



PARLIAMENT OF TASMANIA

**HOUSE OF ASSEMBLY STANDING COMMITTEE
ON COMMUNITY DEVELOPMENT**

Inquiry into Palliative Care

MEMBERS OF THE COMMITTEE

Mrs Rylah (Chair)
Mr Jaensch (Deputy Chair)
Mr Brooks
Ms Dawkins
Ms Ogilvie

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COMMITTEE MEMBERSHIP



CHAIR
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Member for Braddon



DEPUTY CHAIR
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Member for Braddon



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Member for Braddon



Ms Andrea Dawkins MP
Member for Bass



Ms Madeleine Ogilvie MP
Member for Denison

CHAIR'S FOREWORD

Being in touch with the certainties in life, death and taxes, is important for each of us but in particular for the Government. While parliamentarians speak at great length on the issue of taxes and revenue, the former issue, death and dying, is rarely spoken about and when it is the language is full of euphemism and the sentiment is often one of reticence. Politicians' reluctance mirrors a wider societal problem with discussing how we bring discussion of death to the fore and ensure we live well until our death. Understanding, by the community, and facilitation of better palliative care is critically important to empower individuals.

Increased life expectancy is to be celebrated; however, it means we are no longer exposed to death in the same way. Dying has become an increasingly medicalised process which may remove the dying from the care of those who love you and places dying people into medical wards and aged care facilities. This has led to the issue of death and palliative care as being somewhat hidden. It is no longer integral to day to day life and less visible. This means we have become profoundly detached, disassociated from the reality of being mortal.

Public discussion about progress to death, the provision of care and support for those who are dying including the issue of palliative care is challenging. The Committee's desire is to help bring palliative care and the subject of death to life as well as to open the discussion about the options available for ones care as we progress to death. Today there are many choices we can make about our care.

The Committee's interest is a keenness to place the issue of palliative care centre stage. That is, to improve the quality of life for patients, their family and carers during the process of receiving treatment whilst dying. The Committee does not consider the acceleration of the process of dying to form part of the definition or intention of palliative care.

Palliative care should be compassionate and coordinated holistic care involving ongoing sensitive communication with individuals involved in decisions about their own or their loved ones treatment and care.

This inquiry has aimed to highlight the gaps in palliative care services, to rectify the failings in the current legal foundation, to understand the care needs of our community and the need for the delivery of better services at the earliest opportunity. Fundamentally it recognises a need for an informed and planned end-of-life period where individuals can have greater certainty and knowledge. The overwhelming evidence from experts and witnesses is a desire by individuals for greater control of that care plus a desire to know that the care they wish to receive will be supported and thus one can be reassured. Further, that patients will be protected throughout palliation including in their care choices.

Joan Rylah, MP
Chair

1. BACKGROUND, TERMS OF REFERENCE AND CONDUCT OF THE INQUIRY

The Standing Committee on Community Development was established by resolution of the House of Assembly on 26 June 2014 to inquire into and report upon any issues and legislative proposals arising within the scope of the Committee as follows: Aboriginal affairs; arts; corrections; health; human services; justice; police and emergency management; racing; sport and recreation; and women.

The Committee comprised of five Members of the House of Assembly.

The Committee received correspondence from Hon. Michael Ferguson MP, Minister for Health, dated 24 March 2016 requesting the Committee, in accordance with (7)(b) if the committee terms of reference, inquire into and report upon, the matter of care of palliative patients generally, specifically the matters of (1) advance care directives, (2) administration of medical treatment to minors, the (3) administration of emergency medical treatment, and (4) any other matters incidental thereto.

The correspondence advised the Committee that the Tasmanian Law Reform Institute was tasked with reviewing the *Guardianship and Administration Act 1995* and associated laws, and that there was no need for the Committee to inquire upon these matters.

The Committee resolved at its meeting of 7 April 2016 to inquire into the palliative care with the following Terms of Reference:

To inquire into and report 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.*

The Committee notes that the Terms of Reference uses the phrase “advance care directives”. The Committee has adopted the terms “Advance Care Plan” and “advance care planning” in its recommendations to reflect a broader set of processes and considerations.

The Committee notes that some of the evidence received refers to “Advance Care Directives” and that there is a current lack of consistency in terminology.

The Committee resolved to invite, by way of advertisement on the Parliament of Tasmania website and in the three major Tasmanian newspapers, interested persons and organisations to make a submission to the Committee in relation to the Terms of

Reference. In addition to such general invitation, the Committee directly invited a number of persons and organisations to provide the Committee with any information they deemed to be relevant to the inquiry.

The Committee received 26 submissions and held four public hearings, three in Hobart, and one in Launceston, with 30 witnesses.

2. RECOMMENDATIONS

Policy Development

Recommendation 1:

That the Tasmania Government develop a comprehensive framework for palliative care to ensure that quality palliative care is available to all Tasmanians noting likely future increases in demand for services. (page 20)

Recommendation 2:

That the Tasmanian Government create a dedicated oversight body or authority to provide leadership and coordination on matters relating to end-of-life care including: data collection and analysis; advance care planning; public education; and policy development and workforce development across all relevant sectors and providers. (page 91)

Public Education

Recommendation 3:

That the Tasmanian Government:

- investigates developing an overarching strategic communication and education plan covering death, dying and end-of-life planning and care, building on successful programs delivered in Tasmania and elsewhere ; and
- support programs, such as the workshops provided by Palliative Care Tasmania, which foster death literacy and the benefits of end-of-life planning. (page 26)

Advance Care Planning

Recommendation 4:

That the Tasmanian Government establish a legislative basis for Advance Care Plans. (page 47)

Recommendation 5:

That the Tasmanian Government:

- investigate the regulation of outcome-based Advance Care Plans to ensure their consistent application and effect;
- considers the issues of capacity and age in the creation of Advance Care Plans;
- implements a secure register, where Advance Care Plans can be lodged and which permits immediate access by authorised health care workers, including ambulance officers;
- provide education to the public, health workers and other relevant professionals to increase awareness and use of Advance Care Plans and the Register; and
- establish guidelines for medical practitioners to consult the register and consider a patient's Advance Care Plan in treatment decisions. (page 47)

Recommendation 6:

That the Tasmanian Government make recommendations to the Commonwealth to provide unambiguous Medicare funding for General Practitioners to offer advance care planning to patients regardless of the patient's age. (page 47)

Recommendation 7:

That the Tasmanian Government consider the implementation of a Shared Health Record for all patients, which links to Advance Care Plans. (page 48)

Recommendation 8:

That the Tasmanian Government articulates the relative roles and purpose of Enduring Guardianships and Enduring Powers of Attorney in Advance Care Plans and end-of-life decision making. (page 50)

Services

Recommendation 9:

That the Tasmanian Government review and assess the adequacy of the current provision of palliative care to infants and neonates. (page 65)

Recommendation 10:

That the Tasmanian Government increase support services for parents with children in palliative care as well as for parents after their child has died. (page 66)

Recommendation 11:

That the Department of Health and Human Services develop support programs and procedures for bereaved families and friends of palliative care patients. (page 74)

Recommendation 12:

That the Tasmanian Government increase availability of reliable and appropriate respite services for carers, particularly in rural and regional areas. (page 74)

Recommendation 13:

That the Tasmanian Government work to:

- reduce inequities in the access to quality palliative care services available as a result of an individual's socio-economic status, impairment, or geographic location; and
- improve the number of patients receiving earlier referrals to palliative care services. (page 70)

Recommendation 14: That the Tasmanian Government ensures increased support and adequate funding for community palliative care services, including community nursing, so people who wish to can receive end-of-life care at home. (page 88)

Recommendation 15: That the Tasmanian Government seek to reduce the instances of emergency department presentations through improving the regulations regarding the storage of and access to medications at home and in residential aged care facilities for palliative care patients. (page 89)

Recommendation 16:

That the Department of Health and Human Services model the costings for patients as well as the State, for end-of-life care, including but not limited to dying at home, in hospital and hospice. (page 89)

Legislative Reform

Recommendation 17:

That the Tasmanian Government enact in legislation:

- the common law doctrine of double effect to strengthen the legal protection for those who provide end-of-life care; and
- the common law protection for doctors regarding withholding or withdrawing futile treatment. In this regard the Committee recommends Government give consideration to the *South Australian Consent to Medical Treatment and Palliative Care Act 1995*. (page 66)

Competency

Recommendation 18:

That the Tasmanian Government permit competent minors facing end-of-life care to participate in the completion of an Advance Care Plan. (page 66)

Recommendation 19:

That the Tasmanian Government work to improve the community's understanding of dementia and the development of earlier and easier access to palliative care services for patients with dementia, including advance care planning. (page 70)

Training and Professional Development

Recommendation 20:

That the Tasmanian Government ensure all health practitioners in Tasmania, including: doctors, nurses, aged-care workers, and clinical staff, be required to maintain contemporary knowledge and training in end-of-life and advance care planning, including how to introduce the process to patients. (page 79)

Recommendation 21:

That the Tasmanian Government, in consultation with key stake-holders, design a strategy to ensure an appropriate level of high quality palliative care curriculum content in medical, nursing and allied health degrees, including how to have conversations on end-of-life care with patients. (page 79)

Recommendation 22:

That the Tasmanian Government make recommendations to the Australian Medical Council to examine the adequacy of compulsory teaching in medical schools about substitute decision making and substitute medical consent. (page 80)

Data, Investigation and Review

Recommendation 23:

That the Tasmanian Government investigate how to reduce risk of elder abuse of persons receiving palliative care. (page 26)

Recommendation 24:

That the Tasmanian Government establish a requirement for all cases of continuous palliative sedation to be reported to the Department of Health and Human Services. (page 65)

Recommendation 25:

That the Tasmanian Government investigates the reasons for the above national average of persons receiving specialist palliative care who die at home on the North West Coast of Tasmania. (page 89)

Recommendation 26:

That the Tasmanian Government commence collection of de-identified data of palliative care cases, including information relating to whether the person had any form of advance care planning and whether it was followed. (page 91)

3. NEED FOR A SENSE OF CONTROL AND DIGNITY

- 3.1. From early on in the inquiry process it became apparent to the Committee that a sense of control is the key issue for ensuring that patients, and their loved ones, experience a better death. People need to feel in control over their plans for their death, they need to feel in control over their treatment, they need to feel in control over where they are treated and ultimately they need to feel in control over their location at their time of death.
- 3.2. To enable people to have control over their treatment, people need to be aware of the issues that may affect them as they approach their death. If people are aware of the issues that may affect them, they can make the arrangements that should improve their experience, and the experience of their loved ones.
- 3.3. The Committee heard from a number of witnesses of the possibilities and benefits of a “good death”. Dr Helen Lord, Anglican Church in Tasmania, commented:

Good palliative care has the potential to provide dividends for the health of the community, not just in the present but also into the future, as good palliative care associated with a “good” death is associated with better bereavement outcomes.

A “good” death can mean different things to different people. The most important things that researchers have found on interviewing patients facing terminal illness are:

- *good pain and symptom management*
- *being able to participate in decisions about medical treatment and care*
- *having a 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 goodbye*
- *being able to contribute to the wellbeing of others*
- *receiving empathic care which affirms the patient as a unique and whole person.¹*

- 3.4. The Committee also heard that perhaps the term of a “good death” maybe not be the perfect term, but the essential element of improving the experience of dying come down to “control” - Dr Peter Saul, commented:

There is nothing [is] that good about death even in the best of circumstances. It is always sad and sometimes bad...

In terms of what would be the qualities of good death, the fact we lack such a metric makes it very difficult to do quality improvement well. We cannot point to a death and

¹ Submission No. 6, p1

say that was a good death, in any realistic way. I will talk more about the fact that we should.

The overwhelming element people talk about when they talk about a good death is the patient had some control over what happened. It is a very strong theme that comes through all the literature on a good death, is that the patients have some input into the way that occurred... The notion the patient is respected, it seems very important they have dignity...

The area where the law has failed to grasp the nettle is in exactly how it is patients come to exert some control over what happens to them; what is mandatory in terms of what is recorded about them when they go into hospital; what is mandatory about what forms are filled in, how and who is open to; the status of statements made by the patient, how they are documented and reacted to by the hospital, and how that is audited.

We have not grasped the nettle fully of dealing with patients' own viewpoint about how they should be treated.²

3.5. Dr Peter Saul wrote in an article in *The Conversation*:

Advocates would do well to get behind promoting a “right to choose”, with a corollary of an obligation on doctors to communicate; rather than a “right to die”, with its unfortunate corollary of an obligation to kill.³

3.6. Maintaining the patient’s dignity is central to the provision of quality palliative care.

3.7. Mark Brown, Australian Christian Lobby, commented:

Sustaining a patient’s good health may mean saving a life when at risk, or curing illness, but there comes a time when death ought to be accepted. The goal then shifts towards alleviating pain and suffering where possible so that a patient can die comfortably, with full regard to the patient’s dignity.

Palliative care is concerned with caring for, and accompanying, a dying person and his or her family or carers in the closing phase of life. The relief of pain and symptoms is also a strong feature of palliative care. Good palliative care upholds the patient’s dignity and respects their individual needs.⁴

3.8. Dr Brigid McKenna, Archdiocese of Hobart, stressed:

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.

² Transcript, 12 September 2016, p37-38

³ Dr Peter Saul, “From ‘right to die’ to ‘right to choose the way you die’ – the shifting euthanasia debate”, *The Conversation*, 10 November 2015

⁴ Submission No. 12, p2

...

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.⁵

3.9. Fiona Onslow, The District Nurses, commented:

People want choice, control and dignity and they want their symptoms to be well managed and personal social and psychosocial support.⁶

⁵ Submission No. 22, p2

⁶ Submission No. 23, p18

4. PALLIATIVE CARE

- 4.1. Whilst there is no formalised definition of “palliative care” in Tasmania, the most often cited definition in evidence received was the definition provided by the World Health Organization (WHO):

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;*
 - *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.*
- 4.2. The Tasmanian Government, through the Department of Health and Human Services (DHHS) and the Tasmanian Health Service (THS)⁷, provides specialist care services to patients and their families and carers. The Government’s approach to palliative care is based upon the WHO palliative care standards and definitions.
- 4.3. The Tasmanian Health Service presently operates the following Specialist Palliative Care Services (SPCS):
- *A ten-bed inpatient facility, the JW Whittle Palliative Care Unit, at the Repatriation Centre, Hobart;*
 - *Funding for four public palliative care beds at Calvary Healthcare’s St Luke’s Campus in Launceston and beds in rural facilities in the region;*
 - *Hospital Palliative Care Consultation Teams;*
 - *Community Palliative Care Services (North, North West and South) providing consultation, monitoring and support to primary healthcare providers and patients;*
 - *Volunteer service provides trained volunteer support to families and people in need of palliative care across all health care settings; and*

⁷ Submission No. 24, p5

- *Equipment provision (directly or through liaising with private companies).*⁸
- 4.4. The Specialist Palliative Care Service, delivered by the Tasmanian Health Service, a network of specialist palliative care providers, seeks to relieve the physical symptoms of a person’s illness, assist with other issues, which may arise, and support a patient’s carers and families.⁹ Specialist palliative care teams deliver this service by:
- *undertaking a comprehensive assessment;*
 - *focusing on management of symptoms;*
 - *advance care planning;*
 - *addressing emotional, spiritual and cultural aspects;*
 - *including a variety of health professionals in coordinated teams; and*
 - *considering the patient’s choice of setting of care where possible.*¹⁰
- 4.5. Patient services provided by the Specialist Palliative Care Service also provide:
- *relief of pain and other symptoms;*
 - *resources such as equipment needed to aid care at home;*
 - *assistance for families to come together to talk about sensitive issues;*
 - *links to other services such as home help and financial support;*
 - *support for people to meet cultural obligations;*
 - *support for emotional, social and spiritual concerns;*
 - *counselling and grief support; and*
 - *referrals to respite care services.*¹¹
- 4.6. The Specialist Palliative Care Service takes referrals from primary care providers (such as general practice), residential aged care facilities, family and self-referrals, medical specialists, community nursing and the acute sector.¹²
- 4.7. According to Professor Michael Ashby, Tasmania’s palliative care services “are mature, well embedded and of high quality.”¹³
- 4.8. A number of witnesses spoke of the need for increased patient capacity, improved access to palliative care services throughout the State and better access for more people.
- 4.9. Hilde Nilsson, Dying With Dignity Tasmania, commented:

⁸ Submission No. 24, p9

⁹ Submission No. 24, p9-10

¹⁰ Submission No. 24, p9-10

¹¹ Submission No. 24, p9-10

¹² Submission No. 24, p9-10

¹³ Submission No. 18, p4

Palliative care is generally good as long as you get access to it. Getting access is a huge problem.

4.10. Professor Michael Ashby commented:

I genuinely think the coverage and availability of primary care services does differ right around the country. Access to out of hours support and expert nursing is quite stretched. That is certainly an area the state and indeed the federation will have to address in the future. If we're saying we want to put more and more emphasis on community care, care at home and hospital avoidance - because we have to - these are areas that will have resource implications in the future. I guess I'm saying that our specialist services will need to grow to meet existing and future demand, but also primary care services are often as much the answer. If you look at episodes where things don't go so well it is often because people live in an area where those services are stretched.

Planning for the Future

4.11. Tasmania has an aging population, which will see an increase in persons referred to palliative care services¹⁴. The Government must have comprehensive plans for the future to ensure that palliative care services are equipped to meet this growing demand and are capable to provide timely, coordinated and responsive palliative care.¹⁵

4.12. The demand for palliative care services in Tasmania are likely to increase more rapidly than the other states and territories due to the State having the highest overall incidence of cancer, the second highest rate of burden of disease as a result of chronic disease.¹⁶

4.13. Fiona Onslow, The District Nurses, commented:

It is expected that the number of people who die each year in Australia will almost double in the next quarter of a century. Clearly, considerable forward planning is necessary to ensure that all Tasmanians have access to timely, coordinated and responsive palliative care into the future.¹⁷

4.14. The Australian Government funded the Better Access to Palliative Care (BAPC) program, with the objective:

to increase Tasmania's capacity to provide access to community based palliative care for people with life limiting illness, nearing the end of their life, while at a service level it aims to strengthen and enhance linkages between public and private providers and primary, secondary and tertiary providers. Enhancing the capacity of specialist palliative care teams is also a feature.

¹⁴ Submission No. 13, p2

¹⁵ Submission No. 22, p7

¹⁶ Submission No. 24, p8-9

¹⁷ Submission No. 24, p7

BAPC has provided funding to support the work of partner organisations in Tasmania including The District Nurses to establish the hospice@HOME service and to Palliative Care Tasmania (formerly the Tasmanian Association of Hospice and Palliative Care) to deliver a range of community development, education and professional development activities.

