Calvary | Little Company of Mary Health Care Ltd

Hospitality
Healing
Stewardship
Respect

23 March 2018

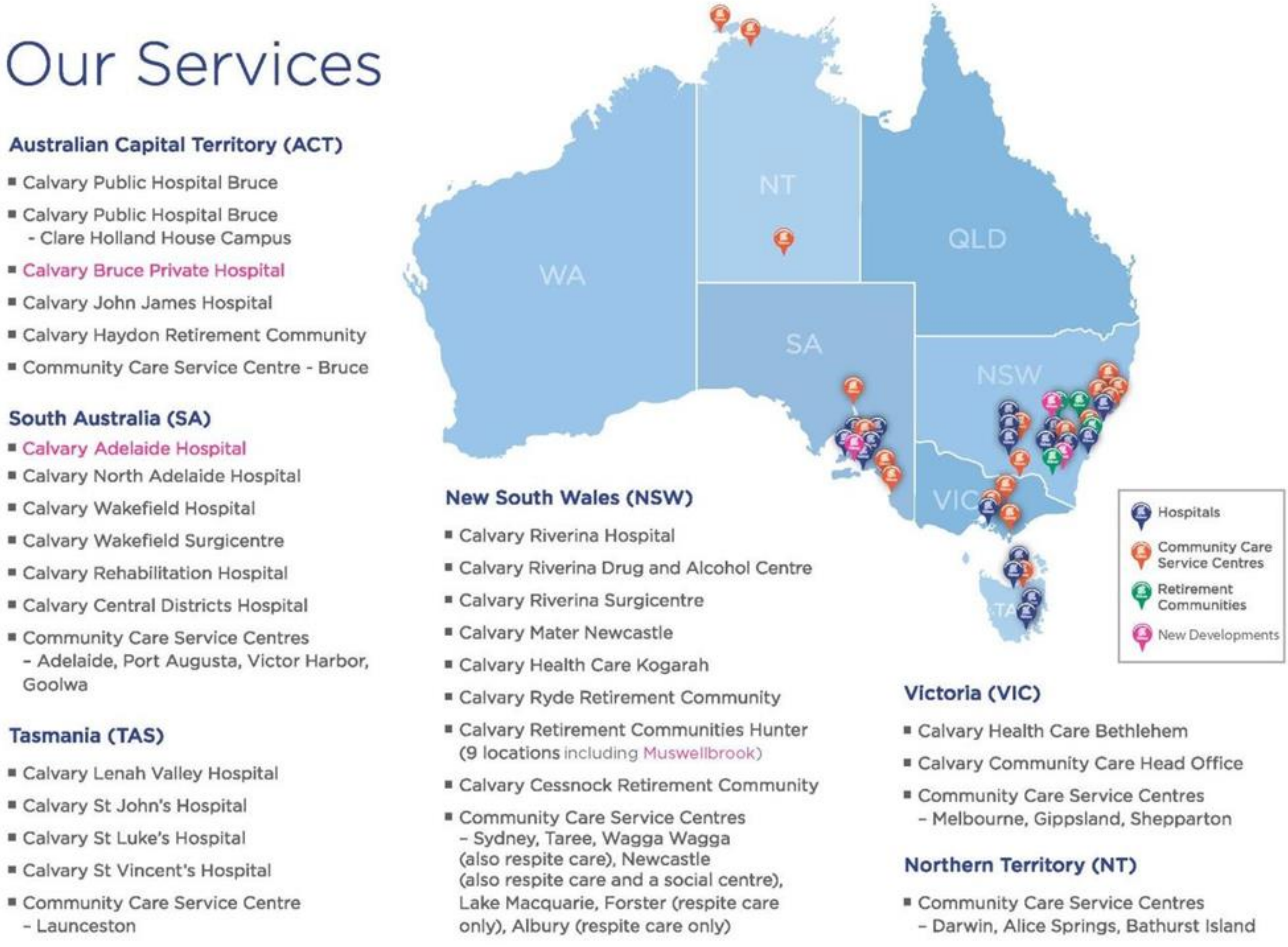
Secretary,
Select Committee on End of Life Choices in the ACT,
Legislative Assembly for the ACT,
GPO Box 1020,
CANBERRA ACT 2601

Dear Select Committee Members,

Little Company of Mary Health Care Ltd. (Calvary) Submission to the Select Committee on End of Life Choices in the ACT

Little Company of Mary Health Care Limited, trading as Calvary, appreciates the opportunity to lodge the following submission with the Select Committee on End of Life Choices in the ACT.

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.

