Calvary | Little Company of Mary Health Care Ltd

Hospitality
Healing
Stewardship
Respect

2 August 2019

Secretary,
Joint Committee on End of Life Choices,
Parliament of South Australia
Parliament House,
GPO Box 572,
Adelaide 5001.

jcendoflifechoices@parliament.sa.gov.au

Dear Joint Committee Members,

Little Company of Mary Health Care Ltd. (Calvary) Submission to the Parliament of South Australia Joint Committee on End of Life Choices

Little Company of Mary Health Care Limited, trading as Calvary, appreciates the opportunity to lodge the following submission to the Parliament of South Australia Joint Committee on End of Life Choices.

Calvary is a charitable Catholic not-for-profit organisation with more than 12,000 staff and volunteers, 15 public and private hospitals, 17 retirement and aged care facilities, and a national network of Community Care centres. We operate across six states and territories within Australia.

Our Services

Australian Capital Territory (ACT)

- Calvary Public Hospital Bruce
- Calvary Public Hospital Bruce - Clare Holland House Campus
- Calvary Bruce Private Hospital
- Calvary John James Hospital
- Calvary Haydon Retirement Community
- Community Care Service Centre - Bruce

South Australia (SA)

- Calvary Adelaide Hospital
- Calvary North Adelaide Hospital
- Calvary Wakefield Hospital
- Calvary Wakefield Surgicentre
- Calvary Rehabilitation Hospital
- Calvary Central Districts Hospital
- Community Care Service Centres – Adelaide, Port Augusta, Victor Harbor, Goolwa

Tasmania (TAS)

- Calvary Lenah Valley Hospital
- Calvary St John's Hospital
- Calvary St Luke's Hospital
- Calvary St Vincent's Hospital
- Community Care Service Centre – Launceston

New South Wales (NSW)

- Calvary Riverina Hospital
- Calvary Riverina Drug and Alcohol Centre
- Calvary Riverina Surgicentre
- Calvary Mater Newcastle
- Calvary Health Care Kogarah
- Calvary Ryde Retirement Community
- Calvary Retirement Communities Hunter (9 locations including Muswellbrook)
- Calvary Cessnock Retirement Community
- Community Care Service Centres – Sydney, Taree, Wagga Wagga (also respite care), Newcastle (also respite care and a social centre), Lake Macquarie, Forster (respite care only), Albury (respite care only)

Victoria (VIC)

- Calvary Health Care Bethlehem
- Calvary Community Care Head Office
- Community Care Service Centres – Melbourne, Gippsland, Shepparton

Northern Territory (NT)

- Community Care Service Centres – Darwin, Alice Springs, Bathurst Island

Since the establishment of Calvary in Sydney in 1885, with the arrival of the Sisters of the Little Company of Mary in Australia, Calvary has become renowned for the provision of health care to the most vulnerable, including those reaching the end of their life. We provide aged and community care, acute and sub-acute care, specialist palliative care and comprehensive care for people in the final years of their life.

Calvary's work in South Australia commenced in 1900. As the map on the previous page illustrates, Calvary's services in South Australia are extensive.

Calvary North Adelaide Hospital (CNAH) and Mary Potter Hospice (MPH)

Calvary North Adelaide Hospital was founded in 1883 by two Catholic philanthropists and handed over to the Sisters of the Little Company of Mary in 1900. It was named "Calvary" in 1928 following a visit by Venerable Mary Potter's niece, Mother M Hilda Potter.

This legacy and a contemporary commitment to excellence in holistic patient care remains central to all the services provided by Calvary North Adelaide Hospital.

Mary Potter Hospice was founded in 1976 and has developed an excellent reputation for inpatient palliative care.

The Calvary North Adelaide Palliative Home Care Service builds on Mary Potter Hospice's reputation for exceptional specialist palliative care and the long held focus of the Sisters of the Little Company of Mary on the care of the dying.

Calvary Central Districts Hospital (CCDH) Palliative and End of Life Care

The Mary Potter Northern Supportive Care Unit at CCDH has five dedicated beds, and provides care for patients with progressive, active, life-limiting disease.

The unit provides comfortable facilities for both patients and family members. Family members may stay overnight and utilise the family room, which caters for younger children. All rooms are equipped with en-suites and a private courtyard to encourage independence and wellbeing.

SA Community Care Program

Calvary Community Care has been caring for Palliative Care clients at the end of life since mid-December 2018.

The service provided involves in-home support and care as required and an on-call service which delivers some over the phone and primarily in-home response 24 hours per day.

Please find attached our submission for your consideration.

