



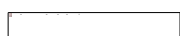
Inquiry into End of Life Choices

Submission to the Legislative Council Standing Committee on Legal and Social Issues

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Alfred Health is the main provider of health services to people living in the inner southeast suburbs of Melbourne and a major provider of specialist state-wide services to the people of Victoria. These services are provided across the continuum of care from ambulatory, to inpatient and home and community based services.

Every day, clinicians working at Alfred Health care for patients at the end of their life and these patients' loved-ones. Ensuring that patients who are dying have a "good death" is a high priority for our organisation

A number of recent Australian publications offer clear principles and actions to improve care at the end of life, including the Grattan Institute Report, Dying Well (Swerissen and Duckett, 2014) and Essential Elements for Safe and High Quality End of Life Care (ACSQHC, 2015). These publications are in part a response to a fear in the community that people are not always treated in accordance with their wishes at the end of their life and may well suffer, through unnecessary medical treatments.

It is the view of Alfred Health that with relatively minor legislative change, policy development especially around the provision of palliative care, education of both the community and clinicians and engagement with the broader community that these fears can be addressed and care improved for patients approaching the end of their lives.

Issues and challenges identified by Alfred Health

A number of barriers to good end of life care have been identified by Alfred Health clinicians. These include: difficulties accessing patient information; a poor understanding of palliative care in the community and amongst clinicians; the multiple obstacles that prevent patients from dying in their place of choice; a misunderstanding of existing legislation about end of life issues; minor flaws in the existing legislation; and clinicians' poor communication skills around end of life issues.

1. Access to patient information

A patient's care is often provided by multiple clinicians in different locations. Sharing and accessing patient information is often difficult. The current patient controlled electronic medical record has failed to improve communication between clinicians. Prompt access to a patient's medical information - including documented treatment wishes - remains sub-optimal.

2. Community and clinician perceptions and understanding of end of life issues

Discussions around death and dying can understandably be difficult for patients and medical staff. There is no mandatory requirement for palliative care training in the undergraduate medical curricula. As a result, many health professionals do not have expertise in end of life communication. When poorly handled by health professionals, these discussions can be distressing for patients and may lead to injurious decisions. A sensitive clinician with a competent ability to discuss end of life issues often results in treatment decisions that accurately reflect a patient's values and provides an opportunity to reassure patients that their last weeks or days need not be painful.

A lack of understanding of palliative care can also impact on the management and support for patients at the end of their life. Patients and families are sometimes hesitant to meet with the palliative care team, as they are "not ready to give up hope". This reflects the misconception that palliative care is only relevant when all active treatment has been withdrawn. Some clinicians believe palliative care is relevant only in the last days of life. This is not the case: palliative care teams can assist with symptom management and provide opportunities for patients and their loved-ones to discuss their fears and concerns. For many patients, involvement of the palliative care team occurs concurrently with active and even life-sustaining treatment in conjunction with other medical teams. Palliative care focuses on quality of life, holistic care and meticulous symptom management. Greater education on the role and benefits of palliative care is of paramount importance.

It is not uncommon for patients to express a desire to die; to request "something to end it all". We hear expressions of suffering such as, "You wouldn't treat a dog like this". Exploring the reasons behind such requests most often reveals one or more issues that are making the patient's life unbearable. For the vast majority of patients, palliative care interventions to address these issues can relieve the problem and the distress associated with it such that the patient no longer wishes to die. For some people, the fear of a painful and undignified death is overwhelming and may even lead them to eschew beneficial treatments. This fear can also feed into requests for euthanasia and physician assisted suicide.

The fear of an undignified death – the fear of pain, agitation or burdensome interventions in the last hours of life - is often expressed in the community. While there is no single cause

for this fear, it may arise from clinicians failing to appreciate that the burdens of treatment have come to outweigh the benefits of treatment. Clinicians may not recognise common symptoms during the last days of life or be familiar with the treatments that may alleviate them; they may not request specialist palliative care input when standard measures are not effective. A minimum level of skill in providing good end of life care is imperative for all staff. The impact on the patient themselves and on the family witnessing this unnecessary and avoidable suffering is often traumatic. Where adequate palliative care is available dying need not be undignified.

3. Supporting patients to die in their place of choice

The Grattan Institute Report, *Dying Well* (Swerissen and Duckett, 2014) suggests that many people prefer to die at home. It is often difficult to support patients in their wish to die at home. Whilst inpatient palliative care services provide 24-hour medical support, there are inadequate resources to assist patients to return home to provide the level of support that can often be required. Delays of 2-3 days in arranging a transfer home often means the patient becomes too frail to travel. Other patients have symptoms that are challenging to manage in a domestic environment with current levels of community resourcing. These people therefore need to be cared for in a hospice or in hospital with support from the palliative care team.

