Attn: Mr Todd Buttsworth,

Submission to the Tasmanian House of Assembly Standing Committee on Community Development Inquiry June 2016

HOPE congratulates the Tasmanian Parliament on initiating this inquiry. While our main focus is to oppose the introduction of euthanasia and assisted suicide, we have also been involved in and promote palliative care and the use of Advance Care Planning. We hope that discussing these matters in your committee will help the Tasmanian Parliament in developing a clear vision and a plan for the development of health services where the needs of all Tasmanians are met.

Patient choice:

The question of patient choice is an important consideration related closely, as it is, to the principle of informed consent. But choice is not simply a slogan. Consideration of the question of choice must also extend to the provision and availability of services to all Tasmanians on an equitable basis and, by extension, to all Australians.

In speaking with Palliative Care Specialists, they are adamant that early referral to Palliative Care services actually enhances patient choice. According to them, when a GP leaves a referral too late in the progress of a disease it limits the ability of Palliative Care to ameliorate symptoms well and to prepare the patient and the family. Tasmania would do well to educate GPs and Specialists in the advantage of the early introduction of Palliative Care personnel into the management of patient needs.

Public perceptions:

The ‘brand’ if you will, of Palliative Care is not well understood by the community at large. This, we believe is principally because most people associate the term in a negative sense with impending death and would rather not think too much about the possibility. It may also be the case that the true nature and capability of Palliative Care in being able to deliver ‘a good death’ in a holistic fashion whilst also providing effective support for the families and loved ones is being obfuscated by the crie de couer for euthanasia and assisted suicide.

We contend that, for euthanasia and assisted suicide to be successfully argued for in the public square, the public need to be convinced of a great need. The regular portrayal of what we might call ‘hard cases’ in our media serve that purpose as do the attendant assertions that people ‘don’t want to die in a hospital bed hooked up to tubes’ or that Palliative Care is not as effective as it really can be. These ‘memes’ while serving their purpose also actively undermine the possibility of people gaining a better understanding of Palliative Care and re-inforce already negative views.
Part of the promotion of Palliative Care, therefore, must be a ‘stripping away of the myths’ and an honest account and portrayal of effective and timely care.

**Selling the Palliative Care message:**

Palliative medicine has developed significantly over the last decade and more. The relief of distress, symptom management, pain control and existential suffering are all addressed in services that take the patient-centred approach that characterises palliative care. Assurances from palliative care specialists that all pain can be dealt with, that excellent care is available, that a ‘good death’ is achievable seem, however, to have done little to ameliorate people’s concerns about end-of-life as seen through the polls on euthanasia in recent years.

Submissions to this inquiry will, no doubt, include anecdotes from relatives of people who perhaps have not experienced such a level of care or who may be facing a difficult prognosis themselves. Their concerns are valid and should be heard. However, it would not be proper nor helpful to simply assume that because some people raise their experiences, difficult and heart-rending as they no doubt are, that euthanasia and assisted suicide is the solution. We need to be prepared to dig deeper, recognising the aphorism that ‘hard cases make bad law’, but also asking the harder questions about the availability of palliative care and the public perception of what good palliative care looks like and how it supports autonomy and patient choice.

Selling the idea and practice of palliative care is not easy. It may be said to be similar to the difficulties in developing the uptake of advanced care planning. No-one really wants to talk about nor hear about death until it insinuates itself into one’s immediate future. *Palliative Care Australia*\(^1\) has some excellent resources and pamphlets available and commonly found in the brochure racks of medical surgeries; but who reads them? A little like a manufacturer’s warranty, perhaps, we never read the details unless we need to.

We know, too, that a little knowledge is a dangerous thing. People know enough about palliative care to leap to the conclusion that to access palliative care will mean that death is imminent - that life as we know it is perhaps already gone and that all that remains is a battle with symptoms that may or may not be successful. But, as one palliative care specialist recently observed: *Palliative Care is not about dying; it is about living until you die.*

We must do more to address these misconceptions; to arrive at a place where palliative care support is embraced as a new travelling companion and an opportunity to be well cared for. We make this plea in the belief that a broader understanding of palliative care and its delivery will address people’s natural concerns about loss of autonomy, loss of control, fear of pain etc. and thereby increase their sense of well-being. Euthanasia has been characterised as arising from the fears of the ‘worried well’. It is an entirely justifiable outcome of public education to reduce such fears.

We are aware that *Palliative Care Victoria* and *Palliative Care Australia* actively promote greater understanding of their craft and services; but as already observed, people naturally tend to avoid such items in the pamphlet racks. Perhaps it is time for a multimedia promotion including mainstream advertising that sells the message about palliative care and end-of-life planning in

\(^1\) See [http://palliativecare.org.au/](http://palliativecare.org.au/)
Victoria. I am reminded of the very successful (it must have been because I remember it!) public campaign 30 years ago that used the slogan: Cancer is a word, not a sentence. Such an initiative on Palliative Care would enhance public wellbeing and should be considered as essential.

**Advanced Care Directives**

We consider it an essential tool in accessing good and timely treatment options that people are prepared to discuss, both formally and informally, their potential preferences at the end-of-life.

We say ‘potential’ deliberately because we firmly believe that ‘directives’ are not appropriate. We prefer the use of ‘plans’ as we will shortly explain.