Yours faithfully,

Mark Green
National Director of Mission
Little Company of Mary Health Care Ltd
Calvary Health Care

Calvary Submission to the Joint Committee of the Parliament of South Australia on End of Life Choices

Responsible for Submission: National Director of Mission

2 August 2019

Contents

Terms of Reference

This submission addresses the following terms of reference of the Joint Committee on End of Life Choices:

a) The practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;
b) The current legal framework, relevant reports and materials in other Australian states and territories and overseas jurisdictions, including the Victorian and Western Australian Parliamentary Inquiries into end-of-life choices, Victoria's Voluntary Assisted Dying Act (2017) and implementation of the associated reforms;
c) What legislative changes may be required, including consideration of:
    i. The appropriateness of the Parliament of South Australia enacting a Bill in similar terms to Victoria's Voluntary Assisted Dying Act (2017);
    ii. An examination of any federal laws that may impact such legislation;
d) Any other related matter.

Definitions

End of Life Care[1] includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the person's body after their death.

People are 'approaching the end-of-life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions;
- general frailty and co-existing conditions that mean that they are expected to die within 12 months;
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition;
- life -threatening acute conditions caused by sudden catastrophic events.

Palliative Care[5] an approach that improves the quality of life of patients and their families facing problems 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:

- aims to 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;
- provides relief from pain and other distressing symptoms;

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[1] Australian Commission on Safety and Quality in Health Care. National Consensus Statement: Essential elements for safe high quality end of life care. 2015.

- affirms life and regards dying as a normal process;
- neither hastens nor postpones 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; and
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.

Euthanasia: the intentional bringing about of the death of a person in order to relieve suffering. It can be either voluntary or non-voluntary.

Physician Assisted Suicide: the intentional giving of assistance, by a doctor, to someone to suicide.

Voluntary Assisted Dying: the term used to describe physician-assisted suicide and euthanasia in the *Voluntary Assisted Dying Act 2017* (Vic).

Introduction

Little Company of Mary Health Care Limited, trading as Calvary, appreciates the opportunity to lodge its submission with the Parliament of South Australia Joint Committee on End of Life Choices.

At the outset, Calvary makes as its own submission, words recently written by Dr Frank Brennan, Departments of Palliative Medicine and Nephrology, St George and Calvary Hospitals, Sydney, New South Wales, Australia in Internal Medicine Journal 49 (2019) 689–693, Royal Australasian College of Physicians.

> Law aims for precision. Medicine, on the other hand, operates in a landscape of uncertainty. So, when the two disciplines meet to focus on issues vital to E/PAS legislation, there may be problems. Those issues include the prognostication of illness, decision-making capacity, screening for depression, the possibility of undue influence and the use of life-ending medications (with likely inter-individual variability in effect). As physicians, we know we cannot be certain about these issues. The laws strain to achieve certainty in language and effect. The law seeks, but medicine cannot provide, such certainty, and yet, with E/PAS, both disciplines must be highly conscious of the irreversible consequences for not getting things right. There is, therefore, an inherent tension at the centre of any E/PAS law. For law is entering the domain of not only medical uncertainty but also the mystery of the human psyche and interpersonal relationships. Uncertainty and mystery are not solid foundations for any legal statute.
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> All E/PAS laws face a series of identical challenges. Those challenges are significant and, arguably, insuperable. Challenges include the criteria of eligibility; prognostication; the assessment of capacity; ensuring the person is not acting under undue influence; the role of doctors, nurses and pharmacists in the process; the role, if any, of palliative medicine and psychiatry and the structure of the process leading up to the final act. Flowing from that are the medical questions that pour out upon this landscape to make this exquisitely vexed area even more problematic for doctors. What lethal medications are used and in what doses? What level of training in counselling, communicating and the use of these medicines should occur? What happens if there is a complication? How prepared is any doctor to commit an act, however legal, that has hitherto been completely contrary to both the law and professional ethics? Ultimately, what will be the experience of the patients, families, doctors, nurses and pharmacists involved in this process? Away from the glare of the public debate, their encounter will be intimate and intense. No law, no public campaign, no training can ever truly prepare the participants.

For these reasons, along with many others, it is important to note at this juncture in our submission that the South Australian Government would not be able to purchase any services associated with any form of physician-assisted suicide, voluntary assisted dying or euthanasia from Calvary. Calvary operates in accordance with the *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia* which calls us to the highest standards of accompaniment of persons who experience suffering. While Calvary accepts that there are a plurality of views on the subject of voluntary assisted dying, Calvary will not offer such a service.

Rather, Calvary's approach to care at end of life

- supports the patient/resident/client to actively participate in decision-making regarding their treatment and care;
- honours their self-determination through the use of advance care planning;
- recognises the role of substitute decision makers/medical treatment decision makers and any other agents acting on behalf of the patient/resident/client;
- provides holistic, comprehensive end of life care; address the physical, spiritual, psychological and social needs of the patient/resident/client and their families, including existential distress, with the goal of reducing suffering.

