

Submission

Ministerial Expert Panel on Voluntary Assisted Dying Discussion Paper

31 May 2019

BACKGROUND

The Aboriginal Health Council of WA (AHCWA) is the peak body for 23 Aboriginal Community Controlled Health Services (ACCHSs) in Western Australia. The ACCHSs are located across geographically diverse metropolitan, rural, remote and regional locations. AHCWA exists to support and act on behalf of our 23 Member services, actively responding to the individual and collective needs of AHCWA members. The principal vision of AHCWA is for Aboriginal people in Western Australia to enjoy the same level of health and wellbeing as all Western Australians. ACCHSs deliver services in response to a complexity of health, prevention, early intervention, and social and emotional wellbeing issues across the lifespan.

In August 2018, the Joint Select Committee on End of Life Choices released its report *My Life, My Choice* which outlined recommendations on strengthening and adapting the health system to deliver end of life and palliative care. In November 2018, in response to these recommendations, the Minister for Health, the Hon. Roger Cook MLA, announced the Government will introduce legislation into Parliament to enable Voluntary Assisted Dying in Western Australia. A Ministerial Expert Panel was convened to advise on the issue and to steer consultations with stakeholders.

AHCWA and its member services welcomes the opportunity to provide advice on the Ministerial Expert Panel's Discussion Paper. AHCWA understands that consultation will inform the drafting of Voluntary Assisted Dying legislation to be considered by the Western Australian Government in the second half of 2019.

AHCWA provides this advice in good faith and on the understanding that, should legislation on Voluntary Assisted Dying be passed, the Government will consult meaningfully with ACCHSs on the design, implementation and delivery of culturally appropriate and safe Voluntary Assisted Dying practices. This should include, but is not limited to, a comprehensive education and information campaign to be undertaken by the State Government to ensure that Aboriginal people and their communities understand the significance and potential impact of any potential legislation.

A key question raised by the discussion paper is 'how should the (Voluntary Assisted Dying) 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?'. The content of this submission aims to address this important question.

THE GUIDING PRINCIPLES

AHCWA and its member services are committed to ensuring that culturally appropriate health care is available to all Aboriginal people, their families, carers and communities across Western Australia. Health services must fully appreciate and understand the unique needs and differences of Aboriginal people across metropolitan, rural and remote communities, throughout WA. New directions in health care must also consider these needs, and it is recommended that this is reflected by the Guiding Principles underpinning Voluntary Assisted Dying.

Central to the way that ACCHSs provide services to Aboriginal people, their families and communities is the ACCHS Model of Care. It is a holistic model which guides the provision of health and well-being services to Aboriginal people within a broader context of culture, family, community, country, language, physical well-being, emotional well-being, and spiritual well-being. Each of these elements is fundamental to the health and well-being of Aboriginal people, their families and communities.

Integral to the ACCHS Model of Care is:

- an Aboriginal workforce delivering primary health care;
- a commitment to involving community members in service provision;
- a multidisciplinary team approach ensuring the complex care needs of Aboriginal people are met; and
- the provision of a culturally safe environment where Aboriginal people feel welcome, understood and empowered.

The ACCHS holistic model of primary health care delivers whole-of-life care, which involves responding to the needs of the whole person and includes family and significant others in health care decisions and treatments. This whole-of-life, whole-of-family approach ensures delivery of culturally secure health services.

ACCHSs consistently report that mainstream health services do not provide health services that are culturally secure, and lack the cultural understanding and knowledge which is so important to building trusting relationships with Aboriginal people. ACCHSs' clients report experiences of racism and cultural bias when accessing mainstream health services. These experiences are often compounded when it comes to end of life matters and decisions for Aboriginal people.

Culturally secure health services across the life span are critical to the planning, development and implementation of all aspects of health service delivery, including services and approaches for assisting Aboriginal people to make informed end of life choices.