Together, significant progress has been made in the design and planning of new services, enhancement of existing services and the further development of the palliative care sector across Tasmania. Future policy work in Tasmania will aim to embed national standards and best practice approaches for palliative care, improve bereavement care and deliver specialist palliative care service models.¹⁸

- 4.15. Debra Rabe, Alcohol Tobacco and Other Drug Council of Tasmania, commented:

*I think it is a timely inquiry and these are issues policy makers in the sector need to have an eye to in ensuring that the right investments are made at the right time to support and work with people as some of the impacts of those earlier life decisions start to manifest themselves in the health system and within their own processes.*¹⁹

- 4.16. Paul Russell, HOPE: Preventing Euthanasia & Assisted Suicide Inc., commented:

*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.*²⁰

Committee Comment

- 4.17. The Committee endorses the use of the World Health Organisation's definition of palliative care.
- 4.18. The Committee notes that Tasmania's aging population and high incidence of chronic diseases places a significantly higher demand on palliative care in Tasmania than in other Australian states. Due to these issues it is imperative that Tasmania takes a leadership position in the development and delivery of a robust palliative care service that adequately addresses the needs of patients currently and into the future.
- 4.19. The Committee notes that witnesses refer to the need for an overarching framework for the delivery of quality palliative care to adequately address the projected increase in demand and inspire confidence in the public that their needs will be met and their advance care plans will be instigated.

¹⁸ Submission No. 24, p5

¹⁹ Transcript, 8 August 2016 (morning), p32

²⁰ Submission No. 2, p5

Recommendation 1:

That the Tasmania Government develops a comprehensive framework for palliative care to ensure that quality palliative care is available to all Tasmanians noting likely future increases in demand for services.

5. PUBLIC PERCEPTIONS AND COMMUNITY EDUCATION

Talking About Death

- 5.1. The first step in improving palliative care is commencing the conversation. Community conversation about death and dying reduces perceptions that these issues are taboo and empowers people to take proactive steps in planning for their end-of-life care.²¹
- 5.2. A cultural change is needed to make people more comfortable discussing death, as Allison Lennox commented:

*We need to nurture more acceptance that people are going to die. In the workplace, in nursing homes, everybody needs to accept that we are all going to die at some stage.*²²

- 5.3. The Committee heard of the need to speak about death and end-of-life care in a “matter of fact” manner and the role the Government can play in facilitating such discussion. Professor Michael Ashby commented:

*I don't think euphemisms help. I don't think the public need us to hide from them the fundamentals of human existence by wrapping them up in euphemisms. If you look at Australia's public health campaign record, we didn't reduce the road toll by beating around the bush... I would strongly urge us to try to get away from the 'passed away' kind of euphemism.*²³

- 5.4. The Committee heard of some health professionals and families struggling to talk about death due to their assumptions that they cannot initiate any discussion of death because patients and families do not want it or that they run the risk of precipitating death if they did²⁴ or that discussing palliative care is a sign the medical system has given up on the patient.²⁵ However, these assumptions appear to be unfounded, as many respondents spoke of the community’s and individual patient’s desire to engage on the topic.²⁶

Increase Public Awareness

- 5.5. The Committee heard of the lack of knowledge in the community of what palliative care is and what it does and does not involve.
- 5.6. The Committee heard from a number of witnesses of the need to increase the public’s awareness of palliative care. To 'sell the story' of palliative care

²¹ Submission No. 16, p1

²² Transcript, 8 August 2016 (morning), p24

²³ Transcript, 8 August 2016 (afternoon), p11

²⁴ Submission No. 18, p5-6

²⁵ Transcript, 8 August 2016 (morning), p40-41

²⁶ Transcript, 8 August 2016 (morning), p40-41

and explode the myths of palliative care thereby increase public confidence.²⁷

- 5.7. In order for people to make good decisions about their palliative care they must be informed of their options and be able to clearly communicate their preferences to their health care team, their carers and family.²⁸

Education

- 5.8. The Committee heard from respondents that past and present end-of-life education programs have delivered numerous benefits.
- 5.9. Paul Russell, HOPE: Preventing Euthanasia & Assisted Suicide Inc., commented:

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...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.²⁹

...

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.³⁰

...

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

²⁷ Transcript, 9 August 2016, p21-22

²⁸ Submission No. 5, p1

²⁹ Submission No. 2, p1

³⁰ Submission No. 2, p1-2

been characterised as arising from the fears of the ‘worried well’. It is an entirely justifiable outcome of public education to reduce such fears.³¹

5.10. Palliative Care Tasmania discussed its work in the educating the public:

PCT is proactive in end of life education and information dissemination, community engagement and advocacy on behalf of the palliative care sector, the community and its members. It works to:

- *Educate service providers, carers, volunteers and the community about palliative care, death literacy (including advance care planning), grief and bereavement and best practice standards;*
- *Provide information about services across Tasmania;*
- *Lead in the continuous development of best practice standards;*
- *Support workers and community sectors involved in the care of people who are dying; and*
- *Advocate for service provision and its future development.*

5.11. Professor Michael Ashby described the program, the Healthy Dying Initiative, as:

Based on the principles of health-promoting palliative care, this initiative aimed to empower the whole community, including the health sector, to deal with death in a more direct, open and therefore ‘healthy’ way. Clinical decision making at the end of life was identified as a priority for policy and procedural reform. There were three initial components of the Healthy Dying Initiative: (1) Goals of Care, (2) advance directive redesign and promotion, and (3) encouragement of health-promoting activities relating to death.³²

5.12. Palliative Care Tasmania argued that such education increases discussion about death and also has positive economic and resource implications:

More people want to know about palliative care, grief and bereavement and death literacy (including Advance Care Planning)...With an aging population and rise in chronic progressive diseases this need will continue to grow.

All of this work has positive economic implications on the current health care system. Through effective end of life planning, encompassing education and community development, that PCT has been able to provide through the BAPC program, the capacity for people to gain a better understanding of their end of life options increases. They are more able to plan to die at home with the appropriate support structures around them, helping to relieve pressure on our acute system through fewer emergency department presentations, lower numbers of terminally ill people in intensive care, and a reduction in terminally ill people requiring ambulatory services, delaying the need to enter aged care facilities, if at all.³³

5.13. Dr Rumbold, La Trobe University, discussed alternative education strategies of which he has been involved with:

³¹ Submission No. 2, p2

³² Submission No. 18, p7

³³ Submission No. 13, p1-2

We have gone into communities, often at the invitation of palliative care services or other community services, and basically done some background on 'death education'. In other words, tell some of the stories around our socio-cultural history of dying and how does that relate to the sort of community and our attitudes now. Obviously not everybody comes to these things but you get a mixture of people. Some of them are immediately engaged with caring for dying people - relatives - and they are looking for some answers and background. Others just have a general curiosity, so you have people who are interested. Out of that interest usually you find a group of people who are interested in improving skills around how to care, what to say and so on. That is a fairly basic discussion about what to say, which often boils down to what not to say. We are interested in targeting the so-called informal listeners, or unintentional listeners, like hairdressers and taxi drivers, people who perhaps hear the stories, and to give them some idea about how to respond and how to refer people on.

After that we have really gone at a community development level into project development. We have a bit of seed funding available. Are there members of the community who, as a group, have an idea they would like to try out, and is it genuinely their idea? Have they got some ideas about making it sustainable and so it goes. We might fund that with a small amount of money which is enough to do a mail-out or an afternoon tea or something like that. From that have come a number of community projects which might include linking the historical society with a local school and trying to do a history project together, building a reflective space in the local cemetery, memorial tree-planting along roadside verges, Christmas tree remembrance stuff. It sounds a little twee but it was a wonderful partnership activity in north-east Victoria because it involved recruiting all the mail van drivers, the local libraries and so forth, to be involved in it.

In that sense, that is the bottom-up material but where we are not doing as well as we would wish to do is in linking those sorts of activities with the formal health services. I think we need a context within which we have more productive conversations between the interested people in the community and the service provided for that community in a way which will start to change the way we plan to deliver services.³⁴

- 5.14. Education materials, irrespective of quality, are pointless if people are not engaging with them. Paul Russell argued for promotion of the discussion through advertising:

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 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.³⁵

³⁴ Transcript, 9 August 2016, p31-32

³⁵ Submission No. 2, p2

Elder Abuse

- 5.1. The Committee heard from respondents of the high risk for elder abuse to occur for persons in palliative care. Mr Mark Brown, Australian Christian Lobby, commented:

There is always going to be the potential, when you are dealing with humans, for things to go wrong. This whole aspect of elder abuse is a real concern, in that particular stage and in general. These most vulnerable people who are often unwell and at the end of their lives turn to those closest to them to look after their best interests. Sadly, you would expect family would be the best group of people they could turn to, but as we are seeing with the huge levels of elder abuse through the Helpline in Tasmania that it's not always a certainty. I was looking at an article in the Mercury where between 3000 and 4500 Tasmanians are, at any time, experiencing elder abuse. The hotline estimated, from what I previously read, on average one per working day.

Committee Comment

- 5.2. The Committee notes that the lack of understanding about palliative care and the hesitancy of some medical practitioners to discuss death exacerbates ignorance of the subject, delays end-of-life planning and patients' access to palliative care services.
- 5.3. The Committee notes that palliative care patients are at a high risk for suffering elder abuse.
- 5.4. The Committee notes that public discussion about death is imperative to improving palliative care outcomes for patients.
- 5.5. The Committee notes that significant cultural change is necessary for this discussion to take place.
- 5.6. The Committee notes the work done by the Tasmanian Government and organisations such as Palliative Care Tasmania, to educate the community about palliative care and to foster discussion.
- 5.7. The Committee notes the need for improved public communication and community engagement and that the workshops conducted by Palliative Care Tasmania are a good example.

Recommendation 3:

That the Tasmanian Government:

- **investigates developing an overarching strategic communication and education plan covering death, dying and end-of-life planning and care, building on successful programs delivered in Tasmania and elsewhere; and,**
- **support programs, such as the workshops provided by Palliative Care Tasmania, which foster death literacy and the benefits of end-of-life planning.**

Recommendation 23:

That the Tasmanian Government investigate how to reduce risk of elder abuse of persons receiving palliative care.

6. ADVANCE CARE PLANNING

6.1. The Committee heard a wide range of views on how people are best prepared for their death. Whilst the views may have differed, the consensus was clear: advance care planning is imperative to improve the patients experience in palliative care; and the earlier the planning begins the better.

6.2. Advance care planning is the term generally used to describe the process of an individual plan and record their values, goals and preferred health and medical care in case they become ill or injured and unable to express these wishes. Advance care planning ideally involves the patient, the patient's family, health care professionals, and support persons, which may involve an:

...assessment of, and discussion about, a person's understanding of their medical condition and prognosis, values, preferences and personal and family resources. Advance care planning is particularly important because the patient may later lose the capacity to participate in discussions when difficult decisions need to be made as the end of their life nears.

Advance care planning supports the individual in communicating their wishes and desired direction about their end of life.³⁶

6.3. Fiona Onslow, The District Nurses, commented:

People want choice, control and dignity and they want their symptoms to be well managed and personal social and psychosocial support. But dying has become highly institutionalised and deaths in hospitals has increased yet paradoxically the likelihood and timing of death is now more predictable. There is more time to prepare for death but dying is not discussed and we are not taking the opportunities we have to help people prepare for death, rather than creating an experience of people being disconnected, confused and distressed as an array of services, interventions, and health professionals intervene when people are dying.³⁷

6.4. Dr Peter Saul commented:

The term 'palliative care' in New South Wales generally means specialist palliative care, even if you do not use capitals for it. We tend to use the term 'palliative approach' or 'palliative intent' if we mean a broader thing than specialist palliative care. I just noticed in your title it was an inquiry into 'Palliative Care' capitalised.

The second term is 'advanced care planning' which I regard as an umbrella term used at any stage of an illness and may be quite an informal process. It may be just even a conversation. Advanced Directives is more specific. It means two different things. One is their so-called living will where there is an actual document produced by the patient

³⁶ Submission No. 24, p13

³⁷ Submission No. 23, p18

says in the event that I do not want this, which is the general format. There is an alternative, which is the appointment of a health care proxy with or without instructions. I would regard those two things as being separate, although the national framework lumps those together into Advanced Care Directives. I would call those two things a separate thing.

The third term is the 'goals of care conversation'. The goals of care conversation is for seriously ill people and it would include a recommendation and may result in treatment limitation on medical orders, such as a resuscitation plan or a goals care plan signed by a doctor not by a patient. It is a different thing from advanced directive or advanced care planning.³⁸

- 6.5. Advance Care Plans have also been referred to as “Living Wills” previously in Tasmania, and that some persons use the two terms interchangeably.

Advance Care Plans

- 6.6. Witnesses referred to Advance Care Plans as being the formalised expression of an individual’s treatment wishes understood as a statement, written or otherwise recorded by a person in anticipation of the person being in a state of incapacity, which is intended to have effect if the person actually becomes incapacitated.

Witnesses stated that there is a variety of documents being utilised as “advance care directives” and there was not a consistent format being used. There is ambiguity regarding the legal standing of these documents.

- 6.7. There was general agreement in submissions that Advance Care Plans can play a valuable role in the delivery of palliative and end of life care.

- 6.8. In its submission, the Tasmanian Government stated:

An ACD [Advance Care Directive] is appropriate for anyone, at any life stage and in respect of any health care situation, including those who:

- have chronic or life-limiting health conditions;*
- are entering residential care facilities;*
- believe their family may have different views, beliefs or value-system, or where there is no family to consult; or*
- have a condition that may lead to a loss of capacity to make decisions.*

- 6.9. The common law position in Tasmania is, as stated by the Tasmanian Government:

Every competent adult has the right to agree to or refuse medical treatment, and an ACD is a way of conveying the person’s consent to particular future treatments and refusal of others at a time when the individual has the capacity to consent.³⁹

³⁸ Transcript, 12 September 2016, p36

³⁹ Submission No. 24, p14-15

- 6.10. Palliative Care Tasmania argues any restriction in relation to creating an Advance Care Plans should relate to a person's competency and not an arbitrary age limit:

*We would support the removal of an age and believe it should be related to the mental competence of a person no matter their stated age.*⁴⁰

- 6.11. Alison Verhoeven, Australian Healthcare and Hospitals Association, argued that:

*ACDs allow for individuals to make their preferences known when crucial health and other personal decisions are required after they have lost decision-making capacity. ACDs are life-management documents individuals may complete in home, community, hospital, institutional and aged care settings.*⁴¹

- 6.12. The Committee heard evidence as to the differing perspectives regarding the legal weight to be given to Advance Care Plans in the context of end-of-life decision making.

- 6.13. Lyn Irwin, Friends of Northern Hospice, stated Advance Care Directives require the following the key factors:

- (1) *What kind of palliative and end of life care a person would envisage for themselves;*
- (2) *Where they wish to die; and*
- (3) *Ensuring that a patient's wishes, as may be embodied in their ACD, are respected and implemented- even where they may be at odds with the views of family members or the institution that is caring for the patient. It must be remembered that while an ACD may have been documented, it is up to others to respect the wishes as stated.*⁴²

- 6.14. Dr Helen Lord, Anglican Church in Tasmania, stated:

*ACDs by their nature are directive rather than mandatory, giving guidance to carers and families when decision making is required.*⁴³

Advance Care Plans: Need to be Promoted

- 6.15. Dr Rosemary Ramsay, Rural Clinical School, discussed the need to promote Advance Care Plans:

With regard to advanced care directives, we consider this to be a reasonable tool to promote discussion on end of life and would support community-based initiatives to raise awareness of advantages for preparing such a document. However, there are many ways that advanced care directives can be promoted. For example, governments could send out information with pensions. Solicitors could be discussing it with their

⁴⁰ Submission No. 13, p4

⁴¹ Submission No. 4, p1

⁴² Submission No. 17, p1-2

⁴³ Submission No. 6, p5

clients when they are there making the will. In fact there could just be advertisements to target the broader family unit to encourage discussion, similar to that which Rosemary was mentioning - the broader family unit, sitting around the table and discussing what the individual would require for end of life.⁴⁴

- 6.16. Professor Michael Ashby also argued for the promotion of Advance Care Plans and the need to adequately resource their implementation:

If advance care planning is to be successful, it needs designated human resources in each major hospital and associated community programs.

Much hope has been invested in advance directives to improve decision-making at the end of life. These aspirations will not be realized unless public expectations change, and clinicians are able and empowered to have these challenging conversations with patients while they still have capacity. Investment in the development and delivery of high quality experiential communication skills learning for medical students and for doctors in established practice, as well as for other health professionals, is necessary.⁴⁵

Benefits of Advance Care Plans

- 6.17. A number of submissions outlined the benefits of Advance Care Plans. Dr Helen Lord, Anglican Church in Tasmania, stated:

Advance Care Directives have the potential to lessen anxiety and enable family and carers to provide dignified, respectful end of life care.⁴⁶

- 6.18. The Committee heard from Alison Lennox, who spoke of the benefits experienced as a result of both her parents having Advance Care Plans prepared, appropriately communicated and respectfully implemented:

Both my parents had written Advanced Care Directives with the help of family and their Doctor. I had happened to hear about the importance of ACDs when my Mother was still in reasonable health and as a family we could talk to her about what she hoped for her end of life care. My father at that stage decided he should be involved too, so happily both had Directives in place as their lives faded.

My mother died in hospital in 2013, but the spirit of the ACD was followed and Mum was kept comfortable and pain free as she faded from this world. I was with Mum and was taken aside in the first 10 minutes of her admission to ED to check that I was 'happy' with the ACD and to be informed that it would be followed. Mum died about 8 hours later without pain, but also without treatment (antibiotics) which may have prolonged her life, but left her unable to live independently ever again, if she survived. This was exactly the scenario we had planned for and it was a blessing that she could sleep pain free and then die peacefully. Mum was a frail 89 year old.

⁴⁴ Transcript, 10 August 2016, p9

⁴⁵ Submission No. 18, p5-6

⁴⁶ Submission No. 6, p5

My father died two and a half years later. His ACD was respected and Palliative Care 'administered' to ensure he didn't suffer from the painful and traumatic effects of seizures which would have ensued, caused by a brain tumor (melanoma). The palliative care he received was of the best quality, with information given freely and truthfully to family members if needed. We were happy to see Dad die with peace and pain free. He was 91.

After this experience, I too have completed an ACD, which I will of course have to update regularly, and I encourage all my friends and family to do so to.