In line with our Code of Ethical Standards, Calvary

- will neither hasten nor prolong death;[2]
- will not intentionally inflict death on patients (that is, provide euthanasia), nor intentionally assist patients, residents or clients to take their own lives (that is, provide physician-assisted suicide);
- will, in alignment with the principles set out in the *Spirit of Calvary*, respond openly, respectfully, without discrimination and sensitively to anyone within our care who expresses a wish to explore or consider physician-assisted suicide;
- Will actively listen to and accompany[3] any person who is nearing end of life, and will not abandon anyone who is in need of care; and
- Will not facilitate or participate in assessments undertaken for the purpose of a patient or resident having access to or making use of the interventions allowed under the *Voluntary Assisted Dying Act 2017 (Vic)*, nor similar statutes in other jurisdictions nor will we provide (or facilitate the provision of) a substance for the same purpose.

Palliative care provides holistic care to patients with debilitating and terminal illness. It is coordinated between the patient, the clinician, and necessary allied supports (including pastoral care) to address the physical, psychological,

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[2] World Health Organization, definition of palliative care, 2004 and WHO fact sheet 2015.

[3] Apostolic Exhortation *Evangelii Gaudium* of the Holy Father Francis to the Bishops, Clergy, Consecrated Persons and the Lay Faithful Chapter 3, *N.169-173, Personal accompaniment in process of growth*[i]

spiritual, and social needs of the individual. Clinicians assist patients and their family in the progression of their condition to improve quality of life, relieve suffering, and provide support for their comfort and wellbeing until their natural death.

Palliative care does not aim to hasten nor prolong death; its charter is to ensure comprehensive comfort to persons navigating life-limiting disease.

Response to Joint Committee Focus Areas

Practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care

More South Australians will need end of life services including palliative care in the coming years than ever before.

South Australia (SA) has the second highest proportion of people over the age of 65 in Australia which will have significant impact on the health system as the population ages. We will see an increasing burden of chronic disease, leading ultimately to a larger number of deaths per year. Yet palliative care rarely rates as a political issue on its own merits except as an alternative to voluntary assisted dying (VAD). We need to embrace and resource palliative care as an integral part of health care that affects everyone in society.

While efforts at all levels of government in Australia are being made to improve end of life care (EOLC), for those delivering service the frustration with systemic barriers inhibiting the care of the dying is palpable. Australia is ranked second in the world for quality and access to palliative care services, which should be an indicator that our palliative care system is well resourced and integrated.

However, where consistent access to appropriate levels of palliative care should be given from the time of diagnosis of a life-limiting illness, the reality is that identification of palliative care needs and referral to palliative care services is late and treatment is fragmented.

We refer the Joint Committee to the Catholic Health Australia's 2019 report, *Palliative Care in the Catholic Sector* for a full elucidation of these issues. Calvary was a significant contributor to this report. Accordingly we incorporate the report and its findings into this submission.

Preferred place of death

There has been a great deal of work undertaken in Australia over the preceding three decades to definitively determine peoples' preferred places of death.

The reality is that despite these many attempts through research, policy and survey we have no clear universally accepted understanding of what choice people would make or what might influence their choice. We know that choices, and influencing factors change over time and with circumstances and that simplistic approaches, bounded by procedural or policy requirements, can be both ineffective and potentially harmful.

Choices about end-of-life care are often negotiated rather than independent; particularly when they relate to the place of care and/or death. Family and social circumstances have to be taken into account and care-giver burden (and benefit) is a key consideration.

Evidence which points to home as the preferred place of death appears to be preferentially accepted by policy makers and funders throughout Australia. This preferential acceptance may, however, be for reasons that address desired *system* efficiencies rather than individual challenges and choices. There is also a substantial body of evidence that suggests that a significant proportion of people with a life-limiting illness, their carers and families, do not prefer home as their place of care.

Anecdotal feedback from Calvary North Adelaide's new Palliative Home Care Service suggests that choice and flexibility are of significant importance to patients and their families / carers. The capacity to access institutional support and respite as required, and to navigate the end-of-life trajectory while maintaining a range of support options enables those made vulnerable by a life-limiting illness to continue to claim a sense of agency through the last stages of their life journeys.

Palliative Care

Palliative and end of life care are terms that attract different meanings for different people. At Calvary, this is what it is meant when we use the terms end-of-life, palliative care, and end-of-life care:

- ***End-of-life*** **(EOL)** refers to that period of time when a person is living with an advanced, progressive, life limiting illness and likely to be in the last 6 to 12 months of their life.
- ***End-of-life care*** **(EOLC)** is care provided to people who are approaching and reaching the end of their life. This care can be provided by all health and community care professionals, regardless of where they work in health, community, specialist palliative care or aged and retirement care services.
- ***Palliative care*** **(PC)** refers to designated specialist services provided by an interdisciplinary team of specialist palliative care professionals whose substantial work is with patients who are approaching the end of their life.

Care of people approaching and reaching the end of life is integral to the mission of the Sisters of the Little Company of Mary.