As the map on the previous page illustrates, our services in the ACT are extensive. In the ACT, Calvary Clare Holland House (CCHH) is recognised as an ACT leader in Specialist Palliative Care.

Our services are valued in the ACT community. Calvary is known for:

- our innovative model of care;
- our interdisciplinary team work in collaboration with patients, GPs, community health, aged, disability and other health services; and
- our efforts to ensure that care is easily accessible and coordinated across inpatient services, centre-based clinics, a day centre, and at home.

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 Select Committee on End of Life Choices in the ACT

Responsible for Submission: National Director of Mission

23 March 2018

Contents

Terms of Reference

This submission addresses the following terms of reference of the Select Committee on End of Life Choices in the ACT:

a. current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care;

b. ACT community views on the desirability of voluntary assisted dying being legislated in the ACT;

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

d. the applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme;

e. the impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change; and

f. any other relevant matter.

Introduction

Little Company of Mary Health Care Limited, trading as Calvary, appreciates the opportunity to lodge its submission with the Select Committee on End of Life Choices in the ACT.

Calvary provides a significant proportion of the health care in the ACT, maintaining over 500 hospital beds across three facilities, with in excess of 90,000 presentations each year across the three Calvary hospitals. Approximately 56,000 of these presentations are at Calvary Public Hospital Bruce.

Situated in Deakin, Calvary John James Hospital is Canberra's largest private hospital with 155 beds and has been part of the Canberra community since March 1970. Calvary John James Hospital provides surgical and medical services along with a special care nursery and a rehabilitation unit. Within the medical ward are palliative beds.

Calvary Bruce Private Hospital provides the Canberra, Belconnen and the Gungahlin precinct with 118 private beds. The Hyson Green unit is the only dedicated private mental health facility in the ACT, providing outpatient mental health services and supports more than 300 patients a year.

Calvary Haydon Retirement Community provides over 100 residential aged care places, and is a leading provider of palliative and end-of-life care in the ACT *via* specialist services from Calvary Clare Holland House (CCHH).

Situated in Belconnen, Calvary Public Hospital Bruce is a 256 bed teaching hospital that offers acute and sub-acute services to the Canberra community. Calvary Clare Holland House (CCHH) is the Calvary Public Hospital Bruce specialist palliative care service. CCHH provides both inpatient and community services at a tertiary level for the ACT (designated level 6 in the CNC). CCHH provides outpatient clinic services, care in the home or residential setting, and also inpatient hospice services. The palliative care service is tailored to each patient, with the main objectives being to enable each patient to have a fulfilling and comfortable lifestyle while navigating a life-limiting illness and whilst still receiving appropriate person-centred care.

Calvary Clare Holland House's Specialist Palliative Care Unit will:

- advise and support the primary care team;
- manage distressing symptoms;

- provide home visits if necessary;
- facilitate access to equipment to support the patient to stay in the home setting as long as possible;
- provide advice over the phone;
- provide inpatient care at the ACT Hospice;
- educate the family carers about best care for the patient; and
- support the bereaved.

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, 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.

It is important to note at this juncture in our submission that the ACT 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.

Definitions of Acronyms and Terms

CALD	***Culturally and Linguistically Diverse*** is a descriptor for people born in countries other than those classified by the Australian Bureau of Statistics (ABS) as “main English speaking countries”.
CHA	**Catholic Health Australia** is the Catholic health and aged care peak association, of which Calvary is a member. CHA represents the interests of approximately 30% of private hospitals, 5% of public hospitals, and 10% of residential aged care Australia-wide.
CCHH	**Calvary Clare Holland House** provides an integrated community and inpatient consultative service in Specialist Palliative Care in the ACT and Southern NSW. The service has Palliative Care Multidisciplinary Specialists providing liaison consultancy to other health services across the health care sector including residential, primary and secondary care providers. The service has a multidisciplinary approach to care, providing outpatients services and clinics, home based community services, inpatient services; in additional to consultancy services. It is classified as a tertiary or specialist level service.
CRC	***Calvary Retirement Community*** CRC Haydon in the ACT offers over 100 residential aged care places in addition to independent living units (ILU) and respite care.
EOL	***End-Of-Life*** 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.