4. Understanding existing legislation related to end of life and Advance Care Plans

Advance Care Plans (ACPs) provide a means for people to plan ahead for a time when they may no longer be able to make, or make known, their treatment decisions. At present, in Victoria, there is legal uncertainty over whether a health professional is obliged to follow an ACP. There is also no immunity provided to health professionals who follow the instructions of an ACP. Health professionals can face threats of legal action from family members who disagree with a patient's ACP. Many residents in residential care have an ACP and it is not uncommon for families to demand active treatment contrary to the resident's ACP. This can result in a dying patient being transferred to an acute hospital against their pre-stated wishes.

A refusal of treatment certificate made under the *Medical Treatment Act 2000* (Vic) is a legally binding document that allows an individual to refuse medical treatment for a current medical condition. It provides immunity for medical practitioners who comply with the refusal of treatment certificate and prohibits them from treating a patient contrary to the certificate. In Victoria, this legislation does not yet apply to ACPs. The differences in legislation and the legal uncertainty around the adherence to ACPs exposes medical practitioners and other health professionals to legal action for negligence if they respect a

patient's wishes for no active treatment, and also if they treat the patient contrary to their wishes.

Poor knowledge among medical staff (and other health professionals) around relevant legislation relating to end of life can lead to scenarios where they may persist with or institute treatments that are no longer of benefit. The current legislation surrounding end of life care is ambiguous and difficult to decipher. This can leave medical staff with uncertainty around their obligation to follow an ACP, particularly in cases where there is some question or challenge from family members.

Amendments could be made to the *Medical Treatment Act 2000* (Vic) in relation to requiring health professionals to give effect to an ACP with appropriate exceptions (as set out in Chapter 13 of the Victorian Law Reform Commission's 2012 report on Guardianship) and providing immunity to health professionals who act in accordance with an ACP. Alfred Health would like to see greater legislative certainty in this area.

Recommendations for the Inquiry to consider

Considering the above issues and challenges, Alfred Health has a number of recommendations for the Inquiry to consider

1. New legislation to clarify the rights and obligations of patients and health professionals and to provide certainty on issues relating to end of life

Alfred Health proposes that current legislation surrounding end of life care issues needs to be clarified. Legislation should be consistent across refusal of treatment certificates and ACPs. Legislation needs to be clear and concise, to enable medical staff and other health professionals to honor their patients' wishes without acting in fear of legal action. Thought should be given to updating Victorian law regarding refusal of treatment certificates to no longer include that these only be relevant when the patient has a 'current condition'. The clause regarding the current condition can be confusing in certain clinical situations. Changes in this legislation would align Victorian law with the approach adopted in a number of other States and Territories.

The changes in legislation need to focus not only on enforceability of ACPs but also the protection of health professionals in circumstances of compliance with an ACP. The currency and age of ACPs remains a major issue and needs to be considered in the legislation to protect health professionals when choosing not to comply with an ACP in certain circumstances. As stated above, these exceptions were set out in Chapter 13 of the Victorian Law Reform Commission's 2012 report on Guardianship.

Alfred health recommends the following four sets of legislative changes:

Recommendation 1; Enforceability of ACPs

1.1 An ACP should be binding on health professionals if:

- (a) it is valid; and
- (b) the plan is relevant to the circumstances that have arisen.

1.2 An ACP does not operate if the maker would not have intended it to apply in the circumstances that have arisen. This occurs if one of the following applies:

- (a) circumstances, including advances in medical science, have changed since the completion of the advanced care plan to the extent that the maker, if they had known of the change in circumstances, would have considered that the terms of the ACP are inappropriate;
- (b) the meaning of the ACP is uncertain; or
- (c) there is persuasive evidence to suggest that the ACP is based on incorrect information or assumptions.

Recommendation 2; Protection for health professionals for compliance with an ACP

2.0 Section 9 of the *Medical Treatment Act 1988* (Vic) be amended to read:

9. Protection of registered health professionals

(1) A registered health professional or a person acting under the direction of a registered health professional who, in good faith and in reliance on a refusal of treatment certificate or an ACP, refuses to perform or continue medical treatment which he or she believes on reasonable grounds has been refused in accordance with this Act or is inconsistent with the advanced care plan is not:

- (a) guilty of misconduct or infamous misconduct in a professional respect; or
- (b) guilty of an offence; or
- (c) liable in any civil proceedings

because of the failure to perform or continue that treatment.

(2) For the purposes of this section a person who acts in good faith in reliance on a refusal of treatment certificate or an ACP but who is not aware that the certificate or ACP has been cancelled, is to be treated as having acted in good faith in reliance on a refusal of treatment certificate or ACP.

