the gap. I have suggested wholly alternative strategies to achieve the goals sought.

Maybe a five year plan of radical reform and renewal could be considered before any further debate concerning a change in legislation as embodied in the present Bill, the significant conceptual and practical faults in which have surely been pointed out by others.

Others will have noted that, because the Bill purports to benefit persons approaching death, and not family, friends, carers, administrators, or even budget holders, NO adequate evaluation will ever be possible, since the proposed beneficiaries cannot appraise the outcome. *No Parliament should support a Bill, not only framed to solve (at grave social risk), a poorly delineated problem, but also which cannot ever be adequately evaluated by those it seeks to benefit.*

I have a vision for what is possible in this island with 500,000 people. We are creative people. We can lead, not follow, the other Australian States in achieving the goals of our citizens, in fostering their sense of responsibility and liberty and yearning for dignity and respect, in relieving their distress wrought by illness, in bearing their burdens and in recognising in all this our radical connectivity.

I represent no-one but myself (in solidarity with the rest of the citizens of Tasmania) and I may have stayed silent too long during the last decade since I returned to reside in this precious place after the varied national and international experiences for which my time in Hobart as a medical academic prepared me.

As a newly fledged Professor of the University of Tasmania (appointed in 1975) I gave my Inaugural Lecture entitled "On Limits and Liberty". The fact that I have in this submission indicated clearly that I think there are limits to our liberty, to our desire for self-determination, essentially because dying is after all a social not individual act. The very fact that the law (seen in this Bill) gives attention to criteria (such as consistency of desire, estimated prognosis for survival, cognitive capacity, freedom from duress) indicates that self-determination cannot be unfettered: this Bill is not enabling the exercise of unlimited autonomy. But I wish to conclude with my wish that as a result of the difficult deliberations of this Parliament and this Inquiry, we Tasmanians may freely face dying in privacy, with trust in the doctors and nurses and others caring for us. And find true peace of mind, not in the assurance that we will be assisted to suicide or given lethal drugs to cause our death at a time we want to be allowed to die, but with trust in our carers, and in the experience of unfettered compassion and respect for our dignity and self-determination, all without being ourselves a source of harm. Such is true liberty and such is possible, of that I am personally convinced.

But Shakespeare should have the last word. He foreshadowed many of the issues faced by our citizens when dying becomes preferable to living, whether from a sense of completion or a wish to be done with life for other reasons. King Lear, in distress on the moors, begs to be allowed to die, despite Edgar's impulse to prevent his passing:

*“Edgar: He faints. My Lord! My lord! / Lear: Break, heart, I prithee break/
Edgar: Look up, my lord! / Kent: Vex not his ghost : O let him pass! He hateth much
That would upon the rack of this rough world/ Stretch him out longer. “*

This Bill articulates well in section 3 (2) underlying guiding principles which can be the basis of goals striven for by all. Could this Bill be then wholly revised so that it would facilitate what Lear sought, for us citizens to be allowed, after due assessment, to be allowed to pass, not as a result of lethal drugs provided or administered by a doctor, but on our own terms in the midst of good care. A request like that of King Lear should prompt an

urgent reassessment of all medical interventions and the appropriateness of care in light of the amended goals set by and with the King and worked for by all. This surely would be the core medical contribution to our living and dying with dignity.

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