Calvary North Adelaide Hospital (CNAH) Mary Potter Hospice (MPH)

Calvary North Adelaide Hospital was founded in 1883 by two Catholic philanthropists and handed over to the Sisters of the Little Company of Mary in 1900. It was named "Calvary" in 1928 following a visit by Venerable Mary Potter's niece, Mother M Hilda Potter. This legacy and a contemporary commitment to excellence in holistic patient care remains central to all the services provided by Calvary North Adelaide Hospital.

Established in 1976, the Mary Potter Hospice has developed an excellent reputation for palliative care through the skilled and dedicated services provided by our multidisciplinary team. Our team consists of doctors, nurses, social worker, physiotherapist, pastoral care and counsellors, all of whom are supported by a committed group of volunteers. Other allied health professionals are also available as required.

Links with the Mary Potter Hospice provide patients in the Palliative Home Care Service, together with their families and carers, 24 hour access to clinical staff with palliative care experience and knowledge.

The Calvary North Adelaide Palliative Home Care Service leverages the resources and expertise available across Calvary North Adelaide Hospital and other Calvary facilities in Adelaide to provide an integrated, multidisciplinary, specialist palliative care service.

In regards to Palliative Care Health Professionals the team consists of the following personnel:

- Palliative Care Medical Consultant
- Palliative Care Senior Medical Officer
- Palliative Care Nurse Practitioner
- Palliative Care Clinical Nurses
- Palliative Care Physiotherapist
- Palliative Care Social Worker that also provides bereavement support and follow up
- Access to Speech Pathologist
- Access to Occupational Therapist
- Access to Dietician
- Palliative Care Volunteer support
- Palliative Care Complimentary Care support including Massage, Music and Art Therapist.

Calvary has a well-established evidence based palliative and end of life care model. The model is used in all of Calvary's care services including hospitals, aged care and community care. There are five steps in the Calvary End of Life Care Journey:

The Palliative Home Care Service supports people with complex palliative care needs to remain at home during the end of life period for increased periods, and to die at home wherever possible, if that is their wish.

The service endeavours to help identify the right balance between home based and inpatient palliative care that may be achieved by exploring and optimising the use of palliative home care for people who wish to die at home. In this way we provide increased choice for patients to remain under the care of Calvary whatever the location of their care (Home or Hospice).

The Palliative Home Care Service attempts to offer a more seamless experience for patients as they transition between care environments. The patient and their family's experience of palliative care reflects a high level of satisfaction with the care and support provided.

Calvary Central Districts Hospital (CCDH) Palliative and End of Life Care

The Mary Potter Northern Supportive Care Unit at CCDH has five dedicated beds, and provides care for patients with progressive, active, life-limiting disease.

Over the 2018/2019 financial year, we cared for 80 patients in this unit.

Supportive care encompasses physical, social, psychological and spiritual care for patients and their family. It aims at minimising the impact of the progressive illness so that patients may have the maximum function and comfort possible, within the limits of their illness.

Calvary supports patients with:

- The control of symptoms
- Respite
- Terminal care

To ensure a seamless transfer between home or hospital, we work closely with the Northern Palliative Care Service, and provide referral to a specialist unit if required.

The unit provides comfortable facilities for both patients and family members. Family members may stay overnight and also utilise the family room, which caters for younger children. All rooms are equipped with en-suites and a private courtyard to encourage independence and wellbeing during a challenging time.

SA Community Care Program

Calvary Community Care has been caring for Palliative Care clients at the end of life since mid-December 2018.

The service provided involves in-home support and care as required and an on-call service which delivers some over the phone and primarily in-home response 24 hours per day. This is the only community palliative care program in South Australia providing this level of support. The care provided includes symptom management, wound and ostomy care, catheter management, activities of daily living, emotional support for the client, their families and carers.

The Palliative Care Team currently comprises 7 Palliative Care Specialist Registered Nurses.

Pastoral support for nursing team comprises of a quarterly debrief and counselling sessions for the Palliative Care team over the phone at any time.

Summary of statistics:

- Client Palliative Care deaths in the community - 61 clients
- Average client referrals per day – 30 referrals per day
- Total client visits since program inception in October 2018 – 18,574 visits
- Total client admissions to program since inception in October 2018 – 1588 clients

Goals of Care

Included in all discussions with the patient and their family is a “Goals of Care Discussion”, which includes the patient’s preferences for end-of-life care. This is documented in the patient’s file.

Case study – Calvary Family Experience story, July 26, 2019

Over one intensive week from July 13 – 20, my family had the privilege of being supported by the incredible women from the Calvary Community Care Team as we cared for our dying mother.

This letter is to express gratitude for the Team and to highlight the intensity of working in this area and the need for more funding for this incredible program of support for those dying at home.

Caring for our Mum at home seemed the perfect idea until we actually realized the complexities and emotional challenges this involved. Linda from the Central Palliative Care Service arranged for daily nursing visits to assist us with caring for Mum. When Calvary Care nurses came to the house we were delighted to have the Catholic connection, and the Mary Potter charism to assist us. However we could not have anticipated the incredible dedication of this small group of women to our Mum, and to us, over that intensive week.