....

My hope is that with more talk and information it will become the norm for people to complete ACD's. I do remember that even one GP we talked to about this issue didn't know where to access any forms about ACD's. Luckily we kept asking and found the information we needed.

Let's hope ACD's and discussion about Palliative Care mean that lives can end with dignity and peace, without the negative hype produced when Euthanasia is mentioned.⁴⁷

- 6.19. Presently there is insufficient research on Advance Care Plans to know how effective they are in delivering an individual's wishes.⁴⁸ However, the Committee did hear much anecdotal evidence that Advance Care Plans do create better outcomes for patients.

- 6.20. Fiona Onslow, The District Nurses, commented:

The data we have gathered demonstrates that we have had an increase in the amount of ACD's that have been taken up by our clients. What it does not tell us presently is if that relates to clients wishes being met and outcomes. Anecdotal information and research to date informs the discussion that the ACD does create better outcomes for choice, as per our case review.

Elements of Advance Care Plans

- 6.21. The Committee heard from witnesses who described the important elements of an Advance Care Plan.

- 6.22. Dr Helen Lord, Anglican Church in Tasmania, provided a comprehensive list of principles and inclusions for Advance Care Plans:

1. An ACD should be written after discussion with:
 - Family and carers
 - Person Responsible, if different from family and carers
 - General practitioner or medical specialist
2. The ACD should include:
 - Preferences for care (place, type of care)

⁴⁷ Submission No. 8, p1

⁴⁸ Submission No. 23, p8-9

- Any limitation of treatment and guidance on the circumstances in which the limitation of treatment should apply, and be guided by information from discussion with a clinician
 - The reasoning or values behind the directive
3. The ACD should be signed by both the patient (Person Concerned) and the Person Responsible
 4. An ACD may include preferences for treatment: however, treatment may not be demanded.
This reduces the stress on carers and on the patient when expectations may not be able to be met.
 5. An ACD may not include requests for euthanasia or physician assisted suicide
 6. Capacity should be assessed and an ACD should be countersigned by a general practitioner or medical specialist to be valid
 7. An ACD should be voluntary and not mandatory
 8. An ACD should be reviewed if there is a significant change in diagnosis or treatment
 9. An ACD should be reviewed 5-10 years
 10. An ACD can only become operative if the person concerned loses capacity.⁴⁹

6.23. The Committee heard from witnesses who proposed that Advance Care Plans could include a list of treatments, such a PEG feedings or resuscitation that a person does not want as part of their palliative treatment.

6.24. Dr Helen Lord raised the value of having a medical professional who knows the patient endorse the form at the time of writing to ensure when a directive needs to be followed there is no question as to capacity.⁵⁰

Proposed Inclusions: Diseases You Don't Have

6.25. The Committee heard from witnesses who proposed that Advance Care Plans should be able to include planning for disorders or diseases that the individual does not have at the time of creating the Advance Care Plans.

6.26. Colleen Johnstone, Palliative Care Tasmania, commented:

In terms of advance care directives, in our opinion and also in some of the national organisations and groups we are party to, we believe that Tasmania has perhaps the most contemporary advance care directive system in the country. In Tasmania you have the ability to plan for diseases that you don't have, so as a fairly healthy 41 year old woman I can plan for the type of care I want when I am dying, even though I have no life-limiting illness.⁵¹

⁴⁹ Submission No. 6, p4-5

⁵⁰ Transcript, 8 August 2016 (morning), p10-11

⁵¹ Transcript, 8 August 2016 (morning), p35

Outcome-based Advance Care Plans

6.27. The Committee heard from a number of witnesses who proposed Advance Care Plans would work best if they are not disorder, disease or treatment specific but make directives in terms of what the outcome of a treatment would be.

6.28. Dr Helen Lord commented:

One form of wording of an ACD that may be recommended is "I wish that treatment aimed at prolonging life be stopped or withheld and palliative care be provided, if at some time in the future it is the opinion of the treating team responsible for my medical care that recovery is unlikely and the outcome of such treatments would be a permanent coma".⁵²

6.29. Professor Michael Ashby commented:

For most of us, we can have some idea of what might be around the next corner but actually we do not know. I would say if you are making an advance directive, make it more principles, values, beliefs and, perhaps, outcomes I think are the most important. I think William Molloy, from Canada, his book Let Me Decide in the early 1990s, I think from memory. He was very keen to say don't say you never want another operation because the one thing that might happen to you is you might break your hip when you are 89. You lack capacity, and the only way to make you comfortable would to pin it. So don't say you never want any operations because there might be an operation available to make you comfortable, rather than make you live longer. That is one example of how flawed that can be.⁵³

6.30. Hilde Nilsson, Dying With Dignity Tasmania, argued that the benefit of an outcomes-based Advance Care Plan is that it should not need reviewing over time:

An advanced care directive that is done properly will say something like, 'If my condition deteriorates to a level where it is unlikely that I will recover', to whatever extent is reasonable to the individual, 'Then I do not want any treatment to prolong my life, but I want maximum effort concentrated on comfort care or whatever you want to say. It is the outcome that should be focused on with an advance care directive. People's values tend to not change that much, as long as they have capacity or are likely to get capacity again, what is written in their advance care directive isn't relevant anyway.'⁵⁴

Proposed Inclusions: Substitute Decision Maker

6.31. The Committee heard from a number of witnesses of the desirability for an Advance Care Plan to nominate one or multiple substitute decision makers or surrogates.

⁵² Submission No. 6, p5

⁵³ Transcript, 8 August 2016 (afternoon), p6

⁵⁴ Transcript, 8 August 2016 (afternoon), p16-17

6.32. Palliative Care Tasmania commented:

While not a legislatively binding document, the Tasmanian ACD for Care at the End of Life is based on the Common Law principle that individuals have the right to refuse consent to any unwanted medical treatment including treatment aimed at prolonging life...

If others understand what a person's wishes are then they are able to speak for them in the event a person lacks capacity. The next step of completing an ACD form is helpful in supporting the Person Responsible in advocating for the Person Concerned.⁵⁵

6.33. Dr Peter Saul commented:

The appointment of a surrogate gives that person control of who does make these decisions. I talk about the five daughters' problem. If you have five daughters, the chance of them all agreeing on what should happen to you are minimal. The great virtue of an advanced care directive or the appointment of a surrogate decision-maker is in fact to clarify who in the family has a view that more closely represents your own, which is in fact the outcome we are looking for as doctors.⁵⁶

6.34. Colleen Johnstone raised concerns about the medical system requesting the naming of a next of kin:

A next of kin has no automatic legal status under guardianship law in Tasmania. It becomes very confusing if a person has appointed an enduring guardian or has nominated a person responsible but they are being asked for their next of kin and medical practitioners are directing questions to that next of kin if the next of kin isn't the substitute decision-maker.⁵⁷

Limitation of Advance Care Plans

6.35. Mark Brown, Australian Christian Lobby, spoke of the limitations of ACDs:

Advanced care directives can be useful to a point, towards assisting family members, decision makers and medical teams to make decisions that are consistent with the wishes of the patient, and are but one element of advanced care planning.

There are limitations to written directives that should be considered:

- *they can be difficult to interpret;*
- *they are a snapshot of past wishes of the patient: patient preferences change as circumstances change;*
- *They can ignore the important distinction of intention.*

Written directives taken by themselves are not always sufficient to ensure that patient choices about future medical treatment and care are respected. Good

⁵⁵ Submission No. 13, p3

⁵⁶ Transcript, 12 September 2016, p39-40

⁵⁷ Transcript, 8 August 2016 (morning), p37

*advanced care planning requires a much broader approach towards respecting patient choices.*⁵⁸

Guidelines

6.36. There is currently no legislative framework for Advance Care Plans in Tasmania. Many witnesses expressed concerns in relation to the uncertainty that the absence of a legislative framework and thus a need for guidelines for Advance Care Plans to be implemented.

6.37. Dr Helen Lord, Anglican Church in Tasmania, stated:

*Guidelines are required to ensure that ACDs accurately reflect a person's wishes, that they are reasonable, and that safeguards are built in to the development and recording of the wishes being expressed.*⁵⁹

6.38. The Tasmanian Government commented:

*The THS has developed a standard form titled Advance Care Directive for Care at the End of Life (Tasmania) to encourage consistency and accuracy when recording an individual's ACD. The THS has also implemented a statewide Advance Care Directive Protocol to guide the use of advance care directives. The purpose of the Protocol is to ensure that patients who are unlikely to benefit from medical treatment aimed at cure receive care appropriate to their condition, and are not subjected to burdensome or futile treatments (particularly cardiopulmonary resuscitation and Medical Emergency Team (MET) calls, especially where this is contrary to their wishes). These documents are maintained by the THS and reviewed against a set schedule to maintain safety, quality and accuracy.*⁶⁰

Legal Status

6.39. Whilst Advance Care Plans may have developed a basis in common law, in the absence of a legislative framework there is an uncertainty to their legal status.

6.40. The Committee received evidence of a range of views in relation to the introduction of a legislative framework.

6.41. Dr Peter Saul commented on the need for defining Advance Care Plans legal status:

I am not unhappy with the common law approach but what we need to do is make it much clearer, what the legal status of these documents is and how the hospital has to respond to such documents if they are presented with them. That is part of the process

⁵⁸ Submission No. 12, p3

⁵⁹ Submission No. 6, p5

⁶⁰ Submission No. 24, p15

*that all the hospitals in Tasmania or wherever, would all do reliably and people can rely on that happening.*⁶¹

6.42. Over half of respondents called for Advance Care Plans to be legislated.

6.43. Professor Margaret Otlowski, University of Tasmania, commented:

*Making legislative provision for advanced care directives would also be an important reform, strengthening the rights of individuals to exercise autonomy in relation to the manner of their dying in the event that they lose decision-making capacity.*⁶²

6.44. Colleen Johnstone that it would:

*... provide more certainty to the community if advanced care directives were legislated, particularly for medical practitioners because there is some confusion, particularly with GPs, about an advance care directive's legal status and concerns about any legal protections afforded to medical practitioners.*⁶³

6.45. Dr Peter Saul, among others, noted that due to the absence of legislation:

Doctors on the whole are very dismissive of advanced care plans broadly, and the directives in particular. Most emergency departments say they are not worth the paper they are written on.

6.46. Dr Peter Saul warned that legislating Advance Care Plans may have a negative affect:

Some jurisdictions have responded by legislating. South Australia has been the most aggressive in this. All this does it drives people to not want to do it. In Victoria there is a refusal of treatment. You rarely see them. Only about 20 a year are given to the Public Advocate in the whole of Victoria. The problem with the legislative approach is it scares people off a little bit.

6.47. A number of respondents argued that the legislation of Advance Care Plans might alleviate uncertainty by medical professionals. Professor Michael Ashby highlighted the concerns of medical professionals in relation to treatment abatement:

*Statutory force for advance directives will be helpful by giving doctors more confidence about absence of legal sanction when they follow the instructions in advance directives.*⁶⁴

6.48. Dr Helen Lord commented:

*If it has to be legally binding you have to have a lot of safeguards in there. We cannot always guarantee this is what is going to happen.*⁶⁵

⁶¹ Transcript, 12 September 2016, p37-38

⁶² Submission No. 3, p1

⁶³ Transcript, 8 August 2016 (morning), p37

⁶⁴ Submission No. 18, p9-10

Alternative Views

6.49. The Committee heard from a number of respondents that Advance Care Plans should not be legislated, as they should be only a guide of the person's wishes.

6.50. Mark Brown, Australian Christian Lobby, commented:

*When a person becomes incompetent, their earlier wishes and values may be a helpful guide, but are problematic for directing specific treatment and care decisions. Additional guidance from the person's representative is important.*⁶⁶

6.51. Dr Peter Saul, commented:

*The problem with a legislated form, as I say, is that people are somewhat scared off by the sheer legality of it. It is also unclear what that does to all the other common law things that they may have done, the conversations they have had, the other things they have written down. You cannot really set aside the common law, even in legislating.*⁶⁷

Legal Status: Common Law

6.52. The Tasmanian Government argued that despite an absence of a statutory framework:

... existing case law from overseas jurisdictions suggests that an ACD will be effective, so long as:

- *The patient was competent at the time the directive was made;*
- *The patient intended and anticipated their decision to apply to the situation that ultimately arose, and is clear and unequivocal;*
- *No undue influence was exerted on the patient in making the directive; and*
- *The person's circumstances have not changed so that the person would no longer have intended it to apply e.g. where, at the time a person made an ACD she or he was a Jehovah's Witness and refused blood transfusions but the person has now renounced that faith.*⁶⁸

6.53. Palliative Care Tasmania commented:

The Tasmanian ACD has not been legally tested in Tasmanian courts. While not a legislatively binding document, the Tasmanian ACD for Care at the End of Life is based on the Common Law principle that individuals have the right to refuse consent to any unwanted medical treatment including treatment aimed at prolonging life. Naming of a preferred Person Responsible to act as substitute decision maker is also an expression of the common law principle of the right to autonomy.

...

⁶⁵ Transcript, 8 August 2016 (morning), p12

⁶⁶ Submission No. 12, p3-4

⁶⁷ Transcript, 12 September 2016, p37-39

⁶⁸ Submission No. 24, p15

Some medical practitioners are confused about the ACD's legal status because it rests in the Common Law rather than on statutory law.⁶⁹

Doctrine of Double Effect and Acts of Omission

- 6.54. Many respondents raised the issue of the doctrine of double effect.
- 6.55. Professor Margaret Otlowski, University of Tasmania, commented on codifying the current common law position as:

... an important step in clarifying rights and duties of relevant parties, particularly with regard to difficult issues in relation to administration of pain-relieving drugs which have the foreseeable effect of hastening death. The common law position, based on the UK Adams Case, is assumed to apply but sits uneasily with the very specific provisions of the Criminal Code in this state. I know from anecdotal information that some medical practitioners see pain relief which may incidentally hasten death as a grey zone and not infrequently concerns are raised about engaging in this practice for fear that it might be interpreted as euthanasia/unlawful killing. This is obviously problematic if it means that some doctors feel inhibited in the pain relief that they can administer, out of fear of legal repercussions. Clarifying the law in this area as has been done in South Australia and also Queensland would, in my opinion, be an important reform.⁷⁰

- 6.56. Professor Margaret Otlowski commented further:

I would urge strong consideration of creating that clear legal exception in the same way that the South Australian act has done and that was mirrored in the Bill that has been put forward that covers things such as doctors acting in good faith; acting in accordance with proper professional standards, including you could specify palliative care, that it is with the right intention, that is the intention of relieving pain and distress, even if it may have the effect of hastening death.

I think the other big area relates to the withdrawal of treatment which can take the form of not doing something but also sometimes involves turning something off, so it can be acts or omissions which effectively constitute a withdrawal.⁷¹

- 6.57. Professor Michael Ashby highlighted the concerns of medical professionals in relation to treatment abatement:

A perceived threat of legal action as result of treatment abatement decisions and palliative-care drug treatment is still widespread, and, although empirical data are lacking, the anecdotal evidence is powerful. Doctors, nurses, allied health personnel, substitute decision-makers, and family and friends may have causal 'anxiety', anxiety that the death in question has been caused by treatment withdrawal or non-initiation or by opioid pain relief or sedative drug administration during the dying process— notwithstanding that opinion polls indicate a majority of Australians agree with assisted dying.

⁶⁹ Submission No. 13, p3

⁷⁰ Submission No. 2, p3

⁷¹ Transcript, 9 August 2016, p17

Health professionals usually have a narrow empirical view of causation, and they should be made aware that the law takes a common sense and multifactorial view, and indeed will often not even apply a causal analysis, focusing more on legality of actions and presence or absence of duties instead. Clarification of what law and ethics really say about death causation in the setting of the care of dying people will show that causal anxiety is largely misplaced, inflated and inappropriate. There is no basis for fear of legal sanction by health professionals when dealing with dying persons if the prevailing standards of palliative care are adhered to.

However, legislators in South Australia felt they still needed to give statutory force to the common law adoption of the doctrine of double effect, and dealt specifically with causation.

Ongoing public and professional education and research will be required to better understand and deal with these deeply engrained fears. Clear jurisdictional messages about the primacy of comfort and dignity in the dying process over length of life will always be helpful, provided that new legal obstacles are not thereby created. It should be noted that the so-called doctrine of double effect, with its origins in catholic moral theology, is a contested concept in law and ethics.⁷²

6.58. Professor Margaret Otlowski commented:

Also significant would be the clarification of the legality of any act or omission by a medical practitioner in the course of treatment of a patient provided that it is done in good faith, in accordance with proper professional standard of medical practice etc. This would overcome lingering concerns in some quarters regarding the withdrawal of medical treatments which are no longer medically indicated (particularly in circumstances where there may be family members who are objecting to the withdrawal of such treatment).⁷³

6.59. Professor Margaret Otlowski commented further:

One area I would like to highlight is that of administration of pain relief, which we know may, in some circumstances, have the effect of shortening life. Even though this is assumed to be a legal and accepted practice in Australia, if you actually go to look for the legal basis of it, it is very thin; in fact you find the contrary. So we rely on a common law principle derived from a House of Lords case - Adams case - the summing up to a jury which indicated as long as you are not intending to hasten death; that your purpose is to relieve pain and suffering, it is a distinction that is drawn between intending and merely foreseeing death. You are not allowed to intend it but if you merely foresee it with the purpose of relieving suffering, that is okay. Yet, if you try to align this with the requirements of the Criminal Code, this is the real challenge. Obviously it covers intentional killing, but it also covers killing knowing where it is likely or probable. So there is a complete disconnect.⁷⁴

⁷² Submission No. 18, p9-10

⁷³ Submission No. 3, p2

⁷⁴ Transcript, 9 August 2016, p17

6.60. Mr Paul Russell, HOPE: Preventing Euthanasia & Assisted Suicide Inc. commented:

Let me first start by noting that the so-called doctrine of double-effect goes back to St Thomas Aquinas originally and that is a fairly long time ago, but in practical terms I am led to believe, particularly in a palliative care setting - and I heard this from an elder care specialist - that their ability to titrate drugs effectively for the patient's needs by virtue of their weight, experience and the degree of pain and suffering they may be experiencing is such now that the risk of that treatment accelerating death by any degree is minimal to the point of almost being non-existent in that setting, but certainly the principle is that it all comes down to intention. If the medical intention and the application of that intention is such that it is to relieve pain and suffering in a patient, even if there is a secondary known possibility that by doing so it may foreshorten their days, then it is an appropriate and ethical achievement if in fact the intention and the method is correct.