EOLC	***End-Of-Life Care*** 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.
LCMHC	***Little Company of Mary Health Care Limited*** is a public not-for-profit company trading as Calvary and Calvary Health Care. Calvary is a provider of holistic person-centred health, aged and community care in a number of states and territories across Australia.
MND	***Motor Neuron Disease*** is the name given to the group of diseases in which the motor neurones undergo degeneration and die. With no nerves to activate them, muscles gradually weaken and waste. The disease can affect a person's ability to walk, speak, swallow and breathe.
PAS	***Physician-Assisted Suicide*** is the termination of one's own life by administration of a lethal substance with the direct or indirect assistance of a physician.
PC	***Palliative Care*** 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.
PEPA	***Program of Experience in the Palliative Approach*** is a national Federal Department of Health-funded palliative care approach to education and training of the health workforce.
RACF	***Residential Aged Care Facility***
TCH	***The Canberra Hospital***
VAD	***Voluntary Assisted Dying*** is the term adopted by the governments of NSW and Victoria in naming their physician-assisted suicide bills.

Response to Select Committee Focus Areas

Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care

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 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.

There is, however, some suggestive evidence in the ACT of a preference for Community based/Home Based Palliative Care. The table below illustrates a clear trend. By 2027 home based palliative services will be double present rates (1404 versus 767) while inpatient services will have halved (114 versus 227). Annualised Growth in the Community Specialty Palliative Care Service (CSPCS), essentially home based palliative care, from 2014-2015 to 2016-2017 is from 7.92% to 8.31%.

Year	**CSPCS**	**Inpatient Unit**
2017-2018	763	227
2018-2019	823	208
2019-2020	889	191
2020-2021	959	175
2021-2022	1035	161
2023-2024	1117	147
2024-2025	1206	135
2025-2026	1301	124
2026-2027	1404	114

Table 1: Annualised growth CCHH Home Based Palliative Care services versus CCHH Inpatient Unit

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:

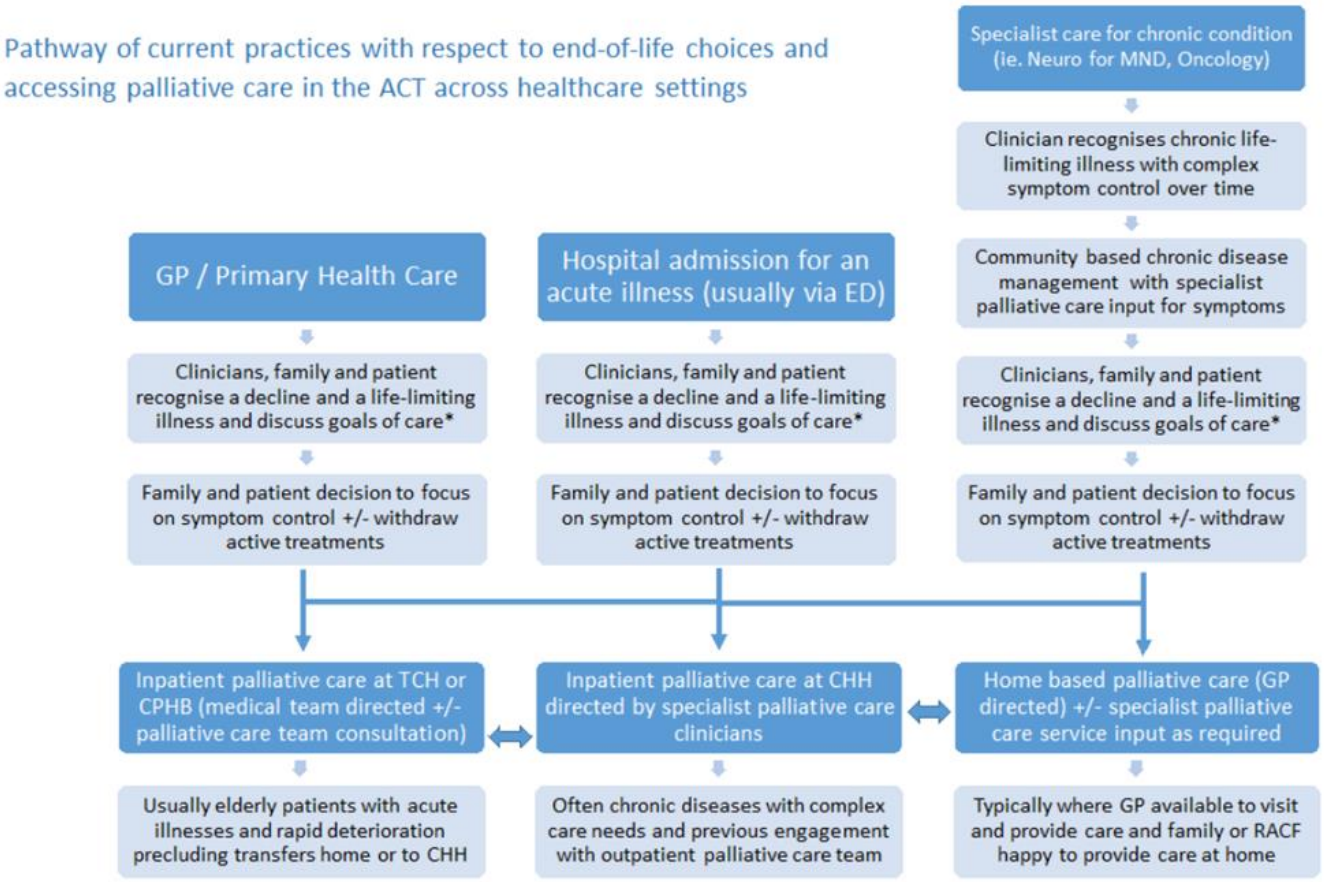
- ***End-of-life* (EOL)** refers to that period of time when a person is living with an advanced, progressive, life limiting illness and likely to be in the last 6 to 12 months of their life.
- ***End-of-life care* (EOLC)** is care provided to people who are approaching and reaching the end of their 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.

