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End of Life issues: a discussion paper

In the last century, medicine and improved public health measures in Australia have been very successful in increasing life expectancy. However, this has changed the pattern of ageing and the pattern of dying. Increased longevity has created a new population of people burdened with complex and chronic disease and "advanced frailty". For this population the traditional models of care, focussing on curative and life-prolonging treatments, without automatically having concurrent goals of enhancing quality of life for patients and their families, can contribute to unnecessary and prolonged suffering at the end of life.[1]

Many people find it hard to face the dependency, helplessness, and discomfort that so often accompanies ageing, chronic disease and impending death. People need increased levels of support from family, carers, health practitioners and chaplains and they need to be respected, cared for and loved as people created and loved by God. They need to be able to have trusting relationships with those charged with their care and feel confident that they are in safe hands and no longer need to worry about what is happening.[2]

The LCA, through Aged Care and other diaconal ministries, has opportunities to serve people at the end of life in physical and psychological caring; and providing spiritual care to assist with a 'good death' for those in our care.[3]

[1] ANZSPM position statement – ANZSPM Position Statement (2014) on Quality End-of-Life Care - Part 1

[2] Catholic Health – Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, 2001; Part II Specific Issues; Chapter 4 Older persons and others with special needs. p35-41
http://www.cha.org.au/code-of-ethical-standards

[3] LCAQD – Lutheran Services – Diaconal Witness Statement on Lutheran Services

Advance care planning

With increased longevity and reduction in unexpected death from infectious diseases, it is more possible to predict, within a small number of years, when death may occur.

Even though the trajectory towards death can be variably predictable, it is important to engage with the process of predicting progress towards death, and advanced care planning can be undertaken for optimum management of this process. Clinical tools have been developed to assist in this process.[4] Advanced care planning is a journey with people and their families, which encompasses starting the conversation; establishing the person's priorities for their life and any goals that are outstanding; discussing values and beliefs; and what will help quality of life; discussing specific details about treatments and symptom management; and documenting the conversation.

There are also legal documentation processes that assist with decision-making particularly as the person may lose capacity. These include having a Will; appointing Enduring Power of Attorney (EPOA) for health and finance; and completing an Advance Health Directive. While Wills and EPOA are beyond the scope of this paper, there is more information about Advance Health Directives in Appendix A.

Palliative care

Definition

Palliative Care applies to non-specialist care and is defined by the World Health Organisation as:

> …an approach to care that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Palliative care also respects the choice of patients and helps their families to deal with practical issues, including coping with loss and grief throughout the illness and in case of bereavement.[5]

[4] Caresearch – PAtoolkit – A Framework for palliative care in community based aged care patients. www.caresearch.com.au; and University of Edinburgh – Supportive and Palliative Care Indicators Tool (SPICT)™ April 2016, www.spict.org.uk

[5] World Health Organisation – Palliative Care - fact sheet number 402, http://www.who.int/mediacentre/factsheets/fs402/en/

Appropriate palliative care is not confined to end-of-life care and can be provided in parallel with curative treatment, having different goals and focus. Palliative care is usually multidisciplinary and it is part of whole-person care that is not disease specific and therefore can be complementary to curative treatment.

"Palliative care is most effective when considered early in the course of the illness. Early palliative care not only improves quality of life for patients but also reduces unnecessary hospitalisations and use of health services. "[6]

Palliative care is never about withdrawing treatment or 'doing nothing'. It requires as much work and expertise as curative treatment but the goals are different. Access to palliative care is considered a human right by the World Health Organisation.

Specialist palliative care is only one component of palliative care service delivery. A sustainable, quality and accessible palliative care system needs to be integrated into primary health care, community and home-based care, as well as supporting care providers such as family and community volunteers.[7]

End-of-Life care

Recognising when a person is approaching the end of their life is essential to delivering appropriate, compassionate and timely end-of-life care. There needs to be rigour in assessment of symptoms including physical, cognitive, psychological, social and spiritual domains. A formal diagnosis of the 'terminal phase' needs to be made so this phase can be managed effectively. Care of the dying should be considered 'urgent care' that is managed by those skilled in this area. It is as important as care for reversible conditions.[8]

When it is recognised that a person has entered the terminal phase, this needs to be communicated to the person, substitute decision makers and families. Uncertainties and ambiguities need to be discussed openly and honestly and communication needs to be on going. This will empower people

[6] World Health Organisation – Palliative Care - fact sheet number 402, http://www.who.int/mediacentre/factsheets/fs402/en/
[7] World Health Organisation – Palliative Care - fact sheet number 402, http://www.who.int/mediacentre/factsheets/fs402/en/
[8] Australian Commission on Safety and Quality in Health Care – National consensus statement: essential elements for safe and high-quality end-of-life care, https://www.safetyandquality.gov.au/publications/national-consensus-statement-essential-elements-for-safe-and-high-quality-paediatric-end-of-life-care/

and their families to direct their own care, where possible, and express needs and wishes for this phase. Documentation of communications is important for future reference and decision-making.

There are ethical issues that need to be considered in end-of-life care.