Some suggest it is a very much a grey area but I do not think it is, and certainly those I talk to do not think it is because they see that it has very little application in good palliative care, but also I think most doctors can understand what it is about intention and they certainly know the effect of the kinds of dosages given. Even though it is difficult in hindsight to look at intent and ask what the doctor intended, I think you can get an indication from that by the dosage and if the dosages are in fact significantly over and above what would be normal to expect to receive, then you may get into an area where you could question the intention.⁷⁵

Legislation in Other Jurisdictions

6.61. Respondents discussed the introduction of relevant legislation in other jurisdictions.

6.62. Paul Russell, HOPE: Preventing Euthanasia & Assisted Suicide Inc., commented:

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.⁷⁶

6.63. Paul Russell commented further:

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

19—Binding and non-binding provisions

⁷⁵ Transcript, 9 August 2016, p25

⁷⁶ Submission No. 2, p3

- (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 nonbinding 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 hypoglycemic 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.⁷⁷

Advance Care Plans: Need for National Consistency

- 6.64. The Committee heard from a number of witnesses arguing the need for national consistency in Advance Care Plans. The submissions called for consistency in the forms used, the terminology and the registration, so that people could have certainty, their wishes would be upheld and reduce the legal risk for health practitioners.^{78 79 80 81 82 83}

⁷⁷ Submission No. 3, p1

⁷⁸ Transcript, 8 August 2016 (morning), p36-7

⁷⁹ Transcript, 8 August 2016 (afternoon), p4

⁸⁰ Submission No. 11, p1

- 6.65. Submissions argued that national consistency is essential as the Australian population is highly mobile and patients frequently moved between states, with some submissions arguing for the need for Advance Care Plans to be recognised interstate.⁸⁴

Rights of the Patients/Doctors' Autonomy

- 6.66. The Committee heard of the conflict between the wishes of a patient and the autonomy of the doctor.

- 6.67. Brigid McKenna, Archdiocese of Hobart, commented:

Patients have legal rights and we have responsibilities to respect those. In those very difficult situations, doctors may be at a loss in that they feel that they too have lost a bit of their autonomy - not as something to exert over a patient but in terms of their professional autonomy. I can appreciate we lose something if we become too legalistic, if we start to talk about very much being a healthcare consumer, a healthcare provider; I have my rights. I suppose what I would see as the best clinical; the best caring environment, we are coming in as equal partners, acknowledging we begin with different vulnerabilities and different levels of expertise. I think, if we have a system that is so totally bound in law to protect the rights of the patient, we do risk that we lose something in terms of professional autonomy - a doctor's or nurse's capacity to care and respond to the situation as they see best. But then too we also have talked about vitalism. All health care providers have trouble letting go at times. We need to find some way of respecting and honouring clearly expressed patient wishes and values.⁸⁵

- 6.68. Mr Paul Russell commented:

Sadly, to me the idea of a binding directive in terms of an advanced care plan is somewhat problematic. Certainly if the plan is refused, the likelihood of conflict between the direction and good medical practices is probably slim, but the problem I believe is deeper than that. I think there is a tendency these days to what I call a 'slot machine' approach to medical care, where the doctor is merely the provider of the service and the patient calls all the shots. It is a little like getting a candy bar from the dispensing machine.⁸⁶

Creating Advance Care Plans

- 6.69. The Committee heard of a number of challenges in implementing Advance Care Plans is getting people to create the document.

- 6.70. Allison Lennox commented:

⁸¹ Transcript, 8 August 2016 (morning), p31

⁸² Transcript, 8 August 2016 (morning), p31

⁸³ Submission No. 4, p1

⁸⁴ Submission No. 4, p1

⁸⁵ Transcript, 9 August 2016, p6

⁸⁶ Transcript, 9 August 2016, p25

*We are getting better about talking about death. Usually it is all hush-hush but it is so much better now talking about palliative care... Getting your hands on the form and then filling it out is the bit perhaps people need a nudge on.*⁸⁷

6.71. The Committee heard from a number of persons that the creation of Advance Care Plans should become part of standard medical practice.

6.72. Palliative Care Tasmania commented:

*Encouraging General Practitioners to have Advance Care Planning conversations with their patients, (especially those with life-limiting, chronic conditions, people newly diagnosed with dementia or other conditions which may impact on decision making capacity), along with discussion of Medical Goals of Care for those people who may wish to refuse life-prolonging treatments is an important step in increasing acceptance of ACDs across the community and the medical professions.*⁸⁸

6.73. Dr Rosemary Ramsay, Rural Clinical School, commented:

Key times would be a new diagnosis, entry to aged care, and at the 75 years and above health checks. In the general practice where I work we have care coordinating nurses who visit people at home when they have a new diagnosis and those nurses prompt us and remind us to renew the conversation.

...

*Our nursing colleagues are very key in the general practice, our practice nurses who do those 75 and above health checks. Simply having it in your practice software to prompt you is also a key thing and our care coordinating nurses also prompt us. We have to have some courage to have those conversations, particularly around dementia diagnosis. It takes time to grow as a doctor but one of my key learnings is that when you are diagnosed with dementia in my practice, you have this conversation and are provided with the documents to take home and read it, bring it back and ask questions.*⁸⁹

6.74. Lyn Irwin, Friends of Northern Hospice, commented:

With regard to the preparation of individual CDs, we believe that they are best managed by General Medical Practitioners (GPs) who already have opportunities to discuss these with their patients, given their close medical and professional relationships. GPs are well-placed to raise, as routine, ACDs for patients of all ages with a life limiting illness, and all patients over the age of 75 years who receive an annual health assessment, E-health records can then hold this information so it can be accessed by appropriate care-givers. This can be reinforced through public advertisements encouraging people to discuss their ACD with their doctors. Advertising would also serve the purpose of raising end of life choices within the boarder family unit. It may be possible for ACDs to be routinely promoted through solicitors when individuals are making their Will.

FONH also support community-based initiatives to raise general public awareness of the need for, and advantages of, everyone preparing an ACD. However, it is not the role of these community organisation to work directly with a specific individual to help them

⁸⁷ Transcript, 8 August 2016 (morning), p18

⁸⁸ Submission No. 13, p3

⁸⁹ Transcript, 10 August 2016, p1

prepare their personal ACD. For example, there may be clinical and/or personal factors to be considered, knowledge of which should remain a private matter protected by the ethics of the doctor-patient relationship.⁹⁰

Medicare Number

6.75. Many respondents stressed the need for financial reimbursement through Medicare that will enable doctors to provide advance care planning, with some respondents apparently were not aware that a Medicare Item Number is available for a GP to have an extended conversation with a patient towards the goal of preparing an Advance Care Plan.

6.76. Colleen Johnstone, Palliative Care Tasmania, commented:

We also tend to find through our work, particularly with general practitioners, that they are not appropriately trained and don't really have the skills to engage in conversations with their patients about dying. The average GP sees around 30 patients a day and one of whom might be someone with a life-limiting illness, and at the moment there is no financial incentive for GPs to sit down and do an advance care directive with a patient. For example, if you have a mental health issue the GP can do a mental health care plan and that can be bulk-billed back to Medicare. We would like to see is the same sort of process applied with advance care directives, so that the GP can spend that time with you and bulk-bill that back to Medicare.⁹¹

6.77. Dr Helen Lord, Anglican Church in Tasmania, commented:

The way general practice is funded at the moment, it would be nice to get a separate item number - but you would to speak to the Commonwealth about that.⁹²

6.78. Ms Onslow, Hobart District Nursing Service, argued for the need for mandatory Advance Care Plans for patients being admitted into palliative care facilities or programs: “so we know that conversation has been had and that people are encouraged to have them in place. We think they provide a good standard of how we are delivering our care for these people”.⁹³

Registration of Advance Care Plans

6.79. Respondents discussed the futility of Advance Care Plans if the documents are not available when needed. Of those respondents who advocated for the use of Advance Care Plans, there was almost universal support for the creation a central repository of Advance Care Plans, specifically one that was available online. The creation of a repository would remove the onus

⁹⁰ Submission No. 17, p1-2

⁹¹ Transcript, 8 August 2016 (morning), p37

⁹² Transcript, 8 August 2016 (morning), p10-11

⁹³ Transcript, 8 August 2016 (morning), p6

of the individual, and create greater certainty for patients and medical professionals.

6.80. Colleen Johnstone, Palliative Care Tasmania, commented:

The other big issue with advance care directives is there is no central repository, so the onus is on the individual. That has a lot of risk and pitfalls. If I lodge my advance care directive at the Royal Hobart Hospital and something happens to me on the north-west coast, that doesn't mean the North West Regional Hospital will have access to my advance care directive. There is also an issue for emergency services. They don't have access to advance care directives and with the current system paramedics are only provided with an address. They are not necessarily provided with the individual's name, so even if they were given access to advance care directives, they don't know who they are going to treat. They don't know the person on the floor is the person the advance care directive is related to. That is a very big issue.⁹⁴

6.81. Many respondents argued that having a central repository would alleviate a number of issues for emergency workers.

6.82. Professor Michael Ashby commented:

...if you go to any emergency department and somebody comes in - we have heard that people's wishes are not always respected - wouldn't it be wonderful if we could immediately locate the forms and there it is in black and white. When our medical record system is up to that then maybe it would be.⁹⁵

6.83. Paul Russell, HOPE: Preventing Euthanasia & Assisted Suicide Inc., commented:

A continuing source of frustration to both governments and patients alike is the problem of ensuring that the persons ACP [Advance Care Plan] 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.⁹⁶

6.84. Lyn Irwin, Friends of Northern Hospice, commented:

In some ways this is where, if an e-health setup could be available to all medical caregivers, it would be easier to see that this person has an advance care directive which states that they do or do not want active treatment, they are palliative and are approaching end of life because there would have been interaction between the GP and the specialist palliative care unit and whatever else.⁹⁷

6.85. Dr Peter Saul commented:

⁹⁴ Transcript, 8 August 2016 (morning), p38

⁹⁵ Transcript, 8 August 2016 (afternoon), p5

⁹⁶ Submission No. 2, p3

⁹⁷ Transcript, 10 August 2016, p11

Our local project My Net Care references your national health identifier so we will have it if people start uploading documents onto our website. It will be picked up by the national identifier and would effectively be a form of registration itself.⁹⁸

Advance Care Plans: Need for Review

6.86. Respondents discussed that Advance Care Plans need to be reviewed as individuals situations change and as continual advancements in medical treatments become available.

6.87. Mr Paul Russell commented:

It might be that people definitely want to talk with their own family members and come up with a set of desires and wants that they can express in a plan, even at a time when they are in good health and there is nothing pervading on the horizon. However these need to be met and interpreted and formulated in the context of care, whether that be with a consult with a GP, an aged care facility or retirement home in that first diagnosis or in planning for a procedure. The more we embed the review of such plans into a landscape of medical care, the more likely the patient's wishes will be expressed properly and the less likely they are to be misinterpreted, both leading to better outcomes in care.⁹⁹

6.88. Dr Helen Lord, Anglican Church in Tasmania, commented:

People who would have perhaps only had a life expectancy of a month or so are now living for longer than a year with reasonable quality of life. There are changes happening with those things. You may well get changes happening in other fields. That is why I think you need to have some sort of review mechanism of it. This is valid for this time. It might be 12 months.¹⁰⁰

Committee Comment

6.89. The Committee notes the strong support for Advance Care Plans by organisations and health care workers involved in palliative care.

6.90. The Committee notes the absence of uniformity of Advance Care Directives/Plans in Tasmania despite the existence of THS Advance Care Directive Protocol.

6.91. The Committee notes the strong support for the establishment of a legislative framework for Advance Care Plans, recognising the specifics of the legislation would need to deal with the non-binding nature of advance care directives as they are currently expressed.

⁹⁸ Transcript, 12 September 2016, p39-40

⁹⁹ Transcript, 9 August 2016, p25

¹⁰⁰ Transcript, 8 August 2016 (morning), p11

- 6.92. The Committee notes the futility of Advance Care Plans if the documents are not available when they are needed and the widespread support for the creation a central repository of Advance Care Plans, specifically one that is available online. The Committee finds that the creation of a repository would remove the onus of the individual, and create greater certainty for patients and medical professionals.
- 6.93. Establishment of a repository will only work if there is a corresponding duty on medical professionals to access the information.
- 6.94. The Committee notes that there needs to be an obligation for medical practitioners to consult Advance Care Plans when providing medical treatment as part of an overall governance/legislative framework for end-of-life care.
- 6.95. The Committee notes that Queensland, Western Australia, and South Australia have codified the doctrine of double effect in legislation.

Recommendation 4:

That the Tasmanian Government establish a legislative basis for Advance Care Plans.

Recommendation 5:

That the Tasmanian Government:

- **investigate the regulation of outcome-based Advance Care Plans to ensure their consistent application and effect;**
- **considers the issues of capacity and age in the creation of Advance Care Plans;**
- **implements a secure register, where Advance Care Plans can be lodged and which permits immediate access by authorised health care workers, including ambulance officers;**
- **provide education to the public, health workers and other relevant professionals to increase awareness and use of Advance Care Plans and the Register; and**
- **establish guidelines for medical practitioners to consult the register and consider a patient's Advance Care Plan in treatment decisions.**

Recommendation 6:

That the Tasmanian Government make recommendations to the Commonwealth to provide unambiguous Medicare funding for General Practitioners to offer advance care planning to patients regardless of the patient's age.

Recommendation 7:

That the Tasmanian Government consider the implementation of a Shared Health Record for all patients, which links to Advance Care Plans.

Enduring Guardianship

6.96. The Committee heard from respondents the role that an enduring guardianship can play in palliative care. The enduring guardianship is governed by the *Guardianship and Administration Act 1995* (the GAA), which also covers guardianship of those with disabilities.

6.97. The Tasmanian Government commented:

The GAA is a fundamental part of the legal framework in Tasmania for medical decisions made at the end of a person's life if the person has lost the capacity to make those decisions.

The GAA provides a statutory basis for consent to medical treatment for persons with a disability, who are incapable of giving consent to the carrying out of medical or dental treatment.¹⁰¹

6.98. The Tasmanian Government commented:

The appointment of an enduring guardian may be done by any person who wishes to have certainty about who will make personal decisions on their behalf if they lose capacity and, in particular, any person who wishes to give specific instructions in the instrument of appointment.

Under Tasmanian law, a formal enduring guardianship form must be completed and registered with the Guardianship and Administration Board in accordance with Part 5 of the GAA.

6.99. Donna Spong, Guardianship and Administration Board, argued that an enduring guardian has greater legal certainty:

The enduring guardian is the legal document. It does not matter what your Medical Goals of Care or what your advanced care directive is. It is more a question for a medical person. A doctor has a duty to preserve life. His/her duty of care depends on what the person responsible, under our act, is saying, or if there is an enduring guardian, what the guardian is saying.

6.100. Lyn Irwin, Friends of Northern Hospice, commented that whilst Advance Care Plans are not legislated, services might be better recommending an enduring guardianship.¹⁰²

¹⁰¹ Submission No. 24, p11-12

¹⁰² Transcript, 10 August 2016, p10

6.101. Dr Helen Lord, Anglican Church in Tasmania, made the following recommendations in relation enduring guardianship and the *Guardianship Administration Act*:

1. *In the event of any family-carer conflict, recommend appointing an Enduring Guardian to ensure a just process*
2. *In the event of a family-carer dispute suggest referral to the Guardianship Board*
3. *If a person concerned is unable to nominate a Person Responsible (due to social isolation) suggest referral to the Guardianship board and have ACD lodged with the Guardianship Board: this will require a new process. This is the suggested way to provide some peace of mind to the socially isolated.*
4. *Remove the current lodgment fee for placing an Enduring Guardianship with the Guardianship Board, as this is a barrier for many groups in the community.*
5. *Ensure that access to Guardianship Board records by treating medical staff is available twenty-four hours a day.*¹⁰³

6.102. Dr Brigid McKenna, Archdiocese of Hobart, commented on the use of a ‘responsible person’ - :

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.*¹⁰⁴

6.103. Dr Helen Lord argued that the appointment of an enduring guardian should be done when the patient lacks the capacity to create an Advance Care Plan:

The Guardianship Board and the creation of an Enduring Guardianship should retain a role in circumstances of potential carer/family dispute, incapacity or inability of a person to make an ACD.

*An Enduring Guardianship agreement should be reviewed every five to ten years, should be available without cost to those at social disadvantage, and should be accessible by medical carers at all times.*¹⁰⁵

¹⁰³ Submission No. 6, p5

¹⁰⁴ Submission No. 22, p9

¹⁰⁵ Submission No. 6, p5

Committee Comment

6.104. The Committee notes the significant confusion by the public and some health care workers in relation to the difference between an Enduring Guardianship and Enduring Power of Attorney.

6.105. The Committee is concerned that confusion may result in individuals falsely assuming they have made sufficient arrangements for their wishes to be followed during end-of-life care.

6.106. The Committee notes the potential for conflict in the hierarchy and interplay of roles of a responsible person in an Advance Care Plan and an enduring guardian.

Recommendation 8:

That the Tasmanian Government articulates the relative roles and purpose of Enduring Guardianships and Enduring Powers of Attorney in Advance Care Plans and end-of-life decision making.

7. TREATMENT

- 7.1. The Committee heard from a number of witnesses about the issues relating to the treatment received by patients in palliative care.

Pain Management

- 7.2. Most respondents raised the issue of pain management.
- 7.3. Professor Michael Ashby commented:

There isn't a single area of medicine that has a 100 per cent score, so why would palliative care be any different? Any claims by us that we can relieve all pain are patently nonsense. I think it is very foolish of certain people in our specialty around the world to convey the impression that they can. I don't think anybody these days would make that claim. What I can say is that we can nearly always make a difference for the better. There would be very few situations in which I would say there is nothing I can do for pain relief. All good drugs act on the brain and there will be side-effects and sometimes doctors are very good at minimising side-effects. The problem is that in our residential facilities, because there have been some very unfortunate incidents with over-sedation and falls. You would be well aware that this Parliament and this Government is responsible for one of the most regulated industries. You go into an aged care facility and there are shelves groaning with large tomes of rules and regulations and reporting mechanisms. It is quite overwhelming. Within that there has been, rightly at one level, a very big push to prevent the over-sedation and inappropriate sedation of the elderly, but it has made practitioners very wary of giving drugs for pain relief and drugs in the dying process when sedation is often needed.¹⁰⁶

- 7.4. Professor Sing, Dying With Dignity Tasmania, discussed submissions to a Victorian Inquiry on assisted dying:

One of the things in the submissions of those people who are opposed to assisted dying, which I find almost incomprehensible, given the major opponents are religious and/or medical, is that I cannot find a single mention - and I did a very detailed exploration of more than 20 submissions - of the people whose suffering continues because palliative care cannot meet it. They talk about pain and say, 'Oh, pain can be relieved'.

