Submission to the Legislative Council Standing Committee on Legal and Social Issues
Inquiry into End of Life Choices

By Associate Professor Peter Hunter on behalf of the Victorian Clinical Leadership Group on care of older people in hospital

Clinical Leadership Group

The Victorian Clinical Leadership Group on care of older people in hospital (CLG) was established in 2012 and brings together experts who provide care for older people. The group includes senior clinicians, consumers, academics and researchers with an interest in the care of older people. Its purpose is to achieve optimal clinical outcomes, improve experience and provide safer care for older people in hospital. The CLG draws on the best available evidence and uses the National Safety and Quality Health Service Standards as leverage to highlight key strategies that hospitals can implement to improve the quality of care provided to older people. The CLG is committed to working together to improve outcomes for older people and sharing their knowledge and experience across Victoria.

Death and Dying

People over the age of 65 years are the largest users of health services in Victoria. As such, all clinicians, regardless of their field of work, need to be aware of the complex issues older people face in hospital. With more people dying at an older age and often with multiple chronic and debilitating illnesses, one of the most important issues facing this population is access to appropriate patient-centred care at the end of life.¹

Although dying is a normal part of life, the development and progress of sophisticated hospital-based medicine has led to it becoming “highly institutionalised”.² More people are now dying in hospitals than ever before and this has been associated with a rise in what is perceived as a “bad death”. People are often not adequately informed of their risk of dying and therefore not prepared for death. A major concern is that people in this situation lose control and have limited options or choice.

A critical element to any discussion around end of life care is to understand what a “good death” is and how it can be achieved. This has been the subject of an influential and important editorial in the British Medical Journal published in 2000. In addition to freedom from pain and suffering, a good death involves having some control over the dying process, particularly how to live the last days of life. This may be in the form of having wishes respected with regards to location of death, access to spiritual or emotional support, control over who is present and who shares the end and importantly, having time to say goodbye.³
Talking about Dying

In many cultures, talking about death is awkward and difficult and sometimes even taboo. This creates barriers to exercising autonomy and voicing end of life wishes. However, there may come a point in the trajectory of many chronic illnesses towards death where capacity to make decisions is lost. This often leads to people dying in a way they would not want and feelings of guilt and uncertainty for their loved ones. The solution to this problem lies in planning and ensuring discussions are held with families and important others about the future wishes of their loved one. People need to plan for what they would like to happen with regards to medical care when they can no longer decide for themselves and substitute decision makers need to be appointed who will be able to make decisions in their best interests.

A 2012 publication by Scarre reports that “while death is inevitable, how we die is highly dependent on the virtues, skills, planning and attention we bring to it, and that the best deaths are well-prepared ones”. In order to alleviate the angst about dying in our culture and to be able to have a “good death”, there needs to be opportunities to talk about and plan for it. In planning, clinicians need to recognise that their patients are entering a terminal phase of their illness where end of life issues need to be the focus. These end of life discussions can be difficult for both the clinician and their patients and are frequently avoided.

Advance Care Planning

Advanced care planning is a process undertaken to make decisions about future health care for a time when decision making capacity is lost. Discussions taking into consideration personal values and judgements are held in consultation with family members, important others and health care providers. This ensures that people make informed decisions and empowers them to have a say about their current and future treatments.

Advanced care planning should take place while people have decision-making capacity and are medically well. Health professionals involved in this process should ideally be a general practitioner or a specialist who has had a longstanding clinical relationship with the person involved. Given this, an acute hospital admission is not necessarily the time for advanced care planning, as it is often a time of acute illness and high emotional stress. Rather, an acute hospital admission would be an opportunity to flag the need for advanced care planning at some time in the near future after discharge from hospital.

Currently in Victoria, the only legislation around planning for health care is the Refusal of Treatment Order in the Medical Treatment Act of 1988 which allows a person over the age of 18 years of sound mind to refuse a medical treatment generally or refuse a medical treatment of a particular kind for a current illness. Medical trespass of this certificate is an assault. The Refusal of Treatment Order does not allow for planning for future medical conditions based on the values and wishes of the person involved.

