Response to the Ministerial Expert Panel on Voluntary Assisted Dying

May 2019
BACKGROUND
St John of God Health Care (SJGHC) is one of Western Australia’s principal providers of end of life care to the community. It is a role of which we are proud, and reflects a core part of our identity in seeking to care for all people, especially those most vulnerable. Arguably, there are few occasions when a person experiences greater vulnerability in life than when it comes to the end of life.

Ensuring that every person in the community has the right to access safe, high quality care, especially at the end of life, is one of the most significant ways in which a community conveys its respect for human life. It is for this reason, that we at SJGHC wish to advocate for the development and expansion of palliative care services, both inpatient and community based.

Every person, has the right to expect that they are treated as respected and valued members of the community, regardless of their age, economic or social status, ability or disability.

As each person approaches the end of their life, this right to respect and dignity becomes even more vital. People should feel confident that their worth is not eroded by virtue of increasing age, or the diagnosis of terminal illness.

Consequently, SJGHC entirely rejects the suggestion that voluntary assisted dying, or any similarly named process, can be regarded as an alternate among a range of options for ‘care’ at end of life. Rather, we regard the legislatively endorsed availability of such pathways as an admission of failure to care appropriately for people in the community who have every right to expect to be able to access the best in medical care at the moment of greatest vulnerability in life.

It is our experience over decades of practice that where access to high quality palliative care is made available, complemented by attendant support for patients, families and carers, that patients’ experience of death is marked by dignity, respect for patient autonomy and decision making, and effective pain and symptom management.

CURRENT SITUATION
People want to die comfortably at home, in the company of family and friends, with the support of effective services. A good death respects a person’s dignity, freedom of choice with regard to care options, and access to requisite support to address their physical, personal, social and spiritual needs. When death comes for each of us, we want to die comfortably in surroundings we choose, however it is often not well planned or discussed, and care is too often fragmented.

Since 2005, the number of deaths registered has increased by around 2.0% per year on average. About half of Australians die in hospital and about a third in residential care. Seventy percent of people want to die at home but only about 14% do so.
Many more people die in the place of their choice when they have access to specialist palliative care support and are able to fully discuss and document their wishes with skilled clinicians\(^1\) \(^2\). For this reason, the availability of adequately funded and resourced specialist palliative care services to people in urban and regional areas is of paramount importance when considering end of life care.

A 2010 Melbourne study (Detering, Hancock, Reade, and Silvester), demonstrated the positive effects of advance care planning with elderly patients, with improved care for patients, and reduced levels of stress, anxiety and depression in surviving relatives.\(^3\)

As an Australian community, we also need to revisit our views when it comes to ageing, and the value we place on people. We need to recognise the contribution that older people make to our communities, to understand care for people as they age as a privilege and recognition of their inherent dignity, rather than a cost burden. We need social policy that supports care for our elderly and vulnerable community members by the community itself, rather than seeking to focus only on care by health and social services.

As a Catholic organisation SJGHC cares about the dignity of the human person, we support informed choice in care, and we prioritise the care of vulnerable people, including those that are dying.

SJGHC provides palliative care services through its hospitals at:

- Bunbury: Specialist palliative care service with ten inpatient beds (private and public), clinical nurse specialist, palliative medical specialist, allied health support, outpatients palliative clinic;
- Murdoch and Murdoch Community Hospice: specialist palliative care service with 20 beds (private and public), day support service, outpatients clinic, clinical nurse specialist, palliative medical specialist, allied health support;
- Subiaco: specialist palliative care service with five beds, hospital wide consultancy service, nurse practitioner, clinical nurse specialist, palliative medical specialist, allied health services, outpatients clinic; and
- Geraldton: specialist palliative care service with five beds (private and public), support provided by General Practitioners with some access to Perth metro palliative medical specialists.

Several SJGHC Hospitals also participate in the Palliative Care Outcomes Collaborative (PCOC), which is a national program working to support improved outcomes for people accessing palliative care services.