Calvary Clare Holland House (CCHH) is a specialist provider, providing service not only to Calvary facilities in the ACT but to other private hospitals and the CHHS and SNSW hospitals, GPs and residential care facilities.

The staff specialists provide a twice weekly round/consultation at Calvary Public Hospital Bruce. They also provide rounds/consultation at the two private hospitals and, when needed (according to admission criteria), accept patients with specialist palliative care needs to the CCHH Inpatient Unit. CCHH won the ACT Quality and Safety Award for its work partnering with residential aged care facilities for palliative 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.

It is useful here to set out the pathway of current practices with respect to end-of-life choices and accessing palliative care in the ACT across the various healthcare settings. Please note however, that the diagram below does not illustrate *all* the touch points to CCHH Specialist Palliative Care Service. For example, a patient may be referred by a GP or other specialist health practitioner to the Community Specialist Palliative Care Service (CSPCS), to an Outpatient clinic for care and or advice. Patients may be referred to CSPCS for Home Based Palliative Care or to the Specialist Palliative Aged Care Team (SPACT) for care within a RACF. To further clarify the diagram below, please note that whether elderly patients are transferred to CCHH would depend on their choice.



Pathway of current practices with respect to end-of-life choices and accessing palliative care in the ACT across healthcare settings

*Goals of care are increasingly being documented in the community where patients and stakeholders complete an “advance care directive” that establishes not only Resuscitation Orders/Goals during acute illnesses, but also objectives around death including patient preferences about when to withdraw active treatment and life-prolonging measures in the setting of an acute illness, preferred location for end of life care and final days, cultural and spiritual requirements and goals surrounding death and dying.

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.

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 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 the acute, sub-acute and RACF settings.

Available Training

Training is provided to medical staff through the accredited Palliative Care specialists under the Royal College of Physicians; and a Diploma of Palliative Care is offered with particular focus on GPs under the Royal College of General Practice. Registrar training is provided at CCHH both within the Inpatient Unit and within the Home Based setting. Clinical supervision is provided by the staff Specialists and didactic education sessions are held at least twice a week.

It is hoped that TCH will become accredited to train palliative care physicians in the near future; which will enable a more comprehensive rotation of staff.

Undergraduate training is provided to Medical Students from the Australian National University through clinical placement and didactic teaching sessions and participation in student examination.

Registered Nursing Students from the University of Canberra and Australian Catholic University undertake clinical placements within both the Inpatient Unit and Specialist Palliative Care Service. Senior nursing staff are invited to present formal lectures in relation to palliative care at each of these universities. Enrolled Nursing Students and Allied Health Assistants from the Canberra Institute of Technology also undertake clinical placements within the Inpatient Unit. Pastoral Care Students also undertake placements at CCHH through the Clinical Pastoral Education Centre.

Allied Health Students, Social Work, Physiotherapy and Occupational Therapy from Canberra University and the Australian Catholic University undertake periods of clinical placement during the academic year.

CCHH is currently contracted to provide education to primary palliative care workers under the banner of the “Program of Experience in the Palliative Approach” (PEPA). PEPA aims to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements, in specialist palliative care services or interactive workshops. This program touches General Practitioners, Nurses, Allied Health Practitioners, Community Care Workers, Aged Care Workers and Aboriginal and Torres Strait Islander health and community professionals.

The PEPA program adapts to a number of varied learning environments utilising workshops, clinical placements within CCHH and clinical placement in Residential Aged Care.