Advance care planning may include completion of an advance care directive (ACD) which is a document that allows people to record their values and wishes for care and treatment for such a time when they do not have the capacity to enact their choices. In order to successfully implement
the ACD, documentation needs to be in a standardised form, accessible and available to healthcare providers when required. The CLG recommends that there is consistency in legislation and practice across Australia with regard to medical treatment, refusal of treatment, medical agency and advance care directives.

It is important that advance care planning is not seen as a one-off event, rather a continuous process of ongoing dialogue between all involved. Documented plans require regular review and there needs to be a system to ensure that the most current version of an ACD is available to all healthcare providers. This is because over time circumstances and people’s wishes may change. Patient controlled medical records may be one option in enabling the provision of the most current information but other approaches need to be investigated, assessed and considered. Clinicians acting on information contained in an ACD need to be confident that it is current and based on the opinions of a person who is fully informed about their clinical condition.

Documentation and evidence of advance care planning allows for autonomy and self-determination. It can provide reassurance to families and loved ones in their consideration of end of life choices and assists doctors in making treatment decisions by respecting their patient’s core values and principles. While this does not have to be mandatory, where documentation has been completed this must be respected when decision-making capacity is lost and failure to do so could be considered harm. Protection for doctors respecting and following the wishes of their patients and family members also needs to be ensured.

Enduring Power of Attorney

The Medical Treatment Act of 1988 and The Guardianship and Administration Act of 1986, allow for the appointment of an Enduring Power of Attorney (medical treatment EPOA). A medical EPOA needs to be witnessed by a person authorised by law to take and receive statutory declarations and only takes effect when the person giving the power loses decision-making capacity. The medical EPOA is able to consent to and refuse medical treatment on behalf of the person who no longer has capacity to make that decision. They must act in the best interest of the person and have knowledge of their wishes, values and expectations at the end of life. Appointment of a medical EPOA can be another way to promote conversations about dying and end of life care.

Hospital admissions are an excellent opportunity for doctors to initiate a discussion regarding goals of care and appointment of a medical EPOA. The CLG believes that all older people attending hospital should be encouraged to appoint a medical EPOA. This discussion can be initiated in the hospital and continued in the community. Hospital information systems should have documentation of medical EPOAs, refusal of treatment certificates and other planning documents and screening for the presence of such documents should be routine for each hospital admission.

The combination of advance care planning and appointment of a medical EPOA will allow for the first step in attaining a good death as it generates discussion amongst family and loved ones and may provide written clarification on what is most important. It also allows for an acceptable means of discussing end of life wishes so that appropriate care and dignity can be provided.
**Public Awareness, Education and the Importance of Good Palliative Care**

There needs to be increased awareness within the Australian community of the limits of health care. The public is frequently misinformed about the effectiveness of medical care in many settings. This requires public engagement and discussions regarding end of life to address these misconceptions and allow for realistic expectations of health care.\(^\text{7}\)

Furthermore, the community needs more information on the end of life choices available to them. They need to know that there is existing legislation that enables them to exercise their autonomy. Currently, there is very little awareness within the Australian public of advance care planning and palliative care.\(^\text{8}\) In a national telephone survey it was found that 14% of respondents had prepared an ACD which was lower than the completion of other planning documents such as wills and financial powers of attorney.\(^\text{9}\) Australia requires a similar program to the “The Conversation Project” which is a grassroots public campaign established in the United States across both traditional and new media to change the culture of discussing end of life issues.\(^\text{10}\)

When a decision is made for the withdrawal or withholding of treatment that is not beneficial, it needs to be understood that this does not equate to cessation of all care nor abandonment of the person. Palliative and comfort care will always be provided and the goals of care will be alleviation of symptoms rather than to cure or prolong life. Most of the concerns people have about physical suffering at the end of life can be addressed through the provision of adequately resourced palliative care services in hospitals and in the community and by improving the skills of all clinicians in the principles of good palliative care.

