



24 June 2016.

Mr Todd Buttsworth
Secretary
Standing Committee on Community Development

todd.buttsworth@parliament.tas.gov.au

Dear Mr Buttsworth

The Office of Life Marriage and Family, a pastoral agency of the Catholic Archdiocese of Hobart, welcomes the opportunity to provide comments on the terms of reference of the Standing Committee on Community Development's Inquiry into Palliative Care:

upon the matter of care of palliative patients generally,
specifically the matters of:

- (i) advance care directives;
- (ii) administration of medical treatments to minors;
- (iii) the administration of emergency medical treatment; and,
- (iv) other matters incidental thereto.

a) The Catholic approach to palliative care

The Catholic Church has a strong and ongoing tradition of caring for people who are dying and for their families, with Catholic providers delivering up to half of all palliative care services across Australia.¹ Our approach to palliative care is oriented to caring for, and accompanying, a dying person and his or her carers in the final phase of life, upholding that person's dignity and respecting his or her spiritual, physical, emotional and social needs. It also encompasses care for bereaved family and others.²

In an address to the Pontifical Council for Life in 2015, Pope Francis said:

¹ Catholic Health Australia, (2010). *Pursuing excellence in palliative Care*, Palliative Care Blueprint Policy.

<http://www.cha.org.au/advocacy/health/192-putting-palliative-care-on-the-national-policy-agenda.html>

² Catholic Health Australia, *Code of ethical standards for Catholic health and aged care services in Australia*. Catholic Health Australia Inc, 2001, 5.6. <http://www.cha.org.au/code-of-ethical-standards.html>

Palliative care is an expression of the truly human attitude of taking care of one another, especially of those who suffer. It is a testimony that the human person is always precious, even if marked by illness and old age. Indeed, the person, under any circumstances, is an asset to him/herself and to others and is loved by God. This is why, when their life becomes very fragile and the end of their earthly existence approaches, we feel the responsibility to assist and accompany them in the best way.³

This passage expresses two fundamental values of palliative care – respect for the dignity of the human person and the exercise of genuine compassion.

Dignity is a term which describes the intrinsic and inestimable worth of the human person. It reminds us that our value as a person does not depend upon characteristics such as our health, capabilities, appearance, or accomplishments. Our value is found in our very being.

This means that in spite of what we feel or think about the ‘quality’ of our lives, we can never lose our dignity. Even if we can no longer speak, or feed, or toilet ourselves, we always retain the dignity of a person. Our lives are always God’s gift to each one of us and to the world. The term ‘dying with dignity’ can mean different things to different people. However, from this perspective ‘dying with dignity’ means living through the dying process in a way which reflects the inherent value of our lives. It involves an acceptance of the natural process of dying as the final chapter of our lives.

No one should, however, have to face death alone. Throughout life, but particularly when we are dying, we need the compassion of other people to affirm our self-worth and the value of our lives. Compassion is much more than kindness, sympathy, or even empathy. Compassion means literally to ‘suffer with’ another person; an experience which leads to practical expressions of respect, love and care. Compassion for people who are dying gives rise to a commitment to do everything possible to relieve suffering and to stay with them until their natural end.

These values were beautifully expressed by Dame Cicely Saunders, a leading figure in the development of modern palliative care, when she wrote:

You matter because you are you.
You matter to the last moment of your life,
And we will do all we can, not only
To help you die peacefully, but also to live until you die.

Palliative care is an integral part of the services and mission of the Catholic Church.

In Tasmania, **Calvary Health Care Tasmania** provides palliative and end of life care in all four Calvary hospitals. Calvary has two units in Tasmania specifically focussed on palliative care. The Gibson Unit at the St John’s Hospital, Hobart, is a purpose built palliative care, haematology, medical oncology, radiation oncology and general medicine unit. The Melwood Palliative Care Unit at the St Luke’s Hospital, Launceston, provides inpatient palliative care for public and private patients to the people of Northern Tasmania. Calvary Health Care Tasmania is committed to delivering compassionate, integrated and holistic health care to people who are approaching or reaching the end of life. All clinical and non-clinical staff are therefore trained in palliative and end of life care.