It seems that the Community Care program is Mary Potter's vision reframed for the 21st century. In our experience, the Calvary Community Care team reflected Mary Potter's desire to love those who are dying

"I cannot but feel I have had a call from God to devote myself to help save souls in their last hour. I have been drawn so strongly to pray for the dying."

Venerable Mary Potter - Calvary website

We experienced women who personified the Mary Potter's call in our home through each nurse's complete dedication to Mum and to us. Their presence, in person and on the phone, reflected Mary Potter's desire to pray for the dying through the practical care of them and their loved ones. Every one of these wonderful women is living their own vocation to those who are dying, in the spirit of Mary Potter.

The Team's purpose was to assist us to support Mum into her death. They reminded me of midwives helping Mum labour into the next life supported, not only by our love and care, but also through the gift of pain and symptom management specifically designed to meet her needs. They also provided a pastoral presence that enabled important discussions while practical tasks were being carried out. Quite a complex skill set!

The conditions in which the Calvary Community Care team carry out their duties are a far cry from an organised, pristine, organisationally controllable hospice environment. Audrey, Lidia, Donna, Rosemary and Sarah, sat in the small kitchen or lounge room, surrounded by people who had come to see Mum, mostly family from interstate. People everywhere, they cleared a little space on the table in which to measure medication, write up notes, respond to questions, comments, or concerns. Their dedication to being with the family to support us to care for Mum, was integral to protecting the rights of Mum to a peaceful, pain-free death.

However the Calvary Community Team resources are stretched, asking a great deal of these women working in a wide variety of situations in family homes. What they achieve is amazing, but they work long hours. A task they may expect to take an hour may become much more in the complexity of family dynamics.

Working under such informal conditions also takes a lot of time. Simple tasks that could happen in a hospice setting, took longer in our home. The nurses offered pastoral care as they worked; listening to stories about Mum; about other deaths in our lives; about the process of dying. I was most impressed by the way each nurse cared for us as well as caring for Mum; listened while they measured medication for us to administer; heard our differences of opinion and never engaged in taking sides, but gently managed the conversations back to Mum's needs and her right to die with dignity and free from pain.

One afternoon Audrey checked that Mum had received an anointing of the sick, so that she could be at peace in her spirit. I was so impressed by this insight.

Our family was not straightforward. Like most families, we had our own complexities. I am embarrassed to say that the Team had to spend more time than they might have otherwise refocusing us on Mum's needs. However each nurse supported and encouraged us rather than criticised us for what we didn't understand. Their professionalism was outstanding.

Caring for our mother at home was a great privilege. It was also challenging and we sometimes felt unequal to the task. Even though we had different nurses the consistency of advice from each member of the Community Care Team was vital so we were not confused. All this takes time, more nursing time perhaps than in a hospice. My sense was that they often worked long hours with no one to hand over to if their shift finished while they were still preparing medications, so they kept going. They managed time well, but they gave more than those funding the program might realise.

Whoever was responsible for the selection of staff, Donna, the Team Leader I presume, has recruited people with sophisticated people skills as well as being experienced in palliative nursing skills. Sitting in people's homes as families learn 'on the job' the palliative approach to dying; how to administer drugs; keep accurate records; requires excellent communication skills as well as nursing expertise. The infrastructure they have devised is incredible. Every detail has been thought about its usability by families and in a home rather than a hospice.

Donna, Audrey, Lydia, Sarah and Rosemary, are highly skilled palliative nurses and highly skilled communicators, working in challenging physical and emotional circumstances. They operated as a team, with love for Mum and care for us. I am sure that Mary Potter would have been proud of them.

Mum died with dignity. Respected, loved and pain-free surrounded by those who love her. It was ultimately a profound experience enabled by the Calvary Community Care Team and the Central Palliative Care Services.

As I said to the nurses as Mum was close to a peaceful and pain-free death: Thank you is too small a word.

(Name and contact details supplied)

Advance Care Planning

Calvary supports the notion that individuals should be assisted to consider and share their goals and preferences for care. Simplistic approaches to advance care planning have, however, been demonstrated, over many decades of work, to have made little impact.

What is understood is that people's preferences and plans change, just as the status of their health changes. What is central to the delivery of high quality care, in any circumstance – but particularly as people approach and reach the end of their life – is communication, honesty and clearly understood purposes and goals, embedded in a model of care that allows for patients and their carers to reiterate or alter their choices in response to the way in which their experience is unfolding.

The introduction of any initiative that improves the opportunities for the general community, health, social or aged care staff to be empowered and resourced to initiate and support conversations that allow for honest and open sharing of information, communication of goals and preferences and development of shared understanding of approaches to care can only ever be supported.