Western Australia benefits from having a dedicated community specialist palliative care service, which links with inpatient palliative care provision in hospitals. In WA, some specialist palliative care is provided through public contracts with private hospitals, including inpatient bed provision.

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3. See https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2844949/
at St John of God Murdoch, St John of God Bunbury, and St John of God Geraldton Hospitals. People are admitted to these services on the basis of need.

Not all private health insurers cover palliative care services, and people may elect not to include this provision if there is an option to do so, in order to reduce their premiums.

LISTENING TO THE WISHES OF PATIENTS
Despite our best efforts, patients can only make informed decisions about care at the end of life if they have access to adequate information. As people approach the end of life, they may be unable to make decisions themselves.

Although systems exist across WA health services to facilitate formal advance care planning and completion of Advance Health Directives (AHD), there is a relatively low instance of the utilisation of plans or directives.

And, when they are utilised, questions often arises as to the validity of such documents, including: How long ago was the document written? How robust was the conversation that led to the decision? Did the patient fully understand the care choices available to them? Was there any coercion? Do the current circumstances actually reflect those detailed in the directive? Further, the documents may also not be readily accessible at the point of care.

While there is often an opportunity to work through these concerns with the family or representative of a patient, where there is conflict between family members it may be difficult to reach a consensus view as to what the patient would request in the event that he or she could speak for themselves.

Useful advance care plans are often prepared by palliative care services in consultation with patients, as they require skilled clinicians with a deep understanding of likely disease progression and advanced communication skills in order to meaningfully reflect and communicate a person’s wishes.

People may also appoint an Enduring Power of Guardianship (WA), someone whom they trust as their Guardian, to make decisions on their behalf when necessary and to ensure that their wishes are known and followed.

Within WA, there has been a recent focus on discussions about ‘Goals of Care’, and recording care preferences on admission to hospital. Implementation of this project across a number of hospitals has highlighted the need for healthcare professionals to develop enhanced communication skills in order to confidently and effectively lead these conversations with patients.
Palliative Care Services in WA

The Need for More Funding and/or Expansion of Services

SJGHC joins with others in the community, including Palliative Care WA, for the establishment of an expert panel in palliative care to provide advice to the Minister for Health. While panels have been established to advise on voluntary assisted dying, and advance health directives, there is still no clear commitment to establish an advisory body to the Minister on palliative care despite this being one of the recommendations of the Joint Select Committee.

When considering the provision of services to the community with regard to end of life care, we would urge that priority is given to increasing funding for those services providing care and support to patients and their families in both inpatient and community settings.

Specialist palliative care services offer physical, psychological, social and spiritual assessment and support to patients and their families in order to optimise quality of life, reduce carer stress, offer support systems to enable people to be cared for as they prefer, and reduce the chance of needing hospitalisation. The focus is on life and living until the time of death, whilst acknowledging that death is a normal process. Support extends to families during bereavement.

Palliative care is often conducted in partnership with active treatment of a progressive disease, but becomes an increasing focus as the patient’s condition progresses. Palliative care teams may be involved with a patient’s care for several months, or even years, prior to death.

However, referrals to specialist palliative care services are sometimes delayed until the patient’s death is imminent. This is far from ideal. Earlier admissions potentially enable complex symptoms to be dealt with and support to be mobilised to enable the person to die in the place of their choice.

Access to specialist palliative care services in regional areas remains very limited, so that people in regional communities are more likely to die in hospital, often removed from family and local communities – a poor and highly undesirable outcome for the patient and those who love them.

The need for adequate resourcing of palliative care services in regional and remote communities is particularly urgent. People living outside metropolitan areas should have equity of access to the care to which they are entitled and have every confidence that their experience of care at end of life will not be determined by where they live.

Access to culturally appropriate care for Indigenous people is also limited in both regional and metropolitan services. Inpatient services need to be able to accommodate larger family networks, with the provision of sufficient space and privacy to enable people to visit their loved one without fear of disturbing others, with access to garden areas, and places for conversation.