Ms OGILVIE - So that you're aware, we have had some conflicting evidence on that.

Ms SING - There is a focus on pain rather than the broader notion of suffering, that it is either pain or existential suffering with none of the physical suffering in between, that it is a choice between offering the relief of palliative care, or all of those things. I find it extremely disturbing because, quite frankly, if I was going into palliative care I would not want to be treated by somebody who didn't believe, or was not being open and honest about the fact that they could not relieve all suffering. There are a lot of descriptions of the aims and purposes of palliative care, the methods and improvements, but I don't believe any system can really improve as well as it should be

¹⁰⁶ Transcript, 8 August 2016 (afternoon), p8-9

able to without admitting that there are people for whom whatever we do is not going to be good enough.¹⁰⁷

- 7.5. Professor Sing commented on the University of Wollongong report, 'Trends in Patient Outcomes: Palliative Care in Australia 2011-15':

The sort of symptoms they report on are these: difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. There is a whole range of physical suffering. Having had the experience of my mother dying over an extended period that is only the tip of the iceberg because it is the whole combination of things. Everything from mouth ulcers so your teeth cannot fit and so you can't eat properly. There are so many things that happen to people at that time of their life.

The important section, I was gob-smacked by when I came across it, was as part of this process they are looking at patients with moderate or severe distress from pain. This is just pain at phase start, who have moved from that moderate or severe situation to either absent or mild pain. Only 50 per cent, their benchmark is 60 per cent across thousands of palliative care episodes, only 50 per cent of people are getting that relief. Being able to move from moderate or severe to mild or absent. There is no mention of that in a lot of material that is coming through from palliative care.

These are not our figures. These are national figures collected across a large number of services - inpatient, community and so on. The point is it is very important that recognition is there. That although palliative care is improving, has improved a lot, and the graphs show that very clearly here too, there is a process for continuing that improvement. Despite their best efforts there are still people - even though there are only a few in percentage terms, it only takes one per cent of deaths in Tasmania to be forty people - in a really bad situation. That is a basis for the kind of concerns we have. That circumstance is really critical to be recognised.¹⁰⁸

The Line Between Pain Management and Palliative Sedation – the Difference of Intent

- 7.6. Respondents raised concerns in relation to the difference between administering pain management and hastening death. There was clear consensus that because there is a grey area, as discussed in Chapter 6 at paragraph 6.52, the inherent difference relates to the intent of the person administering the medication.
- 7.7. Brigid McKenna, Archdiocese of Hobart, commented:

... we were administering pain-relieving medication such as an opiate, like morphine, to a patient and our intention was to relieve the patient's pain and distress -even if we could foresee that that might shorten their life, we would still be very comfortable and

¹⁰⁷ Transcript, 8 August 2016, p13-14

¹⁰⁸ Transcript, 8 August 2016, p14

clear-minded that what we are doing is actually focusing on the patient and relieving their pain, and in no way intending to hasten their death.¹⁰⁹

7.8. Brigid McKenna commented on continuous deep sedation:

It is difficult because people use the term differently. Where I have referred to continuous deep sedation there, we are talking very much about the ultimate end of life, although I would say in some countries that is introduced well before that phase and that is where the controversy lies.

I have seen people who haven't necessarily been in uncontrollable pain or with uncontrollable systems, but are in deep existential distress, but they have been able to participate in the decision making so that has made it somewhat easier. They have decided they would rather be a little bit less aware of what was happening than be fully aware to try to manage that.

You will hear from other people, I am sure, that with so many things in palliative care, very rarely there is a sudden decision to do something. It is little steps so often, and that is what I like about the way the European association talks about sedation. Sometimes sedation is used for a very short period and it is a light sedation. It is now something we can titrate very well to help someone get over a hurdle and give them some relief. People might say, 'I just need some time out'. In terms of those anxieties, existential fears and concerns, that is often how sedation might be used. There are those rare circumstances where someone says, 'I don't want to and I haven't got it within me to go through this anymore'. They are very rare and there are also some catastrophic symptoms, some we know are truly unpleasant to experience as you die.

... Massive hemorrhages and things like that. The palliative care clinicians that I have worked with, if people want to know how they may die - and most people do, in my experience - they will often talk through possible things. 'We can never be sure, but this could happen and in the event of that happening, would you like to be less aware of what was happening?' That is an instance of deep sedation. The focus is on the patient, on the relief of their symptoms and stress. Yes, it may hasten their death but that is not our intention - and it would be seen as appropriate.

... I acknowledge a patient could request and a doctor could initiate continuous deep sedation with euthanasia in mind. We talked about the intention that we have to go back to what people are requesting and choosing to do. I would suggest to you that perhaps, not in Australia but in some other countries, continuous deep sedation is used as a method of euthanasia. That is why I was very keen to put in and make reference to the European Association for Palliative Care¹¹⁰. They deal with continuous deep sedation in depth and clarify the different way it can be administered. There is a depth to their discussion which is important if we are going to be honest about what people might be requesting and what doctors might be administering.¹¹¹

¹⁰⁹ Transcript, 9 August 2016, p3

¹¹⁰ The European Association for Palliative Care (EAPC) is a membership organisation dedicated to the promotion and development of palliative care throughout Europe. EAPC produces palliative care research and policy, operates courses and conferences on palliative care as well as engages in public education.

¹¹¹ Transcript, 9 August 2016, p7-9

- 7.9. Professor Margaret Otlowski, University of Tasmania, discussed the possibility that continual sedation could be considered a “slow form of euthanasia”:

...but I think we can accept that there a difference, also for the health professional in something that is -...something that very actively and immediately has an effect and something, which is for a different purpose and has a slower effect. The circumstances where you know the patient is not going to regain consciousness and you are keeping them comfortable with a bit of mouth care and so on - effectively we know they will die and what is being done is facilitating that. But I think we have to be brave and find a way to accept that that can be part of the medical practice, because what is the alternative? The alternative is unbearable suffering. So we need to be able to carve out the legal exceptions with enough clarity to allow appropriate palliation at end of life so that people don't fear, firstly, that it is going to be alleged to be euthanasia and that there is not a holding back of measures that are necessary for the relief of pain at the end of life.

It is an interesting one in that the refusal of treatment rests on the autonomy a person has and the control they have over their body, and that they cannot be compelled to have things done to their body that they do not consent to. So that means you can reject anything, including nutrition and hydration, if you are a competent person but that freedom of autonomy does not allow you to empower someone else to actively do something to assist you. Even if they are consenting, you can't give legal authority for someone to give active assistance, so it is all to do with rejecting. The authority or the autonomy of an individual doesn't allow permission to have active assistance. So that is why there is no 'right to die' in the sense of active assistance. But, if you think of it in terms of the passive, there is a right to refuse treatment and that in turn can lead you to die. So, in that sense, even though it is not stated as a 'right to die' in the Criminal Code, there is nothing in the Criminal Code I think that would require doctors to continue with futile treatment.¹¹²

- 7.10. The Committee notes that the intent of continual sedation is a humane approach for people to be pain-free as they die.

Futile Treatment

- 7.11. Respondents universally opposed the administration of futile treatment.
- 7.12. Professor Margaret Otlowski, University of Tasmania, was supportive of providing legal protection from medical treatment that is intrusive, burdensome and futile.¹¹³
- 7.13. Mark Brown, Australian Christian Lobby, commented:

Treatment that continues beyond a point where it is burdensome or futile is against good health principles. Treatments are futile if they provide no benefit to a particular patient.

¹¹² Transcript, 9 August 2016, p21-22

¹¹³ Submission No. 3, p2

Treatments are burdensome when they cause distress and suffering, cause difficulties for the patient, or are costly to obtain or provide. Patients have the moral right to refuse any treatment that is futile, or that the patient judges to be overly burdensome or morally unacceptable. Such refusals should always be respected by health care professionals.

Similarly, health care professionals should refrain from providing treatment that is futile or overly burdensome.¹¹⁴

7.14. Brigid McKenna, Archdiocese of Hobart, commented:

We are always trying avoid two extremes, both under treatment and over treatment. From our perspective, a Catholic Christian would see, yes, life is sacred, it is a gift of God but it is not God. Death is inevitable, death will come, and for many Christian people death is perceived as some release. It is a passageway to, we believe, eternal life. We ought not as Catholics, have any great fear of death. That is something we try to foster amongst ourselves and something we would like to be sharing with the community. We are not vitalists. We would very much be encouraging people to feel they can still honour and uphold the dignity and beauty of human life by letting go when the time comes.¹¹⁵

7.15. Brigid McKenna commented further:

Yes, I have certainly witnessed circumstances and situations which have been vitalist more or less. It is pushed. I suppose I would say of that that I believe it to be bad medical practice. That is in keeping with my own formation as a doctor and our own internal code of conduct, as well as a Catholic and someone who has studied ethics. I think there has probably been a bit of a shift but there is still tremendous scope. I suppose I speak here being able to tap into some of the vulnerabilities of health care professionals because there is this desire to do everything that you can. To a certain point that is a really valuable thing. That is what has led to the development of medicine, to the place that we are in, but it is very much a case of our own virtue, I suppose, to be able to contain that and keep the focus on the person, the patient, that is before us.

...the focus needs to be on the dying person. In order to shift that focus you need to first meet with the family's own anxieties, their own fears, their own needs before you can redirect them. Within that then I think there are very emotional psychological issues that you need to deal with, as well making sure that people do understand, particularly if they are Christian people that they are allowed to let go. So, there is information giving, as well as trying to address their own anxieties.¹¹⁶

7.16. Hilde Nilsson, Dying With Dignity Tasmania, argued that there:

...is a lack amongst the medical profession of recognising the point of where what we call active treatment becomes futile and the treatment focus needs to be changed to comfort care and quality of life that is palliative care. There is some recent research led

¹¹⁴ Submission No. 12, p2-3

¹¹⁵ Transcript, 9 August 2016, p2

¹¹⁶ Transcript, 9 August 2016, p4

by the University of New South Wales, published in the *International Journal for Quality in Health Care*, which found that hospital doctors frequently initiate excessive medical or surgical treatment on patients over 75 with advanced, irreversible conditions. It also found that over 90 per cent of elderly patients with cancer who died in hospital were given CPR and then died. That is just gross. I just cannot find words to describe that.

In my clinical role with end-of-life management I did massive education programs about not resuscitating everybody, but there is such a mindset against that. It needs a whole culture change.

...

Professor Ken Hillman and a quote of his that I often refer to is:

*The suspension of death is now routine, as we demand that sick and elderly people trudge on indefinitely.*¹¹⁷

7.17. Professor Margaret Otlowski, University of Tasmania, commented:

*The capacity to keep people alive often leads to almost a responsibility to do things even though they are not going to improve the quality of the patient's life let alone cure the patient. So we would all agree that interventions need to be ethically and clinically appropriate and aimed at actually improving the quality of care at the end of life. The studies that have been done on the problems of care point to a number of difficulties which I think are quite illuminating. Sometimes it is family pressure on the health professionals; sometimes it is breakdown in communication; sometimes it is medico-legal concerns, and that is an underpinning of some of the other points I would like to make.*¹¹⁸

7.18. The Committee notes that it did not receive any evidence of a definition of when treatment becomes futile, highlighting the complications of prescribing legislation to issues which cannot be defined outside of the subjective of the individual. The topic of the doctrine of double effect is discussed in Chapter 6 at 6.51.

7.19. Mark Brown, Australian Christian Lobby, commented on the issue of artificial feedings and the case of *Gardner; re BWV [2003 VSC 173]*:

The legal status in Common Law of the permissibility of the withdrawal of artificial nutrition and hydration was considered in the Victorian case of Gardner; re BWV. In that case, Justice Morris determined that the use of a percutaneous endoscopic gastrostomy (PEG) for artificial nutrition and hydration was a 'medical procedure', because it involves 'protocols, skills and care which draw from, and depend upon, medical knowledge', and careful choice and preparation of materials to be introduced into the body, dosage rates, and measures to prevent infection and regular cleaning of conduits, and thus it fell within the scope of the term found in the Medical Treatment Act 1988 (Vic). By defining artificial nutrition and hydration as a 'medical procedure', rather than 'palliative care', it was held that the withdrawal of artificial nutrition and hydration, under the medical circumstances of that case, would not amount to a criminal act.

¹¹⁷ Transcript, 8 August 2016 (afternoon), p15-16

¹¹⁸ Transcript, 9 August 2016, p17

ACL submits that defining artificial nutrition and hydration as a ‘medical procedure’ under law is highly objectionable. The alternate and better policy position for defining the provision of nutrition and hydration, is that it is a ‘natural’ means of care and not a medical procedure or treatment; this is the case even when it is provided by artificial means such as a naso-gastric or PEG tube.¹¹⁹

7.20. The Committee considers this point needs in-depth legal consideration as this matter is crucial to the issues of palliative care and the rights and responsibilities of both palliative care patients and palliative care providers.

7.21. Professor Otlowski discussed a patient’s common law right to refuse treatment and argued for the right to be legislated:

I think here too there is a lot of ambiguity about what rights patients have to direct that nothing further be done or what the responsibilities of doctors are and the scope of those responsibilities to administer treatment, so I think we could benefit from clarity of these rights and obligations in the same way through clear legislative statements. That has been done in the South Australian bill and the Victorian inquiry also acknowledged the degree of uncertainty around this. This also would benefit from giving statutory effect to what really is common law understanding about a patient's rights to refuse treatment and doctors not having to administer treatments that are futile and so on.¹²⁰

7.22. Dr Brigid McKenna, Archdiocese of Hobart, commented:

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

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) 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.

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).¹²¹

¹¹⁹ Submission No. 12, p4

¹²⁰ Transcript, 9 August 2017, at 18-19

¹²¹ Submission No. 22, p4-5

Administration of Pediatric Medical Treatment and Medical Treatments to Minors

7.23. The Committee heard from a number of respondents of the issues affecting the administration of medical treatment to minors.

7.24. Palliative Care Australia, the national peak body for palliative care, describes palliative care for children as:

...“enabl[ing] the child or adolescent to live in an environment where curative treatment can be part of their life, but not their entire focus. It aims to provide the best quality of life through a holistic approach which supports the physical, emotional, social and spiritual aspects of the child and their family. The goal is to add life to the child’s years, not simply years to the child’s life.”¹²²

7.25. The Tasmanian Government stated that the administration of medical treatment to children is covered under common law and the *Guardianship and Administration Act 1995* and for children with mental illness, the *Mental Health Act 2013*.

7.26. The Tasmanian Government commented:

...overall demand for pediatric palliative care in Tasmania is low... When it is provided, pediatric palliative care planning will occur with a child’s family. Medical and nursing staff will meet with the family and child to discuss care planning, MGO, symptom management and a plan for where care is best provided (home/hospital).

There is a close relationship with the pediatrics unit and treating pediatricians (and often oncologists) and pediatric palliative care specialists in Melbourne may be consulted. Children who will be cared for at home will be referred to community palliative care and community nursing, supported by a pediatric outreach service.

7.27. The Committee notes that there is a gap in processes and procedures for neo-natal, perinatal and families facing the death of a new-born child, which needs to be addressed.

7.28. The Northern Hospice Feasibility Study identified the following needs and considerations of children in providing paediatric palliative care:

- *Families and care providers can be reluctant to move a child receiving palliative care from a familiar environment. For this reason, many families requiring access to pediatric palliative care have a preference for the child to remain in the family home or on the ward where they have received treatment. The familiarity of the environment and staff in these locations provides a sense of comfort for both the child receiving care and their family.*

¹²² Submission No. 24, p18

- To the age of pediatric patients, the make-up of the family group is often quite different to adults receiving palliative care. Family networks for a child are likely to involve multiple generations of the family, potentially including:
 - parents;
 - young siblings/cousins;
 - grandparents; and
 - aunts and uncles.
- The presences of multiple generations within the family group can result in a very large care network, with different needs to adults. When providing pediatric palliative care, the specific requirements of each generational group need to be considered, and appropriate support provided. In particular, care and support for siblings was identified as being very important when they are also of a young age.
- It is important to ensure that the physical care environment is suitable to the needs of the pediatric patient and their large carer group. Inpatient rooms may need to be established in a manner which ensures that they are appropriate for, and can accommodate, multiple generations. Specific considerations include:
- Ensuring that the room is not overly clinical and can be decorated in a way which is appealing to a child (for example, use of child friendly colours, images and bedding).
- Ensuring that play equipment is available for use by younger siblings of the patient. This may be within the room, or in a nearby family area.
- Allowing additional space to accommodate numerous family members at any given time.
- Establishing facilities so that parents can stay with the child while they are receiving care. This may be supporting overnight accommodation in the child's room, or in a family room adjacent to the child.¹²³

7.29. The Tasmanian Government commented in relation to minors and consent to medical treatment:

The administration of medical treatment to minors is informed by the DHHS Clinical Consent Policy, which sets out the legislative requirements and guiding principles for healthcare interventions for a child. The THS has developed a statewide Consent for Procedure or Treatment Protocol to enact the Clinical Consent Policy.

Patient consent is required before treatment may be started or stopped. The Clinical Consent Policy states that in all decisions concerning children or young people their best interests shall be the primary consideration. The family of a child or young person should be heard and involved in their care and treatment, unless it is contrary to his or her best interests for this to occur.

The ability of a parent to consent diminishes as a young person's or child's capacity for decision making increases. The capacity to consent depends on the young person's or child's maturity and the ability to understand and appreciate the proposed healthcare and is dependent on the type of healthcare in question.

Both the Supreme Court and the Family Court have jurisdiction to decide cases relating to medical treatment for children at the end of life. Cases arise in the rare situation where the medical professionals and parents have differing points of view on what is in

¹²³ Cited in Submission No. 24, p18-20

the best interests of a child. Most cases are heard by the Supreme Court, which has power to make decisions for children as part of its 'parens patriae' (protective) jurisdiction. However, the Supreme Court exercises its powers cautiously, and only in cases where the court's intervention is needed - see Re Heather [2003] NSWSC 532.¹²⁴

7.30. Colleen Johnstone, Palliative Care Tasmania, argued minors should be permitted to have input into their care:

The only other thing I would say is that in Tasmania at the moment a person must be 18 to complete an advance care directive. We believe that age should be removed. We believe that if you have the mental competence and can be supported in your decision making you should not be subject to a mandatory age. That is relevant for young people, particularly teenagers. At the moment they can have a say and some control over their care, but they can't do an advance care directive, so we would like to see that changed.