There is a risk, if completion of an end-of-life care plan (or as more commonly practiced – directive) is mandated as an entry requirement to a residential aged care facility, for example, older people will feel pressured or coerced. This is particularly true if the focus of the advance care plan is on transfer to hospital or withholding or withdrawal of treatment. The ongoing communication around goals of care, their clarification and/or amendment should be the focus of any recommendation and mandated requirement – rather than the completion of a document at any single point of time.

Advance Care Planning provides patients, family and decision makers, and clinicians with a single point of focus to identify the ongoing care wishes of the patient together with their wishes when the end of life approaches.

Most importantly, Advance Care Planning identifies decision makers who can determine treatment plans, if and when the patient's decision making capacity is impaired or they are unconscious.

The importance of Advance Care Planning is widely recognised across all sectors and service points in the health and aged care sectors. Nurses, doctors, social workers and counsellors, aged care employees, lawyers and estate planners are all now attuned to the importance and worth of Advance Care Plans.

If necessary, Advance Care Plans can be finalised in Calvary's acute, sub-acute and RACF settings.

Community views on the desirability of voluntary assisted dying being legislated.

Medical and Clinical Workforce

Calvary has publically stated in submissions to the NSW and Victorian governments that it will not participate if any legislation enabling physician-assisted suicide is passed.

The World Medical Association (WMA) agrees with Calvary's assessment. It has publicly stated *"Physician-assisted suicide, like euthanasia, is unethical and must be condemned by the medical profession."* It has called on jurisdictions throughout the world to reject physician-assisted suicide bills, warning that *"vulnerable people will be placed at risk of abuse."*

The Australian Medical Association (AMA) shares this view, opposing the implementation of physician-assisted suicide legislation in Victoria. AMA President Dr Michael Gannon wrote last year:

> *"It has long been recognised that doctors who are closest to providing end-of-life care are those most likely to be opposed to physician-assisted suicide […] the proposal for Voluntary Assisted Dying (VAD) in Victoria, or any other form of euthanasia/physician-assisted suicide in New South Wales, Western Australia, or elsewhere, would be a negative move for our society. It would be a victory for fear over hope, and would in no way enhance the provision of quality end-of-life care."*

General Public

While a number of polls conducted over the past years indicate between 70-85% of Australians are for physician-assisted suicide in principle, studies show that Australians understand little about death, dying and the benefits that can be achieved by high-quality palliative and end-of-life care.

Calvary believes that Australia's support for physician-assisted suicide is informed by, amongst other drivers:

- people's unfamiliarity with death and dying;

- the dehumanisation and objectification of the sick, elderly and frail;
- prolonged death and the rise in dementia;
- the medicalization and institutionalisation of death and dying; and
- the value placed on self-determination and personal autonomy in care, and the fear of its compromise.

Person-centred palliative care works to relieve not only the physical pain of living with a life-limiting illness, but the psychosocial suffering that can be attributed to the aforementioned societal drivers.

Like its practitioners of palliative care, Calvary aims to relieve anxiety and fear informed by misinformation by working with the public to build authentic knowledge about death, dying and end-of-life care.

Recently, Calvary conducted a review of the academic literature concerned with the community attitudes and anxieties around death and dying; the medicalization of death and our death-denying society; patient and resident autonomy in care; dementia and the preservation of dignity in care; and community knowledge and attitudes about palliative and end-of-life care and physician-assisted suicide. This review provides an insight into current attitudes about death and dying in Western societies and can be applied to contemporary Australia.

Authors predominantly represented the disciplines of sociology and psychology. Those representing the field of medicine, and more specifically palliative medicine, provided insights into the practical challenges of supporting patients and family carers to navigate their life-limiting disease(s).

a. Death is a stranger: Australia’s unfamiliarity with death and dying

Contemporary Australia, like other Western countries, is no longer familiar with the process of dying and the natural occurrence of death. Commentators agree that advancements in public health policy and medical science over the past 50-100 years have contributed to our modern ‘death-denying’ society.

b. The institutionalisation of dying: dehumanisation of the sick, elderly and frail

No longer do healthy and able adults or children live in close community with the elderly, sick and frail. Their natural deterioration has become alien, its effects on the body and mind confronting, and circumstances observed as disempowering and undignified, fear-provoking.

c. Longer life or prolonged death and the rise in dementia

The significant rise in the prevalence of dementia must play a crucial role in how the community perceives quality of life and to what extent the dignity of dying persons is preserved. The concept of dignity is directly related to the level of independence and autonomy retained through the course of illness.

d. Death is the enemy: the medicalization of death and dying

For the medical profession, the preciousness of life underlies all clinical disciplines, and its preservation the utmost clinical goal. The medical profession is trained to cure and/or treat physical symptoms of physical disease. For clinicians, death is commonly framed as the enemy to be conquered, and when it occurs, it exposes and highlights incapability and the defeat and failure of modern medicine.

e. The question of dignity: self-determination and personal autonomy in care

A wish for physician-assisted suicide is predominantly informed by an intrinsic fear of loss of autonomy, power and control over both the individual’s body and of the dying process in care.