As Tasmania’s leading aged care provider, the mission of **Southern Cross Care Tasmania** is also often involved in the provision of palliative and end of life care to residents and clients. All staff are trained in the provision of care through a Palliative Approach philosophy and are highly experienced in the

3 Pope Francis, *Address to Pontifical Academy for Life*, 5/3/2015,

https://w2.vatican.va/content/francesco/en/speeches/2015/march/documents/papa-francesco_20150305_pontificia-accademia-vita.html

provision of end of life care to older people. Staff call on the expertise of the specialist palliative care services when necessary.

Earlier this year, the Archdiocese of Hobart published a booklet entitled *Living to the end: a guide for Christians*, which seeks to bring the resources of the Christian perspective to encourage individual reflection and preparation for a good death. Although it is intended as a personal guide, it is also hoped that it will provide insight into how to help others prepare for death. While it is addressed to Christians, people of all faiths or no faith, are invited to explore our faith tradition in the hope that it might provide helpful counsel.⁴

b) The scope and limits of palliative care

i. Holistic care

Although it is a very personal question, when patients, families and health care providers are asked by social researchers to describe what makes a 'good death' the most common themes are:

- Good pain and symptom management,
- Being able to participate in decisions about medical treatment and care
- Knowledge of what to expect during the course of the illness and the opportunity to plan for the events that would follow death.
- The opportunity to attend to religious or spiritual beliefs, review one's life, resolve conflicts, spend time with family and friends, and say good-bye.
- Being able to contribute to the well-being of others, perhaps in the form of gifts, time or knowledge
- Receiving empathetic care which affirms the patient as a unique and whole person.

Notably, for most people psychological, social and spiritual issues are as important as medical concerns, even if the opportunity to address critical psychosocial and spiritual issues often relies upon the management of physical symptoms.⁵

As a human act, dying involves our whole person, body and soul, and involves a range of physical and spiritual needs.

The full and proper scope of palliative care is well expressed by the World Health Organisation's (WHO) definition of palliative care.⁶

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;

⁴ *Living to the end: A guide for Christians* can be read on-line at <http://hobart.catholic.org.au/faith/page/living-and-dying>

⁵ Steinhauer, KE, Clipp, E.C. et al. (2000) In search of a good death: Observations of patients, families, and providers, *Ann Intern Med*, 132:825-832.

⁶ <http://www.who.int/cancer/palliative/definition/en/>

- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

ii. The avoidance of overly burdensome and futile treatment

As expressed by the WHO definition of palliative care, palliative care intends neither to hasten nor postpone death. Catholic Health Australia, in its *Code of Ethical Standards*, further elaborates on the need for end of life care to avoid these two extremes:

“...on the one hand, an insistence on futile and overly-burdensome treatments which merely obstruct death, on the other hand, the deliberate withdrawal of treatment in order to bring about death. Since good medicine treats a person rather than a condition, respect for persons requires that they neither be under-treated nor over-treated; rather, when people are dying they should have access to the care that is appropriate to their condition.”⁷

With regard to decisions about life-sustaining treatments for patients who are terminally ill, Catholic Health Australia states therefore that:

The fundamental ethical principle in this regard is that treatments may legitimately be forgone (withheld or withdrawn) if they are therapeutically futile, overly burdensome to the patient or not reasonably available without disproportionate hardship to the patient, carers or others.⁸

All patients have the legal right to refuse treatment. Alongside traditional medical ethics, the Catholic ethical tradition clearly recognises that people may rightly refuse a medical treatment because it is no longer working (futile) or because it has become overly burdensome, *even if they foresee that death may come sooner as a result of this choice*.

Importantly, decisions to forego medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family, should be clearly distinguished from acts of euthanasia. Euthanasia is an action or omission which of itself and by intention causes death, with the purpose of eliminating all suffering. To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death.⁹

iii. Appropriate provision of nutrition and hydration

Palliative care is provided up until the end of life and is by definition never futile.¹⁰

Even if treatments are withheld or withdrawn because they are therapeutically futile or overly-burdensome, other forms of care such as appropriate feeding, hydration and treatment of infection, comfort care and hygiene should be continued. In particular, food and fluids (nutrition and hydration)

⁷ CHA, *Code of ethical standards*, 5.3.

⁸ CHA, *Code of ethical standards*, 5.9.

⁹ John Paul II.(1995) *Evangelium vitae*, 65.