...

At the moment there is no fixed age relating to consent to accept or refuse medical treatment... Many young people, particularly teenagers, know more about what care they want than the adults treating them, and if they do not, there are supportive parents, family, carers and medical practitioners around them who can provide support to make those decisions.

When you are dying, one of the most fearful things is loss of control. That is particularly important to young people. They may have already had to give up playing cricket or social access to their friends through school or sports, and to then take this control off them, we just would not support that.¹²⁵

7.31. Dr Helen Lord, Anglican Church in Tasmania, commented:

Treatment decisions for minors (those aged under 18 years) are best served by facilitating discussion and communication between parents or guardians, the minor and their clinicians as to what is in the best interest of the child, recognising that there is a range of capacity amongst minors (the Gillick principle) for consent to treatment.

In an emergency situation the authority to consent to or refuse treatment should in general rest with parents or guardians, in the interests of justice and protection of the vulnerable.

If no parent or guardian is available then the default position, as at present, should be to provide emergency treatment in order to preserve life.¹²⁶

7.32. Dr Brigid McKenna, Archdiocese of Hobart, commented on perinatal palliative care treatment:

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.

¹²⁴ Submission No. 24, p18-20

¹²⁵ Transcript, 8 August 2016 (morning), p38-39

¹²⁶ Submission No. 6, p5

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.

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.¹²⁷

7.33. A number of respondents raised concerns about the way the parents have been treated following the death of their child.

7.34. Colleen Johnstone, Palliative Care Tasmania, commented:

There are also organisations like CanTeen and Camp Quality, and there are bereavement support organisations like Bears of Hope and The Compassionate Friends that provide support to bereaved parents. That gets back to education that there are the services available.

It is ensuring people have the information and ability to access those. Our organisation has educated a lot of people across Tasmania, and held forums for bereaved parents. One of the biggest issues for bereaved parents is that many of them feel dumped. That is their words, not mine. They feel dumped after their child has died. If a child has not been receiving care from one of the specialist palliative care teams, it is not automatic that there will be follow-up provided to the parents and the carers.

Palliative care is not just about looking after the person dying; it is looking after the support network around them. If those young people are being seen only by oncology units or pediatric units and the specialist team has not been called in, follow-up may not necessarily occur.

I have had mothers tell me that when their child has died they have been given two hours with the child down here at the Royal Hobart Hospital, and then they have had to put all of the possessions of that child into a wheelie case and they have wheeled that bag out of the hospital and not seen staff, not had follow-up, not known where to go. They have just been handed a stack of brochures. From our perspective, grief and bereavement support and access to that support is an issue right across the palliative care spectrum, but particularly for bereaved parents. We think that is a big gap. 128

¹²⁷ Submission No. 22, p8-9

¹²⁸ Transcript, 8 August 2016 (morning), p38-39

Administration of Emergency Medical Treatment

- 7.35. The Committee heard from a number of respondents in relation to the administration of emergency medical treatment.
- 7.36. The Tasmanian Government stated that there are common medical emergencies in palliative care and these can be anticipated.¹²⁹
- 7.37. The Tasmanian Government stated that discussions on what to expect occurs between clinicians, patients and their family/carers and treatment decisions could be planned for and documented in an Advanced Care Plan.¹³⁰
- 7.38. The Tasmanian Government commented that:

The SPCS has developed Care Management Guidelines for Emergencies in Palliative Care which addresses the common emergencies and provides guidance on appropriate levels of care (in the absence of an existing ACD or other advance care plan).

An adult who is conscious and who appears to be competent may refuse emergency treatment. An adult may also refuse treatment in advance, and an advance refusal of treatment via an ACD will be valid provided the person was competent at the time the treatment was refused, and the refusal covers the circumstances that have later arisen. Where the person's competence or the validity or extent of the person's prior refusal is in doubt then the person's consent may generally be presumed and treatment that is necessary to preserve the person's life and health given on this basis.¹³¹

- 7.39. The Tasmanian Government commented on the complications that exist for emergency medical professionals:

Tasmania's emergency patient transport services are provided by Ambulance Tasmania (AT). Taking into account advance care planning decisions, within the context of emergency services provided by AT, is more complex than within other settings. This reflects the primary role of an ambulance crew to provide for the swift transfer of patients to an emergency department.

AT provides treatment to patients in line with its Clinical Practice Guidelines for Paramedics (Clinical Guidelines) which includes information on palliative care and the use of ACDs. Any care that extends beyond the Clinical Guidelines requires treating paramedics to consult with an on-call Clinical Consultant.

- 7.40. According to the Tasmanian Government:

Tasmanian ambulance crews may withhold resuscitation efforts in the following circumstances:

¹²⁹ Submission No. 24, p22-23

¹³⁰ Submission No. 24, p22-23

¹³¹ Submission No. 24, p22-23

- For an adult (18 years or older) – where a clear and relevant ACD has been completed for a current condition which most likely caused the cardiac arrest.
- For a child (less than 18 years) – where an order, that has been issued by a Court exercising *parens patriae* jurisdiction, is provided to the attending ambulance crew indicating that a cardiopulmonary resuscitation is not to be commenced.
- Where a clear and relevant ACD is available for the patient. If an ACD is known to exist for a patient, this will be taken into account in their treatment. If there is an ACD, but is not to hand, then emergency treatment should be given until such time as the person’s wishes can be ascertained.

An ACD may be sighted by the attending ambulance crew or they may accept in good faith the advice of those present at the scene. If there is any doubt about the application of an ACD the default position of resuscitation is adopted.

Ambulance crews must clearly record full details of the information given to them and the basis for their decision regarding resuscitation. This is particularly important in circumstances where a copy of an ACD or other order has not been sighted.¹³²

7.41. Paul Russell, HOPE: Preventing Euthanasia & Assisted Suicide Inc., commented:

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 focused 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.¹³³

Co-ordination of Palliative Care Services

7.42. Many respondents highlighted the need for well co-ordinated palliative care services.

7.43. Cancer Council Tasmania, commented:

Seamless transitions and communication for patients between multiple care settings providing palliative care services is imperative for holistic person centred care. This includes public and private health services and urban and regional centres.¹³⁴

¹³² Submission No. 24, p23-24

¹³³ Submission No. 2, p4

¹³⁴ Submission No. 5, p1

7.44. Dr Peter Saul commented:

*The main problem in managing end of life broadly is the coordination of care for people who are in the last year of their life. We have now data showing they have an average of 105 contacts with the health system in that year. The main problem we have in improving their care is the lack of coordination of those individual contacts.*¹³⁵

7.45. Ms McGowan, Hobart District Nursing Service, commented:

I have done some work looking at the Canadian model and the Northern Territory, where they have a common health record number. There are a number of things in the system that would change, such as who is prescribing medication; where is medication coming from; who is involved in this person's care; and would there be a quicker, more effective route to access care if someone such as our care coordinators could see their whole record in front of them. There are even the possibilities of research. When you have this common health record and you can see back through childhood, the advantages of phenomenal.

*The Northern Territory model is fabulous and, when you think they are half our population, Tasmania is in the next best position to achieve this. This is something very dear to my heart and we need to seriously look at it. You just mentioned driving to Ross on Saturday. God forbid something should happen to you in Ross and you end up in Launceston General, because they won't bring you back to Hobart. You end up in Launceston and you don't have a common health record, so I think it really is our big next step, especially technologically, in Tasmania.*¹³⁶

7.46. Allison Lennox discussed the challenges she experienced helping her parents gain access to support services which were the result of poor coordination of services:

We did have their help one night, two nights before dad went into hospital, and it was great, but getting on to those systems is very hard. There are all these wonderful services but it is very time consuming. With continence care for dad they said, 'We need to interview your father' - and that was a three-hour interview talking to dad about continence issues. I'd already told them the whole story over the phone but they still had to come and meet him and talk to him about it. That's the last thing he wanted to talk about. That was one massive interview and then the hospice in the home. Although we had all these other things helping us, every time you asked for that next step you knew you had to have another interview process, and dad hated it. He would do it and smile and chat to these people, but it was an invasion and it exhausted him. It was never just 20 minutes; it was this huge questionnaire.

*... I had to answer nearly all the questions. It was giving him a chance but he didn't really understand. Every now and then he would say, 'What are all these people coming for?', and you would try to explain it because you didn't want to keep him out of the process, but I had to answer all those questions; he didn't know. It isn't easy to get these services but once they start - hospice was great; the girl who came was wonderful. We had 24 hours without any of us having to be there because this girl took over for a while.*¹³⁷

¹³⁵ Transcript, 12 September 2016, p36

¹³⁶ Transcript, 8 August 2016 (morning), p6

¹³⁷ Transcript, 8 August 2016 (morning), p19

7.47. Allison Lennox, commented:

Mum and Dad were also cared for by [Service Provider], so they had people coming in to bath and all that. That was a nightmare situation. You could not get anything changed without a massive assessment and a massive interview. I said to them in the end that I would rather do it myself than go through the drama. You just want an extra shower a week. It was a massive process to get that organised.

The [Service Provider] red tape paperwork whatever caused more drama than anything else. If their paperwork could have been shared with everybody else and it was all done by email or phone, then bingo.

Mr JAENSCH - It sound like a job for red tape reduction.

Ms LENNOX - Definitely, I beg you, especially for those providers of in home care. It is a nightmare.

...

Just proving to them constantly that you needed that, and then they seemed to have to come and witness it. You felt they were not trusting what you said. You felt that they felt good about their job because they were coming and spending time with you, but I would say, 'Please just spend time with Mum and Dad, because I need to...' ¹³⁸

Committee Comment

7.48. The Committee notes the lack of support by any respondents for the continuation of futile treatment.

7.49. The Committee notes the concerns of many respondents regarding the uncertainty in the medical profession that sufficient legal protections exist for doctors to withhold medical treatment as part of managing a patient's pain or when such treatment is futile.

7.50. The Committee also notes the concerns by many patients that their wishes to forego further treatment will be honoured.

Recommendation 24:

That the Tasmanian Government establish a requirement for all cases of continuous palliative sedation to be reported to the Department of Health and Human Services.

Recommendation 9:

That the Tasmanian Government review and assess the adequacy of the current provision of palliative care to infants and neonates.

¹³⁸ Transcript, 8 August 2016 (morning), p19-20

Recommendation 10:

That the Tasmanian Government increase support services for parents with children in palliative care as well as for parents after their child has died.

Recommendation 17:

That the Tasmanian Government enact in legislation:

- the common law doctrine of double effect to strengthen the legal protection for those who provide end-of-life care;
- the common law protection for doctors regarding withholding or withdrawing futile treatment. In this regard the Committee recommends Government give consideration to the *South Australian Consent to Medical Treatment and Palliative Care Act 1995*.

Recommendation 18:

That the Tasmanian Government permit competent minors facing end-of-life care to participate in the completion of an Advance Care Plan.

8. ACCESS TO PALLIATIVE CARE

Timeliness

- 8.1. The Committee heard of the benefits of early referrals to palliative care.
- 8.2. Paul Russell, HOPE: Preventing Euthanasia & Assisted Suicide Inc., commented:

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.¹³⁹

- 8.3. Alison Verhoeven, Australian Healthcare and Hospitals Association, commented:

Earlier exposure to palliative care can enhance health providers' professionalism, provision of patient-centred care, psychosocial and spiritual aspects of palliative care, and communication. Early and continuous education and training, legal and otherwise, on end-of-life issues throughout the career of health service providers will reduce legal risk and promote patient autonomy.¹⁴⁰

- 8.4. Colleen Johnstone, Palliative Care Tasmania, commented that: “the more quickly people are referred to palliative care the better their pain is managed and the better their psychosocial needs are managed, and they tend to live longer because their care is under control.¹⁴¹

Hindrances to Accessing Treatment

- 8.5. The Committee heard from respondents about a number of issues that will hinder sections of the population from accessing palliative care in Tasmania. Dr Helen Lord, characterised the Tasmania population as having:

- high rates of persons who are aged, have a disability and or mental health conditions;
- high levels of social disadvantage; lower levels of education; lower levels of health literacy; and higher rates of potentially reversible hospital admissions in comparison with other Australian states;
- highest proportion of the population living in outer regional areas. These areas have more difficulty with access to medical services than those living in inner regional areas.¹⁴²

¹³⁹ Submission No. 2, p1

¹⁴⁰ Submission No. 4, p1

¹⁴¹ Transcript, 8 August 2016 (morning), p40-41

¹⁴² Submission No. 6, p1

- 8.6. Professor Michael Ashby, argued that a person's locality determines the quality of the services available:

I genuinely think the coverage and availability of primary care services does differ right around the country. Access to out of hours support and expert nursing is quite stretched. That is certainly an area the state and indeed the federation will have to address in the future. If we're saying we want to put more and more emphasis on community care, care at home and hospital avoidance - because we have to - these are areas that will have resource implications in the future. I guess I'm saying that our specialist services will need to grow to meet existing and future demand, but also primary care services are often as much the answer. If you look at episodes where things don't go so well it is often because people live in an area where those services are stretched.

... I would say access to general practitioners and medical advice after hours varies depending on where you are and is variable. The same is true of community nursing. If you want to improve things, I think one of the key areas is to make sure those areas are adequately resourced and covered.¹⁴³

- 8.7. Tim Hynes, MND Tasmania, commented:

... there still seems to be quite a lot of variability between the regions about what is available and what is delivered. When I say that, the biggest thing I think you will find is consistency around the palliative care services that people can access in parts of the state, and particularly the multidisciplinary nature of palliative care services. What I mean by that is being able to access nursing allied health, palliative care positions, palliative care volunteers et cetera so they can be well supported and they can get early referral to services. Those teams together in that multidisciplinary environment generally start the conversation around end-of-life planning and advanced-care planning with the GP and the families.¹⁴⁴

- 8.8. Paul Russell, HOPE: Preventing Euthanasia & Assisted Suicide Inc., commented on locality and also poverty:

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.¹⁴⁵

- 8.9. Respondents raised the issue of how illness or disorders of themselves can hinder a person's access to palliative care services.

- 8.10. Dr Brigid McKenna, Archdiocese of Hobart, commented:

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:

¹⁴³ Transcript, 8 August 2016 (afternoon), p2

¹⁴⁴ Transcript, 8 August 2016 (morning), p21

¹⁴⁵ Submission No. 2, p5

- 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.”

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.¹⁴⁶

8.11. The Committee heard that there a number of issues affecting young people and children accessing palliative care in Tasmania.

8.12. Colleen Johnstone, Palliative Care Tasmania, commented:

Because of Tasmania's demographics, we do not have a lot of young people receiving palliative care. The majority of young people who have life-limiting illness are treated in Melbourne and Sydney. We have heard medical practitioners at the Royal Children's Hospital in Melbourne are telling families that there are no pediatric palliative care services available in Tasmania, which is erroneous.

Even though we do not have a named pediatric palliative care service, the three specialist palliative care services across the state provide pediatric services, as does the Hospice at Home program, as do community nursing. Also, young people are supported through the pediatric wards across the state and also the oncology units.¹⁴⁷

Committee Comment

8.13. The Committee notes the over-whelming evidence received that early access to palliative care greatly improves health outcomes for individuals.

8.14. The Committee notes that the access to palliative care is not equal as a result of inconsistent quality and availability of services in various regions

¹⁴⁶ Submission No. 22, p8

¹⁴⁷ Transcript, 8 August 2016 (morning), p38-39

and the challenges to obtaining services for persons who are alone, elderly, handicapped, or infirm.

Recommendation 13:

That the Tasmanian Government work to:

- **reduce inequities in the access to quality palliative care services available as a result of an individual's socio-economic status, impairment, or geographic location; and,**
- **improve the number of patients receiving earlier referrals to palliative care services.**

Recommendation 19:

That the Tasmanian Government work to improve the community's understanding of dementia and the development of earlier and easier access to palliative care services for patients with dementia, including advance care planning.

9. HEALTH CARE WORKERS

- 9.1. The Committee heard of the numerous roles that health care workers perform in the delivery of palliative care and the challenges they face.

Role in Palliative Care

- 9.2. The Tasmanian Government, commented:

Palliative care services are delivered in almost all health settings, including acute, primary, community, and aged care sectors. Palliative care is the responsibility of all health professionals but tends to be delivered by two distinct categories:

1. *primary care providers; and*
2. *health professionals who specialise in palliative care.*

Primary care providers may include medical, nursing or allied healthcare professionals. Specialist health professionals provide specialist palliative care services through a cohesive interdisciplinary network.¹⁴⁸

General Practitioners

- 9.3. Dr Rosemary Ramsay, General Practitioners, North West Region, commented on the complementary role of the general practitioners (GPs) with specialists in the delivery of palliative care services:

Traditionally palliative care in the community in rural Tasmania is provided by general practitioners and community nurses. Specialist palliative care services support GPs in provision of palliative care, but do not have the workforce to take over care of the majority of patients. Indeed patients prefer to have their own GP provide palliative care at home. Palliative care in this district is provided by GPs who provide true “cradle to the grave” care. The General Practitioner is the key medical provider for the majority of palliative care patients. Often the GP will have known the patient and family for many years.¹⁴⁹

- 9.4. Dr Rosemary Ramsay commented on the barriers that exist to GPs providing palliative care:

- Specialist team has taken over the care;
- The Specialist team in this district works in collaboration and reinforces the key role of the General Practitioner;
- Distance to travel to see patients at home can be a barrier to GPs providing home visits in rural and remote areas;
- The care of palliative patients by GPs is poorly remunerated by the Medicare schedule - often GPs provide care that is not funded by Medicare item numbers, this includes provision of prescriptions, and telephone calls to nurses and family, and prolonged home visits.