There needs to be increased funding for palliative care training, education and services, in particular community palliative care. The Grattan Institute report “Dying Well” in 2014, found that currently there is not enough assistance for carers to support people dying at home. The care that is provided is often poorly coordinated and access to these services is limited.\(^\text{7}\) Many people would prefer to die at home if they and their family were properly supported. Flexible programs must be developed and funded that support people dying out of hospital. Current palliative care services are unable to provide urgent or complex care for those dying in the community even though this may be the preferred location of care. Alongside this there needs to be increased capacity to share care in community, residential and hospital settings between primary care physicians, specialists and palliative care clinicians.

Older people do not always have access to specialist palliative care due to differences in their illness trajectories compared to traditional cancer trajectories.\(^\text{1}\) There needs to be more emphasis on training and research within palliative care in recognising end of life trajectories in conditions other than cancer.

The CLG believes that palliative care training should be a requirement for all clinicians. All clinicians need to learn to talk about death with patients and families. Communication with patients regarding their prognosis needs to be improved and clinicians need to learn how to provide good symptom management. Medical culture needs to move away from regarding death as a failure of medicine and accept it as a part of life. This cultural shift also needs to translate into both the public and private sector. This will require education from medical school through to specialist training.

Learning about dying needs to start at an undergraduate level and death and dying should be a
subject in its own right within all health care courses. Clinicians need to be taught to recognise dying as a diagnostic entity. Discussion about dying can’t commence if the clinician hasn’t first recognised this and too often this occurs in the final days or hours of life. This is not only inefficient, as significant resources are utilised keeping people alive who are inevitably and imminently going to die, but it can prevent patients and families from preparing in a timely way for the death.

Ageism and age discrimination are common at the end of life. Older people are often viewed as a homogenous and ever growing group with worsening pathology. According to the World Health Organisation, “older people suffer unnecessarily, owing to widespread underassessment and under-treatment of their problems and lack of access to palliative care”. Decisions around provision or withdrawal of treatment should not be based on age. Treatment decisions need to account for the likely benefit of treatment versus harm to that individual. Ageism in the health system needs to be addressed through a focus on person centred care and individualised management.

**Summary and Recommendations**

In conclusion the CLG has several recommendations to put to the Inquiry that will lead to an improvement in end of life care and address many of the concerns of the community.

- Advance care planning is a critical process in assisting decision making at the end of life. Resources need to be invested to ensure advance care planning occurs in the community. Issues regarding access to most current advanced care plans and directives and consistency between health services need to be addressed.
- Government needs to take the lead in promoting community discussions and improving health literacy around end of life care. We need to learn from the lessons of successful programs such as “The Conversation Project”.
- There must be increased resourcing of palliative care programs in hospitals and in the community and greater integration between the two to provide appropriate support to people at the end of life.

We believe that much of the societal concern regarding end of life is a result of a culture that is afraid to talk about death and dying and the increasing medicalisation of the dying process. This has led to much community discussion about alternative choices such as euthanasia and physician assisted suicide. However, this debate detracts from the pressing need for legislation and adequate resourcing of frameworks that would enable proper planning and preparation for dying. The focus needs to be on the importance of advanced care planning, appointment of medical EPOAs, provision of high quality palliative care to older people at the end of life and improving the health literacy of our community regarding end of life care.
References


2. Swerissen H and Duckett SJ. What can we do to help Australians die the way they want to? Medical Journal of Australia. 2015;202(1):10-12


Inquiry into End of Life Choices

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Chair
Victorian Clinical Leadership Group on care of older people in hospital

SUBMISSION CONTENT:

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To the Honourable Edward O'Donohue
Chair, Legal and Social Issues Committee

Please find attached a submission to the Inquiry into End of Life Choices on behalf of the Victorian Clinical Leadership Group on care of older people in hospital.
We would be glad of the opportunity to discuss this in more detail at a public hearing.

Yours Sincerely

A/Prof Peter Hunter
Chair, Victorian Clinical Leadership Group on care of older people in hospital

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