Comments on the Guiding Principles

AHCWA and its member services support the Guiding Principles underpinning Voluntary Assisted Dying outlined in the Discussion Paper with the following comments:

- AHCWA and its member services support the human rights of individual choice and self-determination in relation to health which underpins the Discussion Paper's principles that 'a person's autonomy should be respected' and that 'people are entitled to genuine choices regarding their treatment and care'.

- AHCWA and its member services support the principle which states; ‘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’. However, AHCWA recommends that greater emphasis is required to ensure that culturally appropriate information about Voluntary Assisted Dying is made available to Aboriginal people, families and communities.
- AHCWA and its member services support ‘people should be encouraged to openly discuss death and dying and their preferences and values should be encouraged and promoted’.
- AHCWA and its member services support the Guiding Principle stating ‘people should be supported in conversations with their health practitioners, family, carers and community about treatment and care preferences’. This principle aligns with the ACCHS Model of Care and the collaborative approach to decision making by Aboriginal people, their families and communities. The family is the prime support system providing care; physically, culturally, spiritually and emotionally. Family provides Aboriginal people with the strength to be who they are and links them with their ancestors; with the past, present and future. Understanding the importance of family to Aboriginal people is vital to their holistic wellbeing.
- AHCWA and its member services support that ‘all people, including health practitioners, have the right to be shown respect for their culture, beliefs, values and personal characteristics’.
- With regard to all the issues being considered, AHCWA and its member services strongly supports the direction of the Ministerial Expert Panel to maintain a careful balance between personal autonomy and appropriate safeguards for people who may consider the option of Voluntary Assisted Dying in the future.

THE PERSON

- AHCWA and its member services support the recommended age and residence eligibility criteria for Voluntary Assisted Dying in the Discussion Paper.
- While each case of Voluntary Assisted Dying will be assessed individually, it is important to note that providing care and support to Aboriginal people considering end of life options requires an individualised approach in the context of their cultural background, beliefs, views and experiences. Aboriginal identity is necessarily interconnected with family, community, the body, emotional well-being, spiritual well-being, language, culture and country.

THE DECISION

AHCWA and its member services support that a decision to access Voluntary Assisted Dying must be voluntary, properly informed, made by a person that has capacity, is current and enduring, and specific to Voluntary Assisted Dying.

Voluntary Decision Making

- The Ministerial Expert Panel’s acknowledgment that some cultures have a collectivist approach to decision making, is vital to understanding how Aboriginal people may choose end of life care. Any guidelines or legislation for Voluntary Assisted Dying must make it clear that autonomous,

voluntary decision making for Aboriginal people is not precluded by a collectivist approach, and should be accepted.

- Clinicians must also be aware that the way Aboriginal people and their families make decisions will differ from individual to individual. This cultural awareness on behalf of clinicians will assist Aboriginal people, families and communities to make choices about their end of life care in alignment with culture.

Decision making should be properly informed

- AHCWA and its member services agree individuals are entitled to understand all end of life options available to them. In particular, there is strong support from ACCHSs that increased funding and education should be directed towards palliative care and Advanced Health Directives.
- While the option of Voluntary Assisted Dying is acknowledged as an end of life option, AHCWA and its member services **do not support** that clinicians should be able to initiate a discussion about Voluntary Assisted Dying with Aboriginal people. This position is based on the following points:
 - Clinicians often use complex medical terminology when discussing treatment options with Aboriginal people. Often this language is not fully understood by Aboriginal people due to language differences, particularly if family members or other support persons are not present at the discussion. This results in the real risk that Aboriginal people may consent to something they don't fully understand.
 - There is also the issue of the disparity of power between a doctor and Aboriginal people; Aboriginal people will often agree with a doctor's advice even if they are not happy with it as they can feel overpowered in the doctor-patient relationship.
 - Despite the appropriate, ethical intent of the health practitioner initiating a discussion of Voluntary Assisted Dying, Aboriginal family members or their community may perceive that undue influence was put on the person to consider this option. This misconception can lead to the risk of blame or 'payback' being carried out against the practitioner or their service for suggesting Voluntary Assisted Dying.
 - There are certain things in Aboriginal culture that are prohibited from doing or talking about. For some Aboriginal people, Voluntary Assisted Dying may not be acceptable to even talk about or consider.
 - A tension exists between the ACCHS Model of Care which promotes healing through early intervention, prevention and holistic care, and Voluntary Assisted Dying which allows and facilitates the end of life.
- AHCWA and its member services strongly recommend that information about all end of life choices, including advanced health directives, palliative care and Voluntary Assisted Dying, is accessible and culturally secure for all Aboriginal people.
 - There are over 90 Aboriginal language groups and dialects in Western Australia, and English, if spoken, is often not an Aboriginal person's first, second or third language.
 - There are English language terms which have no meaning for Aboriginal people and discussions around end of life care must take this into account. For example, even the term 'end of life' is not one that Aboriginal people would use or necessarily recognise as applying