In addition, the particular care needs of people with disability, and those for whom English is a second or third language, are not well catered for under our current systems.

There is also a great need for better access to respite care, whether at home (for example through provision of sitters, and particularly night time relief for carers) or as an inpatient. When carers become tired and struggle to cope, the patient is more likely to be admitted to hospital.
RESPONSE TO THE MINISTERIAL EXPERT PANEL VAD DISCUSSION PAPER

At St John of God Health Care we respect and honour the dignity of each person we serve, recognising that life is sacred from conception until natural death. While responding in a sensitive and non-judgemental manner to the needs and requests of patients, St John of God Health Care does not support voluntary assisted dying.

We note, and endorse the principles, as articulated in the discussion paper, when considering care for people at end of life:

- Every human life has intrinsic value.
- A person’s autonomy should be respected.
- People have the right to be supported in making informed decisions about their medical treatment, and should be given, in a manner they understand, information about medical treatment options, including comfort and palliative care.
- People approaching the end of life should be provided with high quality care to minimise their suffering and maximise their quality of life.
- A therapeutic relationship between a person and their health practitioner should, wherever possible, be supported and maintained.
- People should be encouraged to openly discuss death and dying and their preferences and values should be encouraged and promoted.
- People should be supported in conversations with their health practitioners, family, carers and community about treatment and care preferences.
- People are entitled to genuine choices regarding their treatment and care.
- People should be supported in their right to privacy and confidentiality regarding their choices about treatment and care preferences.
- People who may be vulnerable should be protected from coercion and abuse in relation to end of life choices and decisions.
- All people, including health practitioners, have the right to be shown respect for their culture, beliefs, values and personal characteristics.

It is for these same principles that we cannot hold that a desire to respect the intrinsic value of every human life may be regarded as consistent with any action that intentionally and actively seeks to bring about the premature end of such life. We hold that any health care system that presents its community with voluntary assisted dying as a credible choice for care at end of life has failed in its commitment to deliver excellence in care for people at a time in life when they deserve every assistance and support.

RESPONSE TO SELECTED QUESTIONS

- *What safeguards should there be to ensure that a request is voluntary?*

SJGHC contends that it is not feasible to suggest that there is capacity to propose adequate safeguards to ensure that all requests for voluntary assisted dying are indeed made freely.

Further, data currently available confirms that many people struggle to access the care at end of life that they wish to receive, particularly palliative care provided in the home setting, due to
inadequate resourcing and limited availability. It is therefore not feasible to propose that voluntary assisted dying is a free and voluntary choice when access to preferred modes of care cannot be assured in the current setting.

- **Should health practitioners be able to discuss voluntary assisted dying with their patients in the same way they raise and discuss other health or medical decisions and care options?**

Patients continue to place a high degree of trust and confidence in the judgement of health practitioners, particularly medical doctors. People look to health practitioners for information and advice as to what options for care they should choose. This means that a health care practitioner raising voluntary assisted dying as an option for patients, in the absence of the patient initiating any such request for information, would immediately give rise to a conflict with regard to impartial and independent advice, and void the ‘voluntary’ element of any such process.

Voluntary assisted dying is not consistent with excellence in health care and cannot be plausibly proposed as an alternate model of care. The option of voluntary assisted dying is an admission that patients have not been afforded care that meets their physical, psychological, social or spiritual needs, or those of the people caring for them at end of life.

We therefore reject the suggestion that it be permissible for voluntary assisted dying to be proposed by health practitioners as a credible option for care when discussing end of life care choices with patients.

- **Should there be particular consideration given to people who lose capacity after they have started the process?**

Yes. Where people lose capacity to consent to the voluntary assisted dying process it is not reasonable or safe to suggest that the decision to proceed to actively initiate death remains the free and informed decision of the person.