¹⁰ Radbruch et al on behalf of the board members of the EAPC, 'Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care,' *Palliative Medicine*, 2015, p. 8.

should continue to be provided, even by artificial means, until such time as they are no longer sustaining life or until their means of provision becomes overly burdensome.¹¹

While food and drink should always be made available to conscious patients at the end of life if requested, the desire and need for food and fluids commonly declines and eventually ceases in the last few days of life. This is a normal part of the dying process. Similarly, the medical provision of hydration and nutrition (via PEG, naso-gastric or IV routes) is not indicated during the final phases of the dying process. At this late stage, oral comfort can be maintained by regular mouth care (e.g. mouth swabs dipped in iced water).

iv. Pain and other symptom relief

Christian and traditional medical ethics recognise the value of taking pain and other symptom relieving medications. Under-treatment of pain or distress can cause considerable physical, emotional and spiritual suffering.

To this end, we affirm the use of pain relief (e.g. opioids such as morphine) and sedative medications (e.g. midazolam) for symptom control in palliative and end of life care. If these medications are only introduced where necessary, and the dose is increased gradually and only to the level needed for symptom relief, they *do not* hasten a patient's death.¹²

Wherever possible, people should be involved in their care and treatment plans. As some medications have sedative effects, the patient may wish to balance the level of symptom control they are comfortable with against the level of sedation, so that they can be more aware of their family's presence, or prepare for death. This is a personal decision which should be respected by family and health care practitioners. If people are not able to indicate their wishes, it is reasonable to presume that they would wish to take symptom-relieving medication.¹³

The European Association for Palliative Care (EAPC) provides comprehensive procedural guidelines for the use of 'palliative sedation' in the care of selected palliative care patients with intolerable distress due to physical symptoms, when there is a lack of other methods for palliation within an acceptable time frame and without unacceptable adverse effects. The most common symptoms include agitated delirium, dyspnoea, pain and convulsions. Emergency situations may include massive haemorrhage, asphyxiation, severe terminal dyspnoea or overwhelming pain crisis. The EAPC guidelines cautiously note that occasionally, when patients approach the end of life, sedation may be considered for severe non-physical symptoms such as refractory depression, anxiety, demoralization or existential distress. Special precautions are presented for these clinical circumstances.

While transient or respite sedation may be indicated to provide temporary relief whilst waiting for treatment benefit from other therapeutic approaches, the guidelines clearly state that *continuous deep sedation* should only be considered if the patient is likely to die within days.

In this regard, and warning of its potential for misuse, EAPC insists that palliative sedation should never have the intention to shorten life.

Palliative sedation in those imminently dying must be distinguished from euthanasia. In palliative sedation, the intention is to relieve intolerable suffering, the procedure is to use a sedating drug for symptom control and the successful outcome is the alleviation of distress. In euthanasia, the

¹¹ CHA, *Code of ethical standards*, 5.12.

¹² Good, P.D., Ravenscroft P.J. and Cavenagh, J. (2005) Effects of opioids and sedatives on survival in an Australian inpatient palliative care population. *Internal Medicine Journal*; 35: 512–517.

¹³ Congregation for the Doctrine of the Faith, (1980). *Declaration on Euthanasia*.

intention is to end the life of the patient, the procedure is to administer a lethal drug and the successful outcome is immediate death.¹⁴

v. Euthanasia and physician assisted suicide are not components of palliative care.

Euthanasia is any action or omission which of itself and by intention causes death with the purpose of eliminating all suffering. Physician assisted suicide is a suicide which is intentionally aided by a medical professional.

As already explained throughout this submission, euthanasia (and assisted suicide) must be distinguished from other palliative care decisions which sometimes risk or have the effect of shortening life but which are not intended to hasten death (e.g. the giving of appropriate pain relief, the withdrawal of burdensome treatments).¹⁵

Even if their undertaking is genuinely voluntary, acts of euthanasia are always unethical because they involve the deliberate killing of another human being. Further to this principled objection, are serious concerns for the wider effects that the availability and legalisation of euthanasia and assisted suicide would have upon vulnerable people, as well as the integrity and practice of health care and law.

In 2105, the World Medical Association reaffirmed “its strong belief that euthanasia is in conflict with basic ethical principles of medical practice” and strongly encouraged “all National Medical Associations and physicians to refrain from participating in euthanasia, even if national law allows it or decriminalizes it under certain conditions.”