The author’s home state of South Australia recently reformed their advance care planning/directives model. The previous ‘living wills’ model had experienced a poor uptake in the community. It is hard to say precisely why this was so but we suspect that, apart from the fact that people tend to shy away from such discussions generally, the use of the word ‘will’ conjures up the idea of death, further adding to the misperceptions.

South Australia included the possibility of creating binding directives in respect only to refusal of treatment:

**19—Binding and non-binding provisions**

(1) Subject to this section, a provision of an advance care directive comprising a refusal of particular health care (whether express or implied) will, for the purposes of this Act, be taken to be a binding provision.

Note— Certain provisions of an advance care directive refusing some forms of mandatory medical treatment are void—see section 12(1)(b).

(2) If a binding provision of an advance care directive is expressed to apply, or to be binding, only in specified circumstances, the provision will be taken to be a binding provision only in respect of those circumstances. (3) All other provisions of an advance care directive are non-binding provisions.

While this may seem entirely appropriate, we ask the committee to consider that a binding Advance Care Directive, coming into operation at the time when the patient is deemed to have lost capacity, could be mistakenly applied to an unforeseen incident that caused the loss of capacity, even if only temporarily. So, whereas the patient may have intended that the refusal of treatment would apply at a time when the complications arising from their underlying condition would mean that they would rather be, for example: made comfortable and allowed to die, a minor fall or hypoglycaemic

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3 Ibid.
attack (as an unforeseen event) that also rendered them at a loss of capacity, may well be deemed to be the point at which no remedial intervention is applied (in keeping with the directive).

The South Australian Act also provides for the completion of the directive forms by the person without necessarily any reference to their GP or Specialist and, indeed, at a time when they may have had no diagnosis at all. This may have the unintended consequence that the expressions given in an ACD may not be able to be reasonably interpreted in a clinical setting, causing confusion.

Binding Directives also negate the skills and opinion of the medical specialist in attendance. We think it an entirely negative development to endorse and embed a mentality that suggests that the doctor is merely a provider of services and the patient, the consumer. It is and always should be about a relationship of honesty and trust.

Other problems:

We have heard of cases where people presenting to a hospital for a scheduled procedure, have been asked about their preferences vis-à-vis resuscitation at the point of admission. This is entirely inappropriate. The patient is, understandably, nervous and concerned for the procedure and the outcome and, at that moment of admission, are hardly likely to be in a place to evaluate such questions with a clear mind and with any reasonable process of thought.

The author has also seen where, during a consult in an emergency department, the question of resuscitation is seen very much as an afterthought. It is understandable, in stressful situations, that medical staff are focussed on preserving the life as their priority, but sometimes it seems that the person, their wants and needs, are not immediately considered. Again, that is not the time to be asking a patient to make such decisions. Unfortunately, absent a formal ACP, the medical staff really have no other choice.

Preferred option:

We believe that a Medicare Item Number already exists for a doctor to have an extended conversation with his or her patient towards the goal of preparing an Advance Care Plan. A campaign to encourage doctors to discuss the possibility of completing an ACP with patients and a public awareness campaign encouraging the same could work well together.

The advantage of including the doctor in the discussion will, hopefully, go a long way to legitimizing and de-stigmatising such conversations. It will also, we believe, enhance the decision making process by the insertion of professional advice.

We also believe that the creation of ‘trigger points’ for the review of ACPs will assist with the aim of making sure that the document reflects the contemporary wishes of the patient and reflects fully informed consent.

We see such ‘trigger points’ as, for example:

- Moving to an aged care facility
- Receiving a difficult diagnosis
- Prior to hospitalisation for procedures
- Any other ‘life change’ moment where medical care is part of the change.
Working in this way overcomes any problems that people may have that their ‘Do Not Resuscitate’ statement, or any other statement, will be ignored or overridden. It puts the decision making squarely within the context of the current care of the person. Rather than, perhaps, being seen as a ‘necessary evil’ this type of arrangement may well be seen as a positive development in care, enhancing autonomy and wellbeing.

**ACP Registration:**

A continuing source of frustration to both governments and patients alike is the problem of ensuring that the person’s ACP will be automatically available to medical services as needed; especially in the situation of medical emergency. Absent any knowledge of an ACP and expressions to the contrary, emergency medicine protocols demand the use of resuscitation. This can be very distressing for family members and loved ones if, as expected, they had an understanding that resuscitation would not be applied. It should not be too difficult to arrange a file transfer or file sharing protocol between doctor and specialist or specialist to specialist or, at the very least, the making of notes concerning the content of the person’s ACP. It is the unexpected and emergency situations that cause the most consternation and frustration. Unfortunately, we do not know of any solution.

**Access:**

Even though Australia has been noted internationally as having excellent end-of-life care facilities, it remains that access to quality care is still determined more by a person’s credit card and postcode than it is, perhaps, by the need.

The Grattan Report[^1] also noted that the desire to die at home is a primary need expressed by many Australians that is not matched by the incidence. We see this partly as a problem of late rather than early referral to services but it is also partly as a result of insufficient funding and focus on outreach services to people in their place of residence.

More must be done to shift the focus on end-of-life care towards in-home care wherever possible. Outreach services, co-ordinated with GP services, is likely to also provide significant cost savings as compared with hospice or hospitalisation.

**In summary:**

Overall, we believe, the Tasmanian government’s approach to Palliative Care needs to arise from a coherent vision that creates a sense of wellbeing for all Tasmanians built upon a greater confidence that their needs will always be met. This is much more than the provision of the best standard of care available to all. It is also about the public perception.

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