¹⁴⁸ Submission No. 24, p7-8

¹⁴⁹ Submission No. 14, p1

- GPs may work in an innovative way to provide care, setting aside time for home visits but for many GPs this is not possible, but they manage to provide phone support for patients and nurses, prescriptions and surgery consultations, which goes a long way in Palliative care provision.¹⁵⁰

Attitudinal and Cultural Issues

- 9.5. Respondents raised the concerns with perceived cultural issues affecting health care workers delivery of palliative care treatment.
- 9.6. Professor Michael Ashby, highlighted the attitudinal barriers for clinicians that limit “good end-of-life care”:

Firstly, health professionals and families struggle with death ‘talk’. Based on the assumption that you cannot initiate talk of death because patients and families do not want it and that you run the risk of precipitating death if you do (‘don’t talk about death; it will kill him’), there is a widespread tendency to avoid it. Secondly, there is a pervasive view that you have to do everything to maintain and prolong life otherwise you are causing death (‘you can never give up on a patient’). This is powerfully backed up by a perceived threat of ethical or legal sanction unless all possible treatment is given to patients, no matter how slim the odds of a favourable response or outcome. Thirdly, there is still a lingering doubt that the use of opioids and sedatives in palliative care may contribute to the cause of death, so symptom control is compromised.¹⁵¹

- 9.7. The Committee heard that the cultural background of a healthcare worker may affect their provision of care and discussions around end-of-life care.
- 9.8. Professor Michael Ashby commented:

I think with our overseas-trained graduates, where there is the opportunity, we do work with them on that because different cultures obviously have different thresholds for discussing these things.¹⁵²

Carers and Family Members of Palliative Care Patients

- 9.9. The Committee heard of the experiences of carers and family members of palliative care patients.
- 9.10. Cancer Council Tasmania commented:

Family carers, where present, are integral to the provision of palliative care

Family carers need ongoing support and respite if they are caring for someone at home with a terminal illness. Respite needs to be tailored to the individual needs of the family member, and may include overnight care for the care recipient. They may also need

¹⁵⁰ Submission No. 14, p1

¹⁵¹ Submission No. 18, p5-6

¹⁵² Transcript, 8 April 2017, p3

education around the care needs of someone who is dying and what to expect at end of life. The cultural and linguistic needs of families should be addressed.¹⁵³

9.11. Colleen Johnstone, Palliative Care Tasmania, commented:

*We know nationally carers are worth billions of dollars to the economy but, again, in terms of carers for the dying, there are not enough support services available for those people.*¹⁵⁴

9.12. Colleen Johnstone commented further:

On the north-west coast we have tried to run what we call 'carer days' so that carers can come and get a little bit of the information but have that informal peer support available. Again, the issue we find is that there is no one to look after the dying person so they are not freed up to be able to attend these types of events that we offer. It really gets back to the fact that our support for carers is really abysmal.

*We have great organisations like Carers Tasmania but again Carers Tasmania is not solely focused on carers who care for the dying. We really do need to look at the support we have available for carers.*¹⁵⁵

9.13. The Committee heard of the importance of effective communication by health care workers with the families of patients.

9.14. Mr Paul Russell, HOPE: Preventing Euthanasia & Assisted Suicide Inc., commented:

*In my work, I get calls almost every month from a person in a panic because they think the doctor is doing something they should not be or they reckon their aunt is being euthanased or some such matter. In every case, I think I can say confidently what we have been able to uncover and discuss with these people is that it all came down to a matter of conversation - the kinds of questions not asked, conversations not had, busy doctors, people not hearing what they have been told. It really does, in most cases, I think, from those examples, come down to a matter of communication. It would be little more than that, to be honest. I can remember one instance in particular where I was at a soccer match that my son was playing in, and I spoke with a man whose father was dying. He asked me, and I said, 'Did you ask the questions you are asking me of the care team?'. He said, 'Well, no.' I said 'Why don't you?' He did and he came back to me the next week and he was very satisfied and rather warmed by the whole experience. The father died quite well in the end and he was satisfied that the care was sufficient.*¹⁵⁶

Committee Comment

9.15. The Committee notes the invaluable service that carers provide and the significant savings this creates for the State.

¹⁵³ Submission No. 5, p1

¹⁵⁴ Transcript, 8 August 2016 (morning), p40

¹⁵⁵ Transcript, 8 August 2016 (morning), p40

¹⁵⁶ Transcript, 9 August 2016, p27

9.16. The Committee notes the work and the hardships faced by carers and family members of patients.

Recommendation 11:

That the Department of Health and Human Services develop support programs and procedures for bereaved families and friends of palliative care patients.

Recommendation 12:

That the Tasmanian Government increase availability of reliable and appropriate respite services for carers, particularly in rural and regional areas.

Volunteers

9.17. Lois Berry, Hospice Care Association of North West Tasmania Inc., described the role that volunteers fill in the provision of palliative care:

We provide in-home respite as well as visits to Residential Aged Care facilities and Hospitals. In addition to this we provide transport to appointments, treatments and specialists from the coast to Launceston. All this is provided at no cost to the client-however many people do give a donation towards the Association.

All Volunteers are carefully interviewed and checked, inducted into the Association through a thorough 6 day training program and supported in an ongoing manner around further skill development and knowledge and also debriefing opportunities. A rewarding part of this training is the keenness of Subject Matter Experts to volunteer their time to impart knowledge around Grief, Loss & Bereavement, Palliative Care, Manual Handling, Spirituality and Dementia. Part of my role as Manager is to recruit, train and retain our quality Volunteers.

We are also very fortunate to be the recipients of State Government funding which assists us to provide transport (and reimburse transport costs to Volunteers) and to provide ongoing skill development and finance (at least) two recognition days for Volunteers throughout the year, which generally consists of guest speakers around relevant subjects or topics of interest.

...

I think the integral role for our service is that we are able to sit with and support people with a life limiting illness at their choice of place, where they want to be. There are no designated Hospice beds or stand-alone Hospice on the North West Coast and I feel we are making a difference for clients who are choosing to die at home.¹⁵⁷

Specialist Palliative Care Education and Ongoing Education

9.18. Respondents raised concerns with the lack of specialist palliative care education and training for health care workers.

¹⁵⁷ Submission No. 7, p1-2

9.19. Dr Peter Saul commented:

I totally agree that health literacy about death starts with people in the profession. We have held focus groups with our local community. They say they expect we will initiate conversations about end of life and that we will be well informed in that area. I do not think that has been the case.

A study in Queensland showed that of 487 specialists interviewed, only six could give an account of the law at end of life in their own jurisdiction. That was published by Ben White at the Queensland University of Technology.

The level of knowledge in doctors is low. The level of willingness is extremely variable but does not seem to increase with the junior status of people. The fact you are somebody young or new, does not mean you are more willing to talk about end of life. It requires that we intervene with doctors a lot more to make them more willing to do this.¹⁵⁸

9.20. Colleen Johnstone, Palliative Care Tasmania, commented:

Another important issue is that with GPs and medical practitioners is our western society is focused on cure and a lot of medical practitioners aren't very good at diagnosing death, and if they are they are not very good at communicating to the person that they are going to die. We are advocating for more education, particularly so that when medical practitioners first realise there is no hope of cure that the advance care directive is done, but also medical goals of care are correctly completed.¹⁵⁹

9.21. Professor Ben Canny, University of Tasmania, commented:

I think a broader death literacy in our society is critically important. For people who administer care to individuals, it would be useful for them also to have a degree of literacy about death, a greater knowledge about knowing when they are out of their depth and when to refer and things along those lines.¹⁶⁰

9.22. Dr Rosemary Ramsay, General Practitioners, North West Region, commented:

The Better Access to Palliative Care (BAPC) Program is funded by the Australian Government through the Tasmanian Health Assistance Package (THAP) National Partnership Agreement on Improving Health Services in Tasmania. Funding has been made available for the development and implementation of new and innovative workforce models that contribute to the sustainability of Specialist Palliative Care including strategies to build capacity and capability across the generalist health care services in the delivery of the palliative care. For the last two years funding was available as a program consisting of four, six-month rotations within Specialist Palliative Care Services (SPCS). The General Practitioner Registrar post (Palliative Care) aimed to build capacity and strengthen the role of the General Practitioner primary provider workforce. General Practitioner Registrars (Palliative Care) have received training in palliative care and have returned to General Practice in Tasmania with new knowledge,

¹⁵⁸ Transcript, 12 September 2016, p37

¹⁵⁹ Transcript, 8 August 2016 (morning), p37

¹⁶⁰ Transcript, 9 August 2016, p12

confidence and skills that they then transfer to the primary healthcare setting. This increased capacity includes mentoring and provision of education of other GPs in the practice. The current registrar is returning to her home district with increased skills in palliative care. Future GP registrars with the Specialist Palliative Care service will work in collaboration with the Rural Clinical School University of Tasmania combining palliative care experience with GP teaching including Nursing Home care and the palliative approach in the Nursing home.¹⁶¹

9.23. Cancer Council Tasmania commented:

Primary Health Workers, particularly General Practitioners, community nurses, allied health workers, residential aged care workers are key players in palliative care and need to be trained and well-resourced to provide the care

*These health workers are usually well known to the patient and have been providing ongoing health care for some time. For those people living in rural areas, their local doctor, health services and aged care facilities will be providing the bulk of palliative care. These health workers may need encouragement and support, up to date palliative care training and access to consultancy services from specialist palliative care services for patients and families who have more complex care and support needs. Trained volunteers can also be part of the care team, and provide psychosocial support to families receiving palliative care.*¹⁶²

9.24. Dr Rosemary Ramsay, Rural Clinical School, commented:

The RCS provides palliative care education (communication skills, symptom management, and goals of care education) to undergraduates at the Rural Clinical School. Tutorials for 5th Year medical students occur throughout the year, and while on a two week placement with the Community Specialist Palliative Care Service.

The final Year Medical Students have experience while on placement at Mt St Vincent Nursing Home Teaching in Residential Aged Care (TRAC) where the palliative approach is integrated into teaching in aged care. The students are supervised while on placement by the GP Tutor at Mt St Vincent Nursing Home Teaching in Residential Aged Care (TRAC). Students participate in Inter Professional Learning (IPL) with positive outcomes for the students. The students have participated in the research with Wicking TRAC education from 2013-2015.

*The RCS Clinical Lecturer is the convener for the University of Tasmania School of Medicine 4th and 5th year palliative care education, working with the other palliative care lecturers across the state to review the curriculum and to have standardised online resources and education by the end of 2016.*¹⁶³

9.25. Dr Rosemary Ramsay commented further:

The Specialist Palliative Care Service recently developed the GP Registrar post in palliative care. Future registrars will be trained in Palliative Care and Medical Education in a collaboration between the THS and the RCS to provide ongoing rural generalist

¹⁶¹ Submission No. 14, p2

¹⁶² Submission No. 5, p1

¹⁶³ Submission No. 10, p1

training. Three GP Registrars have completed the post returning to rural practice in Tasmania. A fourth registrar has worked in the combined teaching and palliative care post and is soon to return to rural general practice in Tasmania. The research and evaluation of the post is in the final stages. Achievements of the post include: GPTT has approved the post for extended skills training, RACP has approved the post for the Clinical Diploma in Palliative Medicine, the RACGP and ACRRM are reviewing the post as an Advanced Skills post for rural training. This important post ensures a General Practice workforce with both willingness to work in, and skills in palliative medicine in the future.¹⁶⁴

9.26. Dr Rosemary Ramsay, General Practitioners, North West Region, commented:

Rural GPs in NW Tasmania are involved in teaching medical students including care in Nursing Home and Palliative Care in the home. Rural GP training by registrars in General Practice involves caring for palliative patients in their homes and nursing homes. The GP registrars in the practice are supported in their education by more experienced GPs, with education and mentoring. The care coordination program (CCP) of GP practice nurses providing home care coordination has provided valuable support and guidance for patients as they traverse the health system at a time of transition to palliative care. Such local GP innovations have supported the palliative approach for patients with cancer and non-cancer diagnoses.¹⁶⁵

9.27. Dr Rosemary Ramsay commented further:

It is essential for the GP workforce to develop and to continue with the current model with GPs providing palliative care. It is essential that rural generalist registrars gain skill and experience in palliative care in community and nursing home. Rural generalist training in Northwest Tasmania aims to ensure a GP workforce in the future that will provide palliative care in the patient's home or nursing home.¹⁶⁶

9.28. Dr Rosemary Ramsay commented further:

Patients and families believe that GPs are best placed to provide Advanced Care Planning discussions. GPs also see this as an important part of their role. GPs have received support and training in Advanced Care Planning, Goals of Care discussions and communication at end of life. Education has been ongoing for some decades, and is provided either by the GP clinics or the Specialist Palliative Care Service. GPs are enthusiastic to learn about palliative care, and take up opportunities to learn advanced palliative care skills. Over 40 local GPs have attended the "Decision Assist" Training in the last 6 months. The Specialist Palliative Care Service has provided this training. Local GPs have experienced training with the PEPA (Program of the experience if the palliative approach) training over the last 10 years; these GPs include the GPs from King Island.¹⁶⁷

9.29. Professor Denise Fassett, University of Tasmania, commented:

The opportunity for students to engage in palliative care learning within the

¹⁶⁴ Submission No. 10, p2

¹⁶⁵ Submission No. 14, p2

¹⁶⁶ Submission No. 14, p2

¹⁶⁷ Submission No. 14, p2

University resides within many streams of teaching:

- As an elective available for all interested health professionals, ‘CNA409 The Last Year of Life: Renegotiating and Reinforcing Appropriate Care’ prepares students to care for people in the last year of their lives.
- The Master of Clinical Nursing and the articulation from the Graduate Certificate and Graduate Diploma pathways, offer palliative care teachings, along with the Bachelor of Nursing with Professional Honours (Specialty) in the Oncology specialist stream.
- Palliative care teaching is provided to support the Primary Care Rotation within the Bachelor of Medicine and Bachelor of Surgery (MBBS) within the third, fourth and fifth years.
- The University also provides public lectures and study days that provide for teachings in palliative care support.¹⁶⁸

9.30. Dr Brigid McKenna, Archdiocese of Hobart, commented:

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.

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. This is in spite of the fact that no doctors have ever been prosecuted in Australia for prescribing too much pain relief.

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.¹⁶⁹

9.31. Palliative Care Tasmania commented:

Another key issue is appropriate training of medical professionals. Medicine is geared towards cure and many professionals are not appropriately trained in diagnosing death. Many GP’s in particular also express their lack of confidence in talking to patients about advance care planning and delivering bad news. PCT has developed two short films to help educate in these areas and is also in the process of developing a Medical Goals of Care app.¹⁷⁰

¹⁶⁸ Submission No. 21, p2

¹⁶⁹ Submission No. 22, p9

¹⁷⁰ Submission No. 13, p6

- 9.32. Hilde Nilsson, Dying With Dignity Tasmania, argued that there is a lack of education in the medical profession in relation to referring patients to palliative care services:

*Palliative care is a referral based specialty. The reluctance of doctors to refer to palliative care is the main problem. You can run education sessions for doctors but, like anyone who does that will tell you, the ones that need to come are not necessarily to the ones that do come.*¹⁷¹

- 9.33. Dr Helen Lord, Anglican Church in Tasmania, commented on the need for properly resourced and funded education for GPs, and proposed the best way for this to occur is through to make training bpart of their Continuing Professional Development.¹⁷²

Committee Comment

- 9.34. The Committee commends the invaluable work that carers perform which improves the level of palliative care received by patients in Tasmania.
- 9.35. The Committee notes a lack of funding certainty for some palliative care services in the community.
- 9.36. The Committee notes the central role that general practitioners perform in provision of palliative care, referral to specialist services, as well as educating their patients about palliative care and advance care planning.
- 9.37. The Committee further notes the importance of continued education about palliative care for medical workers.
- 9.38. The Committee notes that the Federal Government funding has ceased for a number of palliative care organisations that provide education in Tasmania, and as a result those organisations may close.

Recommendation 20:

That the Tasmanian Government ensure all health practitioners in Tasmania, including: doctors, nurses, aged-care workers, and clinical staff, be required to maintain contemporary knowledge and training in end-of-life and advance care planning, including how to introduce the process to patients.

Recommendation 21:

That the Tasmanian Government, in consultation with key stake-holders, design a strategy to ensure an appropriate level of high quality palliative care curriculum content in medical, nursing and allied health degrees, including how to have conversations on end-of-life care with patients.

¹⁷¹ Transcript, 8 August 2016 (afternoon), p1-19

¹⁷² Transcript, 8 August 2016 (morning), p14-15

Recommendation 22:

That the Tasmanian Government make recommendations to the Australian Medical Council to examine the adequacy of compulsory teaching in medical schools about substitute decision making and substitute medical consent.

10. CARE FACILITIES

- 10.1. Palliative care is provided in a range of settings, including a patient's own home, care homes, hospitals, hospices, respite care and after-hours services.
- 10.2. The Committee heard of the impact that the different types of care facilities have on the patients experience of dying in palliative care.

Specialised Treatment Facilities

- 10.3. The Committee heard evidence on the role of hospitals in relation to palliative and end of life care. Much specialist palliative care is provided in an acute setting.
- 10.4. Alison Campbell, Calvary St Luke's Hospital, commented:

Calvary's role, in collaboration with Palliative Care North, is to provide an inpatient specialist palliative care service across Northern Tasmania. Using a combined model of four public funded beds and eleven private, we are able to be flexible in ensuring patients receive the care they need in a timely fashion. There is also a bed available to accommodate emergency admissions for patients whose condition is rapidly deteriorating or for the patient who has attempted discharge but has been unable to manage and needs to return for further nursing care.¹⁷³

- 10.5. Dr Brigid McKenna, Archdiocese of Hobart, commented:

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 focused on palliative care. The Gibson Unit at the St John's Hospital, Hobart, is a purpose built palliative care, hematology, 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 nonclinical staff are therefore trained in palliative and end of life care.¹⁷⁴

- 10.6. The Tasmanian Health System operates a ten-bed in patient facility, the JW Whittle Palliative Care Unit at the Repatriation Centre, Hobart.
- 10.7. Ms Janice Lipscombe, Hospice Care Association of North West Tasmania Inc., commented:

On the north-west coast all palliative clients are managed in the community and some have to come to hospital infrequently or at end of life because we don't have a safe

¹⁷³ Submission No. 15, p1

¹⁷⁴ Submission No. 22, p2-3

place to put them for transitions in their care. Our service is rather concerned about that process because we can't guarantee privacy or the right - there are facilities within all the health establishments to accommodate palliative patients but they are not dedicated beds and with our current focus on infection control in Australia I am losing more and more single rooms in hospital settings that once we could protect for palliative patients. Without dedicated beds from a hospice perspective we may have to recommend to the nursing service that we would be better off to put this patient in a safe place at the moment, and when the patient proceeds to hospital there is this huge level of uncertainty - 'Will I be in a four bed ward with screaming mixed people? Will I be in a nice quiet area where I can continue my journey?' - and that is creating anxiety for all service providers.

*I would be really happy with short steps along the way to prove that, and protected beds initially and consumer feedback around how best the needs are met and then upping the ante as the community drive it. I do believe in having a stand-alone hospice but I also have trouble seeing a community like the north-west getting there in a hurry.*¹⁷⁵

Regional Hospitals

- 10.8. Small regional hospitals often provide palliative care services to patients from the local area. Palliative care services are provided through the hospital as specialist services are not available due to the area being geographically isolated and having a small population.