- **If voluntary assisted dying only applies to an illness or disease that is terminal, is specification of a timeframe either desirable or necessary? If a timeframe is to be specified should it be defined as:**
  - reasonably foreseeable outcome of the eligible condition?
  - reasonably foreseeable outcome for this person?

Yes. People need time to understand the range of care and treatment options available to them, and to develop informed choice. Progression of illness or disease may vary markedly from one person to the next, so the provision of time for people to fully understand their diagnosis and anticipated prognosis is an important consideration in any free and voluntary choice of care option at end of life.

The fact that we use language like ‘reasonably foreseeable’ is an acknowledgement that information regarding the course of illness and disease can only serve to guide, rather than predict, the likely experience for patients. Consequently, patients should be afforded every
opportunity to understand their diagnosis and make a free and informed choice with regard to their care.

- **How should the process take community, linguistic and cultural beliefs and practices into account while also ensuring human rights, personal autonomy, privacy and choice? What approaches or initiatives would assist in achieving this balance?**

While the question does not specify religious beliefs and practices, we contend that this is a similar right that any legislation for voluntary assisted dying must recognise. Such recognition must extend to individuals and organisations to exercise the free and voluntary right to object to participate in any activity that conflicts with religious belief or practice.

While S3GHC speaks from its perspective as a Catholic health care provider to the community, we recognise that many people across the community share our concern and opposition to voluntary assisted dying. Members of other faith traditions, and people from culturally diverse backgrounds often choose S3GHC because they trust in our commitment to treat them with respect for the intrinsic value of life and the individual person, especially in moments of great vulnerability in life.

We note and endorse comments by Senator Pat Dodson⁴:

> Where First Nations people are already overrepresented at every stage of our health system, it is irresponsible to vote in favour of another avenue to death. Paving the way for euthanasia and assisted suicide leaves First Nations people even more vulnerable, when our focus should be on working collectively to create laws that help prolong life and restore their right to enjoy a healthy life.

- **Should a medical practitioner or health service that conscientiously objects have an obligation to refer the patient to a practitioner or service that has no objection?**

No. Conscientious objection is a principle that rests on the notion of freedom to refuse to participate in an action based on the beliefs held by an individual or group. It is therefore incompatible to compel a person or group to act in a particular direction as a consequence of exercising conscientious objection. For these same reasons, it is imperative that any person or group exercising conscientious objection be afforded protection from discrimination or unfair treatment as a consequence.

- **Should there be a separate approval and permit process for voluntary assisted dying (over and above any that may relate to the prescription of the medication)?**

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Yes, this would appear to be a critical step in any attempt to provide safeguards to the community, particularly with respect to the protection of highly vulnerable persons where the capacity to establish free and informed consent may be in question.

- Should it be required that voluntary assisted dying is listed as a contributing cause of death on:
  - the Medical Certificate Cause of Death?
  - the publicly available Death Certificate?

Yes. Should the community assent to voluntary assisted dying through legislation enacted by Parliament, the community has a concurrent right to be assured of transparency with regard to the processes giving effect to the legislation, including the strengths and limitations of any safeguarding framework.

The availability of reliable, timely data with regard to the number of people accessing the legislative provision, together with information as to the medical conditions for which it was accessed, ought be regarded as non-negotiable.

**CONCLUSION**

End of life care is an important focus for Catholic health care services like St John of God Health Care. We seek to respect the dignity of each person across the life span, extending care that reflects the wishes and intent of people. At times of particular vulnerability in life, such as end of life, this relationship of respect and preservation of the dignity of each person becomes paramount.

As a provider of health services in the Catholic tradition, SJGHC advocates that any legislative debate intended to govern end of life care be inclusive of provisions to respect the dignity of individual clinicians and Catholic health care providers to exercise conscientious objection should Governments legislate for physician assisted death.

**Dr Shane Kelly MBBS, MBA, MPH, FRACMA, FCHSM, FAIM, FAICD**

**Group Chief Executive Officer**
**St John of God Health Care**

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