Victoria First Peoples’ Consultation:   
Five-year review of the operation of the *Voluntary Assisted Dying Act 2017*

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First created May 2024

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**Suggested citation:** Arabena K., Onademuren, J., Penny, L. & Pittaway, S. 2024. *Victoria First People’s Consultation: Five-year Review of the Operations of the Voluntary Assisted Dying Act 2017*, Karabena Consulting, Melbourne.

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**Acknowledgements:** We acknowledge the Traditional Owners of the Lands on which we live, work and play. It is an honour to grow our families on your Country, the place of your ancestors. As is our culture, we pay respects to Elders past and present. We extend thanks to Aboriginal and Torres Strait Islander people everywhere for your strength, courage and resilience. We also acknowledge our friends, families and allies for giving true value and meaning to the words ‘our fellow Australians’. We are all the richer for our relationships.

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**On the matter of voluntary assisted dying:**

***‘...the two questions we need to ask is, firstly, if we're [the dying patient] not able to talk for ourselves, then who's going to talk for us? The second question is, ‘and would they [the person talking on our behalf] know what we