Recommendation 3; Protection for health professionals for non-compliance with an ACP

- 3.1 A health professional is not affected by an ACP to the extent that the health professional, acting in good faith, does not have actual knowledge that the person has an ACP.
- 3.2 A health professional who acts in reliance on an ACP in good faith and without actual knowledge that the ACP is invalid or cancelled does not incur any liability to the maker or anyone else because of the invalidity or cancellation.
- 3.3 A health professional must take reasonable steps to determine if a patient has made an ACP and to obtain a copy of and read it before deciding on what treatment (if any) the patient is to be offered.
- 3.4 A health professional who fails to take reasonable steps to determine if a patient has made an ACP and provides treatment that is inconsistent with the ACP will not be protected from liability by the provision providing protection for a lack of actual knowledge in clause 3.1 above.
3. A health professional is not required to check on the existence of an ACP if emergency treatment is required.

Recommendation 4; Emergency treatment

- 4.1 If emergency treatment is required and the health professional is aware of an ACP but does not have time to determine if it is valid or if a provision in the ACP is operative, and the health professional believes on reasonable grounds that one of the following applies:
 - (a) circumstances, including advances in medical science, have changed since the completion of the ACP to the extent that the maker, if they had known of the change in circumstances, would have considered the terms of the ACP inappropriate;
 - (b) the terms of the ACP are uncertain; or
 - (c) there is persuasive evidence to suggest that the ACP is based on incorrect information or assumptions

Then the health professional does not incur any liability, either to the maker or anyone else, if the health professional does not act according to the ACP.

NB: Any amending legislation will require a definition of “advanced care plan”.

2. *“Futile treatment” to be replaced with “non-beneficial treatment”*

Alfred Health proposes that the term “futile treatment” no longer be used in connection with end of life medical treatment. Alfred Health considers it should be replaced with the term “non-beneficial treatment”. “Futile” is defined as *“incapable of producing any useful result”*. This is misleading as many treatments do produce “useful results” which are nonetheless unwarranted because of the unacceptable outcomes of the treatment. Treatment is non-beneficial when the treatment burden is greater than the patient is willing to bear, or when the best possible outcome of the treatment falls short of what the patient perceives is an acceptable outcome.

In order to determine what treatment is non-beneficial, it is necessary for health care staff to explore the values of an individual patient, and explain treatment burdens and benefits (i.e. supported decision making). We believe that a shared decision making model should be supported by legislation and should be taught to all health care professionals. There should be investment in providing such training repeatedly to health care staff at all levels of practice, similar to that which is provided for advanced life support. The ACP has a key role to play here and it deserves legislative certainty around its operation. Chapter 13 of the Victorian Law Reform Commission’s 2012 report on Guardianship provides a useful template for this legislation.

3. *Retain medical decision on withholding non-beneficial treatment*

In addition, Alfred Health believes that health care professionals should not be required to provide non-beneficial treatments. Therefore, it is imperative that legislation continues to support and protect health care professionals who withhold or withdraw treatments that are non-beneficial (as defined above) without the requirement for consent from a patient or their substitute decision maker. This approach is consistent with current common law. A requirement for consent to withdraw non-beneficial treatment leads to the provision of non-beneficial treatments. This requirement for consent to treatment withdrawal may also lead to psychological distress in those providing consent for the withdrawal/withholding of treatments.

4. *Improved resourcing of Community and Hospital Palliative Care*

In order to support patients to die with dignity, health professionals need to have the knowledge and skills to be able to identify patients who are dying. There needs to be greater education of health care practitioners and the general community about the broader role of palliative care. Some mandated minimal curriculum for medical, nursing and allied health practitioners is recommended.

Access to specialist palliative care services is imperative in order to support generalist staff, provide education and provide input for those patients with difficult symptoms.

Symptom management is a core component of good end of life care and all medical practitioners should have basic skills in this area. Refractory symptoms benefit from specialist palliative care consultation. Many doctors are not comfortable exploring a patient's fears around dying, thus patients should have access to practitioners with skills in this area. Specialist palliative care services have expertise in providing excellent end of life care for patient groups with unique and complex needs.

Palliative care services need to be robustly resourced so that they can respond to the needs of patients and support other clinicians. Investment in community palliative care is vital to enable patients to die in their place of choice. Resources to enable this are currently inadequate.

5. Funding for clinician education in communication skills

Many clinicians lack the necessary educations and skills to discuss end of life issues with patients and their families. As a result, clinicians may feel uncomfortable discussing death and dying with their patients and as a consequence avoid such discussions.