In a review of the literature, Kehl (2006) recognised that being in control was overwhelmingly agreed to be the most important and common element of a good death.

Woo, Maytal and Stern (2006) state that for many patients, dignity is directly related to the level of independence and autonomy retained through the course of illness.

In an important study conducted by Ganzini, Nelson and Schmidt et al. (2000) about what motivated patients to pursue physician-assisted suicide in Oregon, it was determined that the most common reasons for the request were:

1. Loss of independence (57%);
2. Poor quality of life (55%);
3. Ready to die (54%);
4. Wanted to control circumstances of death (53%);
5. Saw continued existence as pointless (47%);
6. Physical pain (43%);
7. Loss of dignity (42%); and
8. Viewed self as burden (38%).

It is important to note the disparity in prevalence between ‘Loss of independence’ (57%) as a reason for assisted suicide and ‘Physical pain’ (43%). This study alone demonstrates, that in Western societies at least, loss of independence is a significantly more common motivator for assisted suicide than physical pain or perceived loss of dignity.

These underlying issues inform community support, in principle, for physician-assisted suicide. They are by and large not related to unmanageable pain, however the fear of unmanageable pain is a key driver.

For example, data from 2016 on the Oregon *Death with Dignity Act* provides an insight into patient anxiety. It points to the 296 people euthanized since the law’s introduction who identified ‘inadequate pain control or concern about it’ as a concern informing their request. **In this case, it is important to make the distinction between unmanageable pain and the fear that unmanageable pain may come.**

These challenges underlie any proposal to implement an “assisted dying scheme”. It is Calvary’s view that if the challenges above are more systematically addressed, the need for an “assisted dying” pathway (and the expenditure of the resources associated with its introduction) will be significantly reduced.

Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed.

Any individual living with advanced terminal disease should be considered particularly vulnerable and persons who request physician-assisted suicide especially so.

Calvary is of the view that if a physician-assisted suicide regime were in place the highest levels of safeguards would be needed to protect the interests of individuals living with life-limiting disease, however it is problematic to determine appropriate safeguards to ensure a request for physician assisted suicide (PAS) is a true request or indeed voluntary, because there may exist a great many external variables that could impact on the individual’s capacity for choice.

For example, a psychiatrist trained in the psychiatric assessment of patients with advanced terminal disease may be capable of appropriately assessing the cognitive status of the individual, however there may be societal, community, and personal pressures unidentified or otherwise not judiciously considered. Such pressures could include financial concerns, inadequate access to alternative services, physical, financial and psychological abuse, misinformation about treatment options, or a reduced sense of self that may impact significantly on the individual's choice to make a request.

Additionally, it is problematic to act on a request for PAS when the cognitive status of an individual at end-of-life may change significantly from week-to-week or day-to-day. For example, of the approximately 50,000 palliative care patients admitted to Australian hospitals each year, less than 1% express a sustained desire for physician-assisted suicide and so the evidence is overwhelming that high-quality palliative care is highly effective (Hudson et al, 2015).

If this is the case, the failure to adequately ensure that every person who needs access to high quality end of life services receives it, represents a failure of the state to provide for its people.

Persistent Knowledge Gaps

There is currently a high level of misunderstanding and misrepresentation around the positive health outcomes that can be achieved with palliative care.

The specialist skills attributed to palliative medicine are currently neither commonplace nor incorporated into existing healthcare professional curricula.

The response to a request for PAS would require a professional, highly-experienced, compassionate and individualised response. Such a response requires exceptional skills, judicious timing, and the capacity and commitment to engage in shared decision-making with the individual and the family, particularly when confronting the less tangible existential aspects of suffering.

Such an expert response, informed by specialist knowledge, expertise in advanced disease and end-of-life care, and a tradition in compassionate patient-centred care, in turn informs the individual about the realities of death and dying and their options for treatment and works to relieve fears and anxieties.

Particularly Vulnerable Populations

Marginalised groups such as CALD Australians, the elderly and frail, prisoners, homeless, mentally and physically disabled, those living alone without supportive families, Aboriginal and Torres Strait Islander peoples, and individuals susceptible to elder and other forms of abuse are particularly vulnerable subsets of a group already rendered marginalised by advanced terminal disease.

For these individuals, susceptibility to mixed messaging and misinformation around treatment options and the value of such interventions is already problematic. Special care needs to be taken by palliative practitioners and other health professionals to ensure a compassionate, individualised response is provided to inform individuals from these demographics.

The applicability of voluntary assisted dying schemes operating in other jurisdictions, particularly the Victorian scheme.

Care Funding Gaps

Failure to adequately fund palliative care services. The Victorian Parliament, through a rigorous Legislative Council inquiry process, has identified gaps in palliative care and Palliative Care Victoria (PCV) has stated that there is an annual $65m funding shortfall in service delivery.