Palliative Care at Home

- 10.9. Respondents highlighted the desire of most people to die at home rather than in a specialist medical facility but evidence shows that relatively few are able to do achieve this outcome.

- 10.10. Dr Brigid McKenna, Archdiocese of Hobart, commented:

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.

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.

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."

¹⁷⁵ Transcript, 10 August 2016, p20

*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.*¹⁷⁶

10.11. Paul Russell, HOPE: Preventing Euthanasia & Assisted Suicide Inc., commented:

The Grattan Report 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, coordinated with GP services, is likely to also provide significant cost savings as compared with hospice or hospitalisation.*¹⁷⁷

10.12. Cancer Council Tasmania commented that:

*If a person is choosing to die at home, they may require access to afterhours nursing or medical care, and training for family carers in how to administer pain relief medication effectively.*¹⁷⁸

10.13. Mark Brown, Australian Christian Lobby, commented:

Good quality palliative care is the compassionate response to those who are approaching the end of their life and need the care and management of health care professionals. Appropriate palliative care allows those with a chronic terminal illness or disability to access pain relief and management, and to die comfortably in a home or hospice setting.

According to the Grattan Institute, between 60 and 70 percent of Australians would prefer to die at home, yet only around 14 percent in fact do so. In comparison to other OECD nations, Australia lags behind. We can do better.

*Further support and funding to this vital area of health care is needed. Government should lead in funding and implementing policy that increases services and delivery of palliative care so that more Tasmanians can end their days as they wish: at home under palliative care.*¹⁷⁹

10.14. Dr Rosemary Ramsay, General Practitioners, North West Region, commented:

Studies have shown that many Australians have a preference to die in their own home. Despite this preference, a study by Palliative Care Australia found that approximately

¹⁷⁶ Submission No. 22, p7

¹⁷⁷ Submission No. 2, p3

¹⁷⁸ Submission No. 5, p1

¹⁷⁹ Submission No. 12, p2

16% of Australians die in their own home and 10% in nursing home. In North West Tasmania during the last 18 months over 60% of Specialist Palliative Care patients died in their own home or Nursing home, well above national and international trends. This suggests that we have come some way to addressing the wishes of patients and families in the North West of Tasmania.¹⁸⁰

10.15. Lyn Irwin, Friends of Northern Hospice, commented:

The most popular option is to die at home, but in the large majority of cases this becomes impossible. As definitive disease treatment for a patient's illness transitions to palliative care and then finally to end-of-life care, there is usually a strong preference to avoid any further contact with hospitals. Palliative care can often be home based care which can be provided by family and /or services for weeks or months, but as the process progresses to end-of-life, care is more likely to move from home to 24 hour institutional care. The preferred model for this is a dedicated, home-like, non-clinical environment with a hospice¹⁸¹

10.16. Dr Bruce Rumbold OAM, La Trobe University, commented:

For almost a century we have been treating dying as primarily a health service responsibility. Increasingly death has occurred in institutions, not people's homes. Even the 1970s revival of public interest in dying, expressed in community based hospice programs that aspired to provide holistic care, has been channeled into health service--based palliative care programs (Rumbold 1998). Current discussions about end of life decision--making are thus predominantly about receiving or refusing medical treatment, or requesting medical provision of assisted death.

Already the Australian healthcare system is struggling to provide palliative care to the minority of citizens who can access it. As the recent Grattan Report documents (Swerissen & Duckett, 2014), demand will increase markedly in the coming decades, with the number of deaths in Australia predicted to double by 2030. New models for end of life care need to be found to ensure equitable provision of services, and to meet people's expressed preferences to die at home.¹⁸²

10.17. According to Palliative Care Tasmania :

Through effective end of life planning, encompassing education and community development, that [Palliative Care Tasmania] has been able to provide through the BPC program, the capacity for people to gain a better understanding of their end-of-life choices increases.

They are more able to plan to die at home with the appropriate support structures around them, helping to relieve pressure on our acute system through fewer emergency department presentations, lower numbers of terminally ill people in intensive care, and a reduction in terminally ill people requiring ambulatory services, delaying the need to enter aged care facilities, if at all.¹⁸³

¹⁸⁰ Submission No. 14, p1

¹⁸¹ Submission No. 17, p2

¹⁸² Submission No. 20, p1

¹⁸³ Submission No. 13, p1-2

10.18. Fiona Onslow, The District Nurses, argued that the availability of emergency medicines is imperative in enabling people to die at home. The District Nurses have developed and are currently implementing an Emergency Medicine Kit, which they envisage reduce hospital admission rates for palliative care patients by allowing for ongoing access to emergency medication in the community.¹⁸⁴

10.19. Fiona Onslow commented:

Our projections tell us that in 5 years that 73% of people will be achieving their goal to die at home. A significant shift out of acute facilities would be achieved.

We would also have achieved a significant turn of the statistics, when 70% of people wish to die at home and only 14% have been achieving this to date, the change to the predicated rate will be significant in just 5 years.

...

What we do know is that dying at home is a choice AND dying at home can be a reality when we meet the gaps that incur in fragmented care arrangements.¹⁸⁵

10.20. Dr Rosemary Ramsay, Rural Clinical School, commented on the need for Community Health Nurses to enable palliative care at home:

Hospice at Home offers care coordination but it does not have those nurses who do the syringe drivers or the daily visits in our district. That is all done by the government community nurses. If there was someone with a complex dressing, from a cancer and a syringe driver, and symptoms that need reporting back to the GP, that is [done by] community nurses.¹⁸⁶

10.21. Ms Kim McGowan, Hobart District Nursing Service, commented:

The Hospice at Home project has produced some amazing outcomes. Some of them obviously economics, some social, but I think for both of us the most moving outcomes have been for families. Although it is fairly obvious to you and everyone else, people have a better death within their home with good medication management. The most positive area has been how bereavement for families has changed and how the project has contributed to people not needing anti-depressants, not having multiple visits to doctors after the loss of a family member, being able to go back to work in a reasonable time, not having those years of grieving in a bad way that affects all society. Grief and loss has an effect on all of us.¹⁸⁷

10.22. Tim Hynes, MND Tasmania, commented:

The other thing I was going to say is a lot of people desire to be able to stay at home and die. There are not a lot of people, from our anecdotal evidence, who would choose to go into a residential facility even if it was age appropriate. The Hospice at Home and some of the programs that the Better Access to Palliative Care program has been

¹⁸⁴ Submission No. 23, p10-14

¹⁸⁵ Submission No. 23, p19-20

¹⁸⁶ Transcript, 10 August 2016, p5

¹⁸⁷ Transcript, 8 August 2016 (morning session), p1-2

*funding have been incredibly important statewide to increase services in the home for end of life. I think their criteria was the last 12 months of life. That increase in nursing support and other support has been critical across the state. The question is what happens when the money runs out for that program.*¹⁸⁸

Challenges With Dying at Home

10.23. Ms Campbell, Calvary Health Care, St Luke's Hospital, commented:

Certainly it is an area that needs enormous resourcing. It is very, very resource hungry. People's homes are not set up like palliative care wards. They don't have the right beds, they don't have the right equipment and they may not have facilities downstairs for toileting. If they are obese - and we all know about obesity in the community - that just makes everything triply difficult; to have the right equipment that is weight-tested, weight-rated and has all the capacity that will not put that person in danger. The wrong equipment can make for very poor outcomes for people. I think that is perhaps an area that if we are considering how to help people to have their wish of dying at home it really has to be resourced enormously.

*I had the experience of trying to help my mother to die at home a couple of years ago in Scotland. In the end, it wasn't feasible not because everyone wasn't willing - everyone was - but physically and emotionally, it is very demanding for people. Relatives often cannot go the distance. That is when we get them in Melwood. The wonderful thing then is that you have this multi-disciplinary, inter-disciplinary team of people who can come in, and pick up the family who are often so exhausted and so stressed. The social worker can assist them with all sorts of financial questions. I think that is all very hard to replicate in the home. Those issues percolate to the top and often become 'the thing' that people remember about the death.*¹⁸⁹

10.24. Lyn Irwin, Friends of Northern Hospice, raised concerns in relation to palliative care patients receiving treatment in emergency wards:

We have been informed that the Department of Emergency Medicine (DEM) at Launceston General Hospital receives palliative patients on a regular basis. By its very nature this results in inappropriate tests, treatments and admissions to the acute hospital. These patients have been unable to successfully receive end-of-life care at home. This has been confirmed by canvassing the observations Nurse Unit Managers of various department with the LGH.

*We appreciate how overextended the resources are at the LGH Emergency Department. However, we also know that dying patients taken to ED by their families, often spend their last days and hours on a trolley or in an ED bay. This is inappropriate and immensely distressing for the dying person and their family.*¹⁹⁰

¹⁸⁸ Transcript, 8 August 2016 (morning), p26

¹⁸⁹ Transcript, 10 August 2016, p20

¹⁹⁰ Submission No. 17, p2

Home as in the Community

- 10.25. Kim McGowan, Hobart District Nursing Service, commented that for some people their community may be their preferred facility to die:

Whereas we always said 'in home' we are now saying 'in community' because for some people the best and preferred place to die is not in the bricks and mortar of their own home. It may well be their community hospital or in another place of their choosing. If half the people in your community hospital are related to you or you worked with or grew up with, that may well be the most friendly comfortable place for you to die, rather than to die in a home that is perhaps five kilometres outside of town or you do not have family within your own home.¹⁹¹

Acknowledging That an Aged Care Facility is a Home

- 10.26. Dr Rosemary Ramsay, Rural Clinical School, commented that for some people their aged care facility is their home may be their preferred facility to die:

People in nursing homes deserve to die in that nursing home as much as people in their own homes. If you live in a nursing home, that is your home and you shouldn't have to be transferred to an acute facility in order to die. This doesn't occur that often but it still is occurring, and I think we could be providing more support for our nursing colleagues and GPs who provide nursing home care.¹⁹²

- 10.27. Cancer Council Tasmania commented on training for aged care workers:

Residential aged care staff need to understand the palliative care approach and be able to advocate for, and administer, effective pain and symptom management for residents at the end of their life.¹⁹³

Use of Emergency Wards

- 10.28. The Committee heard that failures in advance care planning, including the exhaustion of carers, could result in persons ending up in emergency departments.

- 10.29. Lyn Irwin, Friends of Northern Hospice commented:

End-of-life care, however, requires 24-hours-a-day attention for perhaps days by more than one person. The relatives who have been caring for the dying person up to this point are often exhausted and frightened if it has been a long-term process. If suddenly there is a major change should a person's condition change rapidly, like increased pain or dyspnoea or something like that, and it is usually outside office hours, more often

¹⁹¹ Transcript, 8 August 2016 (morning session), p1-2

¹⁹² Transcript, 10 August 2016, p1

¹⁹³ Submission No. 5, p1

than not an ambulance is called and transportation to hospital occurs. This has happened on numerous occasions and is another reason why a dedicated end-of-life facility is necessary. People coming into the emergency department are subject to acute care medicine, as you would expect in an ED, so that is blood tests, IV scans or whatever. Really it is another reason for hospital cost blowouts and things like bed-block because these people should not be there in the first place. This is not appropriate for an emergency department. It is hardly an environment conducive to a comfortable, dignified death.¹⁹⁴

Committee Comment

- 10.30. The Committee notes the significant number of Tasmanians wishing to die at home and the comparatively few people who are able to die at home.
- 10.31. The Committee notes the high rates of persons who are receiving specialist palliative care die at home on the North West Coast of Tasmania. The Committee recognises that this is well above the national average and stresses that further investigation is required to determine whether this anomaly is an outcome of the high quality of care available and not a lack of specialist facilities.
- 10.32. The Committee acknowledges “home” can have many definitions, including a person’s residence, an aged care facility or within one’s community.
- 10.33. The Committee commends the work done by The District Nurses in developing an Emergency Medicine Kit. This aims to improve the number of persons who are able to receive palliative care at home and reduce unnecessary hospital admissions.
- 10.34. The Committee notes the importance of early referral to palliative care as well as the need for adequate funding for outreach services and community nursing resources. These will improve the possibility of dying at home, which research shows is the preferred option for the majority of the community.

Recommendation 14:

That the Tasmanian Government ensures increased support and adequate funding for community palliative care services, including community nursing, so people who wish to can receive end-of-life care at home.

¹⁹⁴ Transcript, 10 August 2016 at 10

Recommendation 15:

That the Tasmanian Government seek to reduce the instances of emergency department presentations through improving the regulations regarding the storage of and access to medications at home and in residential aged care facilities for palliative care patients.

Recommendation 16:

That the Department of Health and Human Services model the costings for patients as well as the State, for end-of-life care, including but not limited to dying at home, in hospital and hospice.

Recommendation 25:

That the Tasmanian Government investigates the reasons for the above national average of persons receiving specialist palliative care who die at home on the North West Coast of Tasmania.

11. NEED FOR OVERSIGHT, CORRELATION AND REVIEW

11.1. The Committee heard of the absence of, and the need for, greater oversight of palliative care in Tasmania.

11.2. Dr Peter Saul, recommended that deaths be audited:

*...but that some elements of that audit include quality of death as well as preventability. Actual evidence about how and where people are dying and in what circumstances would be incredibly helpful in guiding any future changes that Tasmania may want to make.*¹⁹⁵

Coroner

11.3. Victor Stojcevski, Coronial Division, in his appearance before the Committee described the role of the Coroner in investigating deaths, and why deaths in palliative care do not regularly come to them for review:

'A coroner must, wherever appropriate, make recommendations with respect to always preventing further deaths and on any other matter that the Coroner considers appropriate'. Section 28(2) is read in the context of section 28(1). It is not an investigation at large.

...

Over my two and half years there, and going back trying to look at 10 years of caseload, we have not had any cases where palliative care has become an issue for the Coroner. That goes to the definition in the legislation of reportable death.

...

Section 4B of the act is relevant here. 'Reportable death means a death where the body of a deceased person is in Tasmania or the death has occurred in Tasmania ...' - that is a jurisdictional issue - '... being a death that appears to have been unexpected, unnatural or violent or to have resulted directly or indirectly from an accident or injury' - the key terms are unexpected and unnatural or violent. In a palliative setting there is not going to be a lot of those deaths reported to the Coroner because they are neither unexpected nor are they unnatural...

...

*The other one is the medical setting that occurs during a medical procedure - and note 'medical procedure' because I will come back to that in a moment - or after a medical procedure where the death may be causally related to the procedure and a medical practitioner would not, immediately before the procedure was undertaken, have reasonably expected the death. If the medical practitioner could reasonably have expected the death, then it would not necessarily be reportable.*¹⁹⁶

11.4. Victor Stojcevski commented on what the Coroner would do if people had concerns of the practices of a palliative care health care work:

I note the relevant section of the Criminal Code is a bit grey about this area. On a self-reporting or police reporting basis, if a family member thinks a medical practitioner did

¹⁹⁵ Transcript, 12 September 2016, p39-40

¹⁹⁶ Transcript, 12 September 2016, p1-9

*something untoward in hastening a person's death, then we will advise that person they should report it to the police.*¹⁹⁷

- 11.5. The Committee heard a hospital's Mortality and Morbidity Review Committee only reviews deaths occurring in that hospital.¹⁹⁸

Committee Comment

- 11.6. The Committee notes that in Tasmania there is an absence of oversight of palliative care and deaths in palliative care not provided in a hospital setting.
- 11.7. The Committee notes the absence of the collection of data about palliative care in Tasmania leading to missed opportunities in terms of analysis and continuous improvement.

Recommendation 2:

That the Tasmanian Government create a dedicated oversight body or authority to provide leadership and coordination on matters relating to end-of-life care including: data collection and analysis; advance care planning; public education; and policy development and workforce development across all relevant sectors and providers.

Recommendation 26:

That the Tasmanian Government commence collection of de-identified data of palliative care cases, including information relating to whether the person had any form of advance care planning and whether it was followed.

¹⁹⁷ Transcript, 12 September 2016, p1-9

¹⁹⁸ Transcript, 12 September 2016, p1-9

12. FAITH AND SPIRITUALITY IN PALLIATIVE CARE

- 12.1. A significant proportion of palliative care services are provided currently and historically by faith-based organisations.
- 12.2. The Committee heard from many respondents of the roles that faith and spirituality play in palliative care. Faith and spirituality influence patients' treatment choices.
- 12.3. The Committee also heard that for many persons, their spirituality is considered an integral part of their treatment.
- 12.4. Dr Helen Lord, Anglican Church in Tasmania, commented:

Existential Distress and Suffering in Palliative Care

Issues for patients: The relief of existential distress and suffering are important issues in palliative care. These are often managed exclusively by palliative care providers. Hope and compassion are needed to manage these situations and many patients value the input of a spiritual adviser or pastoral supporter. There is a need to ensure that these approaches are integrated into palliative care services.

Issues for palliative care staff: Palliative care is delivered in Tasmania in a high pressure environment. Palliative care workers have high rates of post-traumatic stress. There is a need to incorporate support for staff into palliative care services.¹⁹⁹

- 12.5. Dr Helen Lord commented:

Relationship between spirituality and religion in palliative care

Spirituality means different things to different people, and may or may not be equivalent to religion.

People when asked about spirituality talk about relationships, meaning, connectedness, identity, affirmation of personhood and, in the palliative care setting, preparation for death.

Committee Comment

- 12.6. The Committee acknowledges the deep and strong level of contribution that the faith-based community has in the provision of end-of-life care in Tasmania.

¹⁹⁹ Submission No. 6, p15

APPENDICES

Appendix A: Submissions Received

- Mr Robert Richardson
- HOPE: Preventing Euthanasia & Assisted Suicide Inc.
- Professor Margaret Otlowski, University of Tasmania
- Australian Healthcare and Hospitals Association
- Cancer Council Tasmania
- Anglican Church of Tasmania
- The Hospice Care Association of North West Tasmania Inc.
- Ms Alison Lennox
- Motor Neurone Disease Association of Tasmania Inc.
- Rural Clinical School
- Alcohol, Tobacco and Other Drugs Council Tasmania Inc.
- Australian Christian Lobby
- Palliative Care Tasmania
- Dr Rosemary Ramsay
- Calvary Health Care Tasmania
- Hospice Volunteers South Tas
- Friends of Northern Hospice
- Professor Michael Ashby, University of Tasmania
- Dying With Dignity Tasmania
- Dr Bruce Rumbold OAM
- Faculty of Health, University of Tasmania

- Office of Life, Marriage and Family, Archdiocese of Hobart
- The District Nurses
- Tasmanian Government