Additional funding is required to educate clinicians in end of life communication and the associated issues. This education needs to begin within universities and continue throughout all levels of medical training. Various programs are already available for medical and nursing staff at Alfred Health. These include the *Breaking Bad News* workshops and the *End of Life Communications Course*. Increasing staff participation in these or similar programs would be of value in developing greater communication skills for staff. Alfred Health is striving to develop a workforce that delivers excellent end of life care. As the community becomes more empowered in decisions around their medical treatment, particularly at the end of life, we need a workforce that is equipped to meet their expectations; a workforce that is skilled at what may be difficult end of life conversations.

6. Government support for greater community and family engagement that will improve health literacy on end of life care and issues

Alfred Health believes that one of the fundamental problems with care at the end of life is that patients, families and their loved ones have never had the opportunity to talk about their wishes for their end of life care. Discussing dying can be a difficult, awkward or a taboo topic for families. While advance care planning is important, it is perhaps the conversation that is most important, families talking about dying and articulating their wishes and preferences amongst themselves. This is the premise of The Conversation

Project, a community driven collaboration with the Institute of Healthcare Improvement in the United States, which began in 2010. The project aims to encourage people to talk about their end of life wishes because these wishes “are better happening at the kitchen table rather than in the intensive care unit”. The Conversation Project is an example of a successful, community driven approach to issues around dying. Any approach that focuses on developing a clear understanding of family member’s and loved ones’ end of life wishes is critical to alleviate community concerns about the burden of suffering in the last days of life. We believe there would be great value in developing a comparable project in Victoria.

The “Discover, Decide, Discuss” awareness campaign is another valuable campaign. This campaign prompted community members to initiate a discussion with their loved ones about organ donation. Registrations on the Australian Organ Donor Register (AODR) have doubled throughout the campaign, and families are increasingly aware of their loved ones’ wishes. Taking a similar approach regarding end of life care preferences would potentially stimulate conversation about this important issue.

7. Establishing a state-wide database for recording patients’ end of life and medical treatment decisions: Improvements in accessibility and transfer of patient wishes relating to end of life care

Alfred Health believes the best way for a patient’s choices to be given effect is by them talking to their families before death is imminent. The accessibility of documents such as ACPs, refusal of treatment certificates and the appointment of an Enduring Medical Attorney is another barrier to ensuring that a person’s wishes are followed. Clinicians are often concerned about how up to date and how “legitimate” the end of life documentation is and whether it still reflects the patient’s current preferences and wishes. At present, in Victoria, there is no centralised repository of these documents and no consistent system across the state to ensure their accessibility. The Australian Organ Donor Register (AODR) is a national repository of the personal preferences of Australians with regard to organ and tissue donation. It is run by Medicare, and allows anyone to voluntarily add his or her information to the register. A small number of specialised staff can access the register, allowing immediate identification of the registration status for people anywhere in Australia. Alfred Health suggests that a similar centralised system of recording end of life preferences, such as ACPs, refusal of treatment certificates and the appointment of an Enduring Medical Attorney would increase the likelihood of a patient’s wishes being respected. Clinical triggers are in place to help staff identify potential organ donors, and all missed potential donors are audited and reviewed. Similarly, prompts for staff to search for relevant documents setting out a patient’s choices and the identity of an Enduring Medical Attorney, as well as the review of cases where these documents were not accessed or followed, will raise awareness amongst health care staff of the availability of these documents and assist with respecting a patient’s end of life wishes.

Conclusion

In summary, Alfred Health has a number of recommendations for the inquiry to consider that will, if implemented, improve end of life care. These changes will help address a number of the concerns that the Victorian community have about death and dying.

These include:

1. Changes in legislation related to Advance Care Planning.
2. Increased resources to improve the capacity for Advance Care Planning in the community and to consider a state-wide database for key documentation that assists decision making at the end of life.
3. A significant increase in the resources provided to both community and hospital palliative care services including the education and training of clinicians in palliative care and communication of issues around death and dying.
4. Promotion of an ongoing community discussion around end of life care that will improve people's understanding of death and dying, dispel myths about dying and reduce some of the current taboos around these discussions.

There is much talk about the problems in the Victorian community around death and dying being addressed by the introduction of legislation to support euthanasia and physician assisted suicide. This is not however the view of the majority of clinicians working at Alfred Health. With adequate resourcing to allow better planning for death, better clinical support at the end of life and relatively minor changes in legislation, Victorians would have much greater confidence as they approach the end of life and be free from the fear that they will have an undignified death.

References

1. Australian Commission on Safety and Quality in Health Care. (2015) *National Consensus Statement: essential elements for safe and high-quality end-of-life care*. Sydney: ACSQHC
2. Swerissen, H and Duckett, S. (2014) *Dying Well*. Melbourne: Grattan Institute.
3. Victorian Law Reform Commission (2012) *Guardianship final report 24*. Melbourne: Victorian Law Reform Commission