Additionally, the WHO states that “Physician-assisted suicide, like euthanasia, is unethical and must be condemned by the medical profession. Where the assistance of the physician is intentionally and deliberately directed at enabling an individual to end his or her own life, the physician acts unethically.”¹⁶

The position of Palliative Care Australia is that “Euthanasia and assisted suicide are not part of palliative care practice”.¹⁷

The European Association for Palliative Care (EAPC) also again rejected the inclusion of euthanasia and physician assisted suicide within the practice of palliative care in a 2015 Position Paper. Their closing statement of their White Paper is particularly instructive:

Certainly, even the best palliative care model or service cannot prevent patients sometimes asking for hastened death. However, there is a fundamental difference in the approach to these patients between euthanasia and palliative care. Proponents of the legalization of euthanasia take the request of the patient as the point of reference of the patient’s autonomy and try to comply with this personal preference. Palliative care experts should also acknowledge the requests for euthanasia in those patients who express them, but make this the starting point of holistic care, beginning with comprehensive assessment and communication and trying to understand the motivation and attitude behind the patient’s wish.

¹⁴ Cherny, Radbruch and the Board of the the European Association for Palliative Care, (2009) ‘The European Association for Palliative Care recommended framework for the use of sedation in palliative care,’ *Palliative Medicine*, 23(7) 581–593. <http://www.eapcnet.eu/LinkClick.aspx?fileticket=RKDokneiDJc%3d&tabid=38>

¹⁵ CHA, *Code of ethical standards*, 5.20.

¹⁶ The World Medical Association's Declaration on Euthanasia, adopted by the 38th World Medical Assembly, Madrid, Spain, October 1987 and reaffirmed by the 170th WMA Council Session, Divonne-les-Bains, France, May 2005; Statement on Physician-Assisted Suicide, adopted by the 44th World Medical Assembly, Marbella, Spain, September 1992 and editorially revised by the 170th WMA Council Session, Divonne-les-Bains, France, May 2005. <http://www.wma.net/en/30publications/10policies/e13b/>

¹⁷ *Euthanasia and Physician Assisted Suicide. Position Statement*, Palliative Care Australia, 2011. <http://palliativecare.org.au/wp-content/uploads/2015/08/PCA-position-statement-Euthanasia-and-Physician-Assisted-Suicide.pdf>

In conclusion, patients requesting a lethal injection to end their suffering by the induction of death are a great challenge in palliative care. Those patients deserve not only the best form of medical therapy for symptom control but also special psychosocial and spiritual counselling, based on individual respect and understanding in situations of misery and despair.

Palliative care is based on the view that even in a patient's most miserable moments, sensitive communication, based on trust and partnership, can improve the situation and change views that his or her life is worth living.¹⁸

Underlying the clear position of these and the vast majority of professional health care associations around the world, is the understanding that intentional killing is unethical and fundamentally opposed to the goals of health care. Once the goals of medicine become not only life, health, and comfort, but also death, doctors can no longer promise *always* to protect and promote the life and health of their patients, undermining the trust upon which the doctor-patient relationship depends.

As John Keown argues "...the fact that, through depression, pain or loneliness, some patients may lose sight of their worth is no argument for endorsing their misguided judgement that their life is no longer worth living. Were the law to allow patients to be intentionally killed by their doctors, it would be accepting that there are two categories of patients: those whose lives are worth living, and those who are better off dead. What signal, moreover, would that send out to people who are sick, elderly disabled or dying?"¹⁹ Vulnerable patients may need to be protected from pressures which lower their self-esteem or encourage self-abandonment.²⁰

In addition to being fundamentally incompatible with the ethos and goals of palliative care, there is emerging evidence that where euthanasia and assisted suicide are legalised, so-called 'safeguards' are being ignored, vulnerable people are being euthanised without their explicit request and informed consent, and eligibility criteria for who can access voluntary euthanasia and assisted suicide is open to contest and risks being expanded to include vulnerable people (so-called 'bracket creep').²¹

c) The care of palliative patients

Some particular issues related to the care of palliative patients for the Committee's consideration include:

i. Greater investment in community-based support

It is expected that the number of people who die each year in Australia will almost double in the next quarter of a century.²² Clearly, considerable forward planning is necessary to ensure that all Tasmanians have access to timely, coordinated and responsive palliative care into the future.

One important area for development is community-based care. A recent national report by the Grattan Institute (2014) found that dying in Australia is more institutionalised than in the rest of the world.

¹⁸ Radbruch et al on behalf of the board members of the EAPC, 'Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care,' *Palliative Medicine*, 2015, p. 13.