- It is important not to harm people approaching the end-of-life by providing burdensome investigations and treatments that can be of no benefit.
- Doctors are not obliged to initiate or continue treatments that will not offer a reasonable hope of benefit or improve the person's quality of life (unless required by law).
- People also have the right to refuse treatments. This may be in advance, formally in an advance health directive or informally in documentation of conversation or consultation with the person.
- Giving palliative care is legal so long as the health professional's intention is to reduce or relieve a patient's pain and suffering, not hasten death. This is the case even if the health professional knows death may be hastened by providing palliative care. This is known as the 'doctrine of double effect'. However the majority of interventions given in end-of-life care by skilled health care teams neither hasten nor obstruct the person's natural dying.[9] [10]

Care of the person and their family extends beyond death. Respectful treatment of remains and observance of cultural or religious practices need to be considered. Families also need to be cared for with appropriate time and space to grieve and follow up with bereavement counselling if this is wanted.[11]

If end-of-life care is well managed, symptoms should be minimised and the transition from life on earth, through death, to life in eternity is made as smooth as possible. In most cases, suffering at the end of life can be prevented, or significantly reduced. It is often suffering and loss of control that people are frightened of more than death itself.

Euthanasia

The Lutheran Church of Australia (LCA) has limited formal statements on end-of-life issues. A number of papers speak of respect for life, e.g. those dealing with abortion, assisted reproductive technologies and capital punishment. The LCA's Commission on Social and Bioethical Questions (CSBQ) issued a Euthanasia or Mercy Killing (1981) statement that was endorsed by Synod (see http://www.lca.org.au/departments/commissions/social-bioethical-questions/), which is still relevant,

[9] Australian Commission on Safety and Quality in Health Care – National consensus statement: essential elements for safe and high-quality end-of-life care, https://www.safetyandquality.gov.au/publications/national-consensus-statement-essential-elements-for-safe-and-high-quality-paediatric-end-of-life-care/
[10] End of Life Law in Australia - https://end-of-life.qut.edu.au
[11] Australian Commission on Safety and Quality in Health Care – National consensus statement: essential elements for safe and high-quality end-of-life care, https://www.safetyandquality.gov.au/publications/national-consensus-statement-essential-elements-for-safe-and-high-quality-paediatric-end-of-life-care/

but is now 35 years old and does not address recent developments in end-of-life issues such as Advance Care Directives.

The LCA upholds the CSBQ euthanasia statement. Rather than euthanasia, the church calls for greater efforts to improve and extend palliative care and other measures to reduce suffering in our society. Such measures have demonstrated productive outcomes in the management of pain and the care of those at the end of their earthly life.

Definition

Euthanasia is a deliberate, intentional act of one person to end the life of another person in order to relieve that person's suffering. The term euthanasia is often used in different ways. Three of the most common are:

- Voluntary euthanasia**:** Euthanasia is performed at the request of the person whose life is ended, and that person is competent (has sufficient decision-making capacity).
- Non-voluntary euthanasia: Euthanasia is performed and the person is not competent. They are deemed to be 'suffering' by others and are not able to consent.
- Involuntary euthanasia: Euthanasia is performed and the person is competent but has not expressed the wish to die or has expressed a wish that he or she does not die. They are deemed to be 'suffering' by others.[12]

Physician-assisted suicide occurs where a person requests a doctor to assist them in committing suicide, for example, a doctor provides a person with a prescription to obtain a lethal dose of drugs

Legal issues

Both euthanasia and assisted suicide are currently illegal in all Australian States and Territories, and may result in a person being charged with murder, manslaughter or assisting suicide.

If euthanasia is legalised this will raise many complex issues for both secular and church organisations. The specific details will depend on the wording of the legislation.

The majority of health organisations remain opposed to euthanasia.[13]

[12] https://end-of-life.qut.edu.au/about/glossary#547630

[13] Australian Medical Association – Position Statement on Euthanasia and Physician Assisted Suicide 2016, https://ama.com.au/position-statement/euthanasia-and-physician-assisted-suicide-2016; and ANZSPM position statement – ANZSPM Position Statement (2013) on The Practice of Euthanasia & Assisted Suicide

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The Committee for Ministry with the Ageing invites your feedback on this discussion paper via cma@lca.org.au

Appendix A

Legal standing of Advance Health Directives in Australia

State	Legislation	Statutory document	Common law document	Comments
Queensland	Powers of Attorney act 1998	yes	no	Advance health directive
South Australia	Advance Care directives act 2013	yes	yes	Advance care directive
Victoria *current*	Medical treatment act 1988	uncertain	uncertain	Refusal of treatment certificate
Victoria *from March 2018*	Medical treatment planning and decisions act 2016	yes	yes	Advanced care directive.
New South Wales	-	no	yes	Uncertain if specific document
Tasmania	-	no	yes	Uncertain if specific document
Australian Capital Territory	Medical Treatment act 2006	yes	yes	Health direction
Northern Territory	Advance personal planning act 2013	yes	yes	An advance personal plan
Western Australia	Guardianship and administration act 1990	yes	yes	Advance Health directive.

Conditions for making an Advance health directive

- Over 18
- Decision making capacity/competence
- Voluntary and uncoerced
- In writing (usually specific form)
- Signed
- Witnessed – various models

More detailed information is available from https://end-of-life.qut.edu.au/advance-directives