These concerns are the first priority for reform of the legislative framework for end-of-life choice decisions in Victoria. Funding measures announced as part of the consideration of the Bill failed to bridge the gaps identified in the Legislative Council Inquiry report and by PCV.

The adequacy of existing services is therefore the *a priori* question for the South Australian Parliament.

Inadequate Safeguards

Though the question of safeguards was arguably addressed in the Victorian legislation, there are weaknesses. Persons with mental illness may be able to access the regime due to weaknesses in the proposed review provisions for psychological assessment.

There is the risk that people with depression can activate the PAS regime due to the episodic nature of their condition. Depression is very difficult to diagnose. Indigenous persons with high disability rates are particularly vulnerable. There is a significant risk of elder abuse including through the inconvenient reality of inheritance impatience that can allow subtle emotional pressure to be placed on dying persons who feel they are a burden to their families.

The Victorian legislation has significant social and public policy ramifications. It is in the interests of the common good that people who wish to gain access to a state sanctioned service to end their own lives have first had the opportunity to experience high quality care at the end of life and/or palliative care and that they should have tested its benefits.

People are valuable, no matter what they are experiencing and no matter how they perceive themselves.

Decision making capacity is something which grows with the person and is shaped by their experience. The legal definition and presumption of decision making capacity has limits. Mental illness is recognised as a potential impairment to this capacity. There are other circumstances which may impinge upon this capacity when a person is considering suicide including:

- the degree to which they can gain access to support and suitable care, which may be impinged through loneliness and isolation, extreme age, grief and lack of a support network;
- the fact of elder abuse, family conflicts and other pressures, real or imagined;
- experiences of past abuse and trauma;
- poor self-esteem and experiences of rejection by significant others;
- their physical condition, the nature of the disease and cognitive impacts;
- other changes of which they are presently afraid (not being able to stay at home).

It is well known that people with cancer and other life threatening diseases have a higher incidence of depression.

What safeguards will be in place to ensure adequate treatment not just of their depression but of the whole person?

Some existing patient groups have cognitive changes associated with the disease process, which also change over time. Health professional competency in terms of assessment of this cognitive change is variable, can be complex and may require neuropsychology testing.

A medical practitioner, making an assessment of capacity, may not have a full and comprehensive knowledge of the person seeking assistance to end his or her own life.

Quality health care manages the causes of patients' distress rather than ending life. In our experience, requests to terminate life prematurely are uncommon and often a cry for help. Calvary's experience is that a person's desire for hastened death changes over time and reduces when care is good.

It is not good policy to consider euthanasia legislation before ensuring there is universal access in the State to good end-of-life care. Every Victorian is going to die, just as every South Australian will die. We want each person to have an experience of dying well. Not every Victorian or South Australian will want assistance taking their own life.

Adverse Assessments

'Doctor shopping' is also a significant issue. If a potential applicant for the VAD regime in Victoria receives an adverse assessment of their capacity to make an informed decision, then there is nothing to stop that person remaking their request to a series of doctors until they receive the outcome they seek.

While adverse assessments are recorded in Victoria, these records will not be available to medical practitioners asked to provide an assessment. The door is fully open to doctor shopping, which is a major gap in safeguards under the Victorian legislation.

Providing evidence of residency in South Australia

'Suicide tourism' was an issue raised in Parliamentary debate on the Victorian legislation. Legal opinion made available to legislators questioned the effectiveness of measures to enforce the definition of 'ordinarily residing' in the State for the prescribed 12-month period. No record keeping of this residency test is mandated.

There is no effective measure under the act to prove residency (like evidence to being a party to a residential tenancy agreement or other proof of a sustained location of residence). There is no effective mechanism to stop an applicant to the VAD scheme in Victoria effectively residing outside the State but seeking medical approval for access to the scheme from a medical practitioner registered within the State.

Drug Regimen

The Victorian Parliament approved the medically assisted dying regime without having chosen the lethal drug: the "medically assisted dying substance".

The solution has been to allow a single pharmacy to dispense the drug presumably under a special access regime operative under the Therapeutic Goods Act (TGA) of the Commonwealth where compounding pharmacists can produce a cocktail of drugs from components that are approved for other uses.

Evidence from overseas jurisdictions is that the choice of the (lethal) drug is highly problematical, and drugs have often had to be changed due to adverse effects including prolonging death and suffering in a number of cases.

Any other relevant matter.

Calvary adheres to the Catholic Health Australia (CHA) *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia.* In the chapter titled 'Decision making in health care' the Code provides direction around the rights of the patient, especially in the context of end-of-life treatment. The extent to which *the Code* supports a dignified death devoid of unnecessary discomfort is largely misunderstood by people not familiar with *the Code*.

Calvary cannot support the notion that assisting a person to suicide, or to end their life directly and intentionally, is an expression of care. We strive to eliminate suffering, but not the people who are experiencing the pain or physical incapability that may inform their suffering.

Conclusion

Calvary would be happy to make further submissions, either orally or in writing, as required.

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