¹⁹ Keown, J. 'Mr Marty's muddle: a superficial and selective case for euthanasia in Europe,' *Journal of Medical Ethics*, 2006; 32:31-2.

²⁰ CHA, *Code of ethical standards*, 5.5.

²¹ For a concise summary see, Graham, H. & Pritchard, J. (2013) *Voluntary euthanasia and 'assisted dying' in Tasmania: A response to Giddings & McKim*. <http://www.bestcare.com.au/documents/reports/Voluntary-Euthanasia-and-Assisted-Dying-in-Tasmania-A-Response-to-Giddings-and-McKim-Oct2013.pdf>

See also Jones, D.A. *Assisted suicide and euthanasia: a guide to the evidence*. (2015) Anscombe Bioethics Centre, Oxford. <http://www.bioethics.org.uk/evidenceguide.html>

²² Swerissen, H. and Duckett, S. *Dying well*. Grattan Institute Report No. 2014-10, September 2014, pp. 6,7.

Indeed, people are twice as likely to die at home in countries such as New Zealand, the United States, Ireland and France, than in Australia.²³

Despite the fact that 70 per cent of Australian people want to die at home, only about 14 per cent do so. The report noted that “Community and medical attitudes plus a lack of funds for formal community care mean that about half of Australians die in hospital, and about a third in residential care.”

The development of primary care services capability and capacity to provide palliative care, as well as additional investment in generalist palliative care services and in specialist care services for home or non-hospital based care is an important priority for the future.

ii. Care at the end of life for people with dementia:

A national survey conducted for Alzheimer’s Australia in 2014 found that many family carers report that people with dementia have difficulty getting access to appropriate palliative care services:

- 58% stated that the person with dementia did not have access to palliative care specialists
- 68% indicated that the person with dementia did not have access to hospice care
- 49% indicated that there was no support available in the community at end of life
- 26% reported they were dissatisfied with the care the person with dementia received at the end of life.
- 22% of former family carers felt that pain was not managed well at end of life for the person with dementia

As explained in the report: “Dementia has characteristics that make it different from other terminal conditions. It has an unpredictable trajectory and there can be difficult issues around capacity, decision making and communication. As a result, people with dementia may struggle to get access to palliative care services or hospices that meet their needs.”²⁴

A targeted approach to improving the provision of palliative care to people with dementia should be an important focus of any attempts to improve the provision of quality palliative care in Tasmania.

iii. Perinatal palliative care

Another specific area for consideration, which has been the recent focus of Catholic Health Australia, is perinatal palliative care. In Australia, there are approximately 1,200 infants who die every year before their first birthday, most in the first days or weeks of life, but with no palliative care services available to these babies or support for their families.²⁵

In their submission to the 2015 Consultation on End-of-Life Care in Victoria, Catholic Health Australia wrote:

Significant barriers to the provision of perinatal palliative care remain, including the lack of appropriately trained health care professionals, resources to finance care, and scientific research to inform evidence-based policies and treatment. Studies are needed to identify the infrastructure and resources health care providers need to be able to support improved communication with patients and overcome barriers to the delivery of perinatal palliative care.

²³ Ibid, p.2.

²⁴ Alzheimer’s Australia, 2014. *End of life care for people with dementia: Survey report*. February 2014, https://fightdementia.org.au/files/EOI_ExecSummary_Web_Version.pdf p. 5.

²⁵ Wilkinson, Dominic. ‘We need palliative care for babies facing certain death,’ *The Conversation*, July 15, 2013. <http://theconversation.com/we-need-palliative-care-for-babies-facing-certain-death-15932>

Strategies are needed to integrate the joint clinical management and philosophies of palliative care, intensive care, antenatal and postnatal care teams in order to guarantee continuity of care and respect the process of parenthood. Early management of an infant's pain or symptoms is important to reduce suffering, as is effective communication and education of the family to inform decision-making.²⁶

A range of on-line perinatal palliative care resources have been developed with the support of Catholic Health Australia and made available at <http://www.pnpc.org.au/>

iv. Education for health care professionals and the community

Regrettably, there appears to be ongoing ethical and legal confusion over the distinction between palliative care and euthanasia, which manifests itself in poor standards of care for patients at the end of their lives.