CCHH provides a comprehensive in-service program for the multidisciplinary team at CCHH and more widely to the general hospital. Included in this program is:

- mandatory training,
- palliative care specific education (didactic) journal club,
- visiting speakers, for example, Paediatricians, CALD, Aboriginal and Torres Strait Islander, and
- workshops and sponsorship to local and national conferences pertaining to palliative care.

The staff from TCH Palliative and Supportive Care are invited to the regular medical staff training sessions and journal club.

These training and education activities are delivered at no charge to acute care providers, sub-acute care providers, RACFs, community nursing and in some instances directly to patients and their family.

A rolling program of training and education is conducted for acute and sub-acute throughout each year, and as requested or required by other agencies and organisations. Training is provided regularly to Palliative Care ACT members, and also to other peak health representative groups in the ACT.

ACT community views on the desirability of voluntary assisted dying being legislated in the ACT.

Medical and Clinical Workforce

Calvary provides a significant proportion of the health care in the ACT, maintaining over 500 hospital beds across three facilities, with in excess of 90,000 presentations per year at the Calvary facilities in Bruce and Deakin. Calvary also provides over 100 residential aged care places, and is a leading provider of palliative and end of life care in the ACT via specialist services offered through Clare Holland House.

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

Physician-assisted suicide laws were last year debated in the parliaments of Australia's two most populous states, in addition to Tasmania, and in 2016, South Australia.

In both Tasmania and South Australia, the bills were defeated. In New South Wales, the Voluntary Assisted Dying (VAD) Bill was defeated by one vote in the upper house. In Victoria, the Bill was passed by both the Legislative Assembly and Legislative Council. Physician-assisted suicide will be made law in Victoria and is planned to be accessible to residents of the state in mid-2019.

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 to the ACT, 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 ACT government.

Inadequate Safeguards

The question of safeguards was not dealt with adequately in the Victorian legislation. 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 Canberran will die. We want each person to have an experience of dying well. Not every Victorian or Canberran 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 the ACT

'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.

Given the close proximity of the ACT to NSW, this is a critical issue for the ACT jurisdiction to consider. Were the ACT to approve a VAD scheme, and if the Victorian model was adopted, an applicant residing just across the NSW border could access the arrangement in defiance of legislation operative in NSW.

ACT would risk becoming a very attractive site for assisted suicide applicants from NSW. This would reduce safeguards considerably in the Territory and would frustrate the legislative intent of any legal change to approve medically assisted suicide or euthanasia. The proximity of the border with NSW makes it extremely difficult to effectively enforce a VAD scheme without a complementary arrangement in NSW.

Drug Regimen Undisclosed

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

The proposed solution is to allow pharmacists to dispense the drug 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.

This exemption to the normal TGA approval process is intended to be used in limited circumstances for persons with specific medical needs. It is not intended to be applied for a generic class of clients like those seeking access to a legislated VAD scheme. So, the Victorian Parliament has approved a scheme without research into the appropriate drug and its effectiveness, without even specifying the drug or outlining a process for its approval that is consistent with normal TGA approaches.

Evidence from overseas jurisdictions is that the choice of the 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. The failure of the Victorian scheme to adequately explain which drug will be used and how it will be tested and approved to normal TGA standards is perhaps the most significant failure of the Victorian physician-assisted suicide model.

We specifically refer the Select Committee to *Calvary Position Statement – Victoria Assisted Dying,* 15 August 2017 available at https://www.calvarycare.org.au/wp-content/uploads/2017/08/calvary-position-vad-20170815-final.pdf This document outlines in greater detail Calvary's concerns with drug regimen.

The impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change.

Calvary supports the points made in Catholic Health Australia's (CHA) submission to the Select Committee on this key issue.

The capacity of the ACT to determine its own policy on PAS is limited by the statement in the Australian Capital Territory (Self-Government) ACT 1988 - SECT 23 Matters excluded from power to make laws which states:

> *'(1A) The Assembly has no power to make laws permitting or having the effect of permitting (whether subject to conditions or not) the form of intentional killing of another called euthanasia (which includes mercy killing) or the assisting of a person to terminate his or her life.'*

The ACT would require cooperation from the Federal Government in order to develop a policy legalising physician-assisted suicide. The Federal Government has up until this point demonstrated an unwillingness to engage with the issue of PAS which could make the establishment of a policy in the ACT very difficult, time consuming, and costly.

Calvary, like CHA is of the view that it should be a priority of the ACT government to allocate their time and resources to improving access and funding of necessary palliative care services and supports.

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.

References

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