to them or their circumstances. Discussing end of life choices with Aboriginal people in medical terms may not be appropriate.

- Information on end of life choices must be culturally secure. Culture encompasses values, beliefs, customs and practices that are central to the health and wellbeing of an Aboriginal person. Culture is not only to be acknowledged by health providers; it is to be engaged with and respected.
- For example, clinicians may need to ensure that carers, family members or support workers are available to explain care options in the Aboriginal person's terms and in alignment with their cultural beliefs.

A person must have capacity to make the decision

- AHCWA strongly supports a person being assessed for their decision making capacity as an important safeguard for Voluntary Assisted Dying. The Discussion Paper states that clinicians need to be educated, trained and supported in assessing for capacity.
- AHCWA and its member services reiterate the need for assessors to be aware of culture when assessing decision making capacity specific to Voluntary Assisted Dying for Aboriginal people.

ELIGIBLE CONDITIONS

- Large numbers of Aboriginal people live with chronic disease and it is conceivable under proposed legislation that they may be eligible for Voluntary Assisted Dying.
- AHCWA and its member services recommend that careful consideration is given to the inclusion of chronic disease within the eligibility criteria for Voluntary Assisted Dying, and that any legislation provides clear direction for doctors assessing the prognosis and suffering of a person living with chronic disease.
- If large numbers of Aboriginal people with chronic disease are eligible for and choose Voluntary Assisted Dying, the WA Government must be aware of the ramifications this will have for grief and continuity within Aboriginal communities. There may be a significant increase in demand from ACCHSs to provide social and emotional well-being support which, in turn, may require funding support from the Government.

THE PROCESS

Use of a navigator and other resources to improve access

- The Ministerial Expert Panel's acknowledgment that, in some communities, an association with Voluntary Assisted Dying may impact the community's trust in the local health practitioner or health service, is very applicable for Aboriginal communities. In particular, there is a risk that palliative care services, that have established respectful and trusting relationships with Aboriginal families and communities, may be negatively impacted by the introduction of Voluntary Assisted Dying.
- The panel's suggestion that a team of navigators be established to assist people in their end of life decision making is supported. However, AHCWA and its member services strongly

recommend that these positions are provided to Aboriginal people and that appropriate training and ongoing support is provided. AHCWA needs to be involved in the planning, design and implementation of any navigator program.

- AHCWA supports the Discussion Paper's proposal to have a telephone access line, community education and resources to assist people considering Voluntary Assisted Dying but also strongly recommends all potential participants must be provided with face-to-face advice. This reduces the risk of misinformation, poor understanding and the potential for community backlash.

Conscientious Objection by clinicians

- The option for health services to contentiously object to providing Voluntary Assisted Dying assessment and intervention is strongly supported in any proposed legislation. It is important that any legislation clearly determines if a service is able to apply a blanket objection to providing Voluntary Assisted Dying on behalf of all its clinicians, or if individual clinicians can be exempt from a service's blanket objection if they contentiously approve of Voluntary Assisted Dying.
- Should legislation be passed, ACCHSs within AHCWA's membership will have to carefully consider if they are prepared to provide this service. For the ongoing maintenance of necessary therapeutic relationships between ACCHSs and their local communities, access to external doctors must be available.
- Any doctor, whether supportive of Voluntary Assisted Dying or not, must be sensitive to the client and their family, and provide comfort and reassurance at all times.

Compulsory cultural competence for health professionals

- It is likely that some Aboriginal people who choose Voluntary Assisted Dying may not be assessed or cared for by an ACCHS. It is, therefore, essential that all health professionals involved in the Voluntary Assisted Dying process are culturally competent, and this would necessarily involve cultural competency training being undertaken. AHCWA and its member services would strongly support that cultural competency training should be face-to-face rather than through an on-line learning portal.
- Cultural competency is also essential for mainstream inpatient services providing Voluntary Assisted Dying. Rules of hospitals and mainstream health services, including numbers of visitors, times of visits and requirements around what can or cannot be brought in for patients, represent barriers for Aboriginal people in gaining access to and receiving culturally secure health and end of life services. These rules represent barriers for Aboriginal people to make informed, end of life decisions and choices.
- A key element for cultural competence for health professionals is an awareness of the Spiritual determinant of social and emotional well-being. Spirituality is identified as being the most essential requirement for health as the spiritual essence of a person is their life force. The Spirit determines Aboriginal people as individuals and as a collective, who and what they are, where they have come from and where they are going; key considerations at the end of life.
- Clinicians working with Aboriginal people in remote and very remote areas must understand the communities in which they live may adhere to very strong cultural traditions and beliefs. For

example, some issues may only be ‘men’s business’ or ‘women’s business’ and it’s essential that this is respected by the clinician involved.

The importance of being on country

- Central to the identity of Aboriginal people is connection to country; they are linked to the land through birth, ancestors, culture and identity. Aboriginal lore and spirituality are heavily intertwined with the land and being on country.
- If Voluntary Assisted Dying is an option for an Aboriginal person, priority needs to be given to a patient journey which enables their preference for dying on country or in a health facility of their choice. For example, Aboriginal people who live in rural, regional or remote locations must not be compelled to travel to Perth.
- Being away from home and country can lead to stress and anxiety, and contributes to an unhealthy state of mind, body and soul. Aboriginal people choosing Voluntary Assisted Dying must be supported to plan for their death to occur on country.

Administering Voluntary Assisted Dying

- The Discussion Paper proposes that medication to facilitate Voluntary Assisted Dying be self-administered; a doctor may be able to administer the medication if the person is physically unable to do it themselves. The paper also proposes that unused medication be returned to the pharmacist by a designated contact person, thus implying the potential for excess medication being dispensed.
- As Aboriginal families often live together, with multiple generations sharing the same house, there is a safety concern about the unregulated presence of highly harmful medication in the home. Careful consideration about potential safeguards for this is essential. One option would be to mandate that a medical professional is in attendance to supervise, remove and store the unused medication.

DEATH CERTIFICATION

- It is not clear from the paper if any consideration has been given to how insurances (for example, life insurance) is effected by a person’s decision to accept Voluntary Assisted Dying.
- It is the experience of ACCHS that life insurance is often not paid if a person has taken their own life. It is suggested that consideration is given to how a death may be certified and documented and the effect this has for the validity of life insurance policies.

RECOMMENDATIONS FOR IMPLEMENTATION

ACCHS are committed to end of life choices, continually calling for more funding for palliative care, and encouraging clients to talk more about their wishes.

AHCWA and its member services call for genuine co-design and collaboration on implementation of Voluntary Assisted Dying practices. This must include:

- developing appropriate and culturally secure information;

- ensuring cultural competence for practitioners;
- providing support for ACCHS who may decide to conscientiously object to providing Voluntary Assisted Dying services; and
- developing support frameworks for the families and communities of Aboriginal people who may choose Voluntary Assisted Dying.

Meaningful dialogue with AHCWA, ACCHS's, Aboriginal people and communities is essential to developing end of life services and resources in Western Australia. AHCWA and its member services must be at the forefront of any discussion, and AHCWA offers to bring together all ACCHS, to develop culturally secure approaches for end of life health care matters, with and for Aboriginal people.