The aforementioned Alzheimer's Australia Survey found low levels of awareness amongst health care professionals about the rights of a person to refuse or discontinue medical treatment at the end of life:

- 8% of care professionals indicated that they did not think patients had a legal right to refuse medical treatment or have existing interventions withdrawn.
- 12% did not think that people have the right to refuse food or fluids, with an additional 17% being unsure.
- 11% indicated that they thought refusal of antibiotics was not a legal option for people at end of life.²⁷

Equally concerning, 27% of care professionals did not think adequate pain control (if it might also hasten death) was a legal choice for people in Australia or were unsure.²⁸ This is in spite of the fact that no doctors have ever been prosecuted in Australia for prescribing too much pain relief.²⁹

Both the health sector and the broader community require further education about ethical and legal options for end of life care. Doctors in particular should be better informed of the protection offered by the current common law.

d) Advanced care directives

The Catholic Church encourages prospective and current patients and residents in Catholic health and aged care facilities or any other facility, to reflect on their future health care needs and to appoint a person who will represent them if they are unable to make their own decisions or express their wishes.

Catholic Health Australia and the Australian Catholic Bishops Conference provide an important source of information for people considering their future health care needs, and source of guidance for health care professionals, that is consistent with Catholic and good secular ethics. Their website My Future

²⁶ Catholic Health Australia, *Submission to the Legal and Social Issues Committee, Consultation on End-of-Life Care in Victoria*, 2015.

²⁷ Alzheimer's Australia, 2014. *End of life care for people with dementia: Survey report*. February 2014, https://fightdementia.org.au/files/EOI_ExecSummary_Web_Version.pdf pp. 6, 9.

²⁸ ²⁸ *ibid*

²⁹ Komesaroff, P & Charles, S.A. (2015) 'A minimalist legislative solution to the problem of euthanasia,' *Medical Journal of Australia*, 202 (9), pp.480-82.

Care <http://myfuturecare.org.au/> provides guidance and free resources, including an Advance Care Plan to:

- Help people nominate a representative to make health care decisions based on their wishes and values;
- Help people provide reasonable and adequate guidance for their representative; and
- Recognise the issues that need to be taken into account to achieve this.

A variety of approaches already exist in the wider community to guide future medical treatment. These often encourage the use of ‘advanced care directives’ or ‘living wills’ to document a person’s wishes about specific medical treatment in case an illness or accident leaves him or her unable to communicate.

Catholic Health Australia, however, recommends that people appoint a person to represent them, rather than try to write down specific advanced directives. An advantage of this approach is that a representative is able to respond to changing circumstances based on the subject’s advice, the advice of his or her health care professionals, and the representative’s own good judgement.

Within this approach, people may choose to provide their representative with guidance about their wishes or values, (verbally or in writing, or by having it recorded in their doctor’s records). They may, for example, wish to clarify the burdens they would find unacceptable, requesting only the kind of treatment or care that can be provided at home, without the need for prolonged hospital care. Other people will be content to allow their representative to make decisions for them.

In summary, the Catholic approach to advanced care planning tends to be *descriptive* rather than *prescriptive* in order to more accurately respond to the dynamic and unpredictable experience of illness or injury.

Because we know that a time may come when we are unable to make decisions about our own care, it is a good idea to ensure that someone we trust will be in a position to make such decisions for us. For the same reason, it can be sensible to let trusted people know our values and our wishes for medical treatment, to help guide them to make such decisions.

No one, however, should be compelled to issue instructions about future care, nor should any guidance we leave be too prescriptive. Disability and dependence may be unavoidable in our later years, and we should not expect to control the dying process fully. We should leave those entrusted with our care free to respond to the course of illness as it unfolds in the mystery of our lives. 30

Accordingly, advanced care plans should be used as a guide rather than a mandated document for use in end of life care. Where there is legislation in place with regards to formally appointing legal representatives, there should be no further requirement for legislation to mandate advanced care plans. As Catholic Health Australia recently explained:

Earlier expressions of advanced care plans provide evidence of the individual’s past wishes, however the ability for health care professionals to make decisions, with the guidance of the individual’s appointed representative must remain.³¹

³⁰ Catholic Health Australia (2015). *A guide for people considering their future health care*. Available at <http://myfuturecare.org.au/resources/>

³¹ Catholic Health Australia, *Submission* to the Legal and Social Issues Committee, Consultation on End-of-Life Care in Victoria, 2015, p.11.

e) Conclusion

Thank you for the opportunity to contribute to this important inquiry.

I would be happy to answer any questions or participate in further discussion with the Standing Committee on Community Development.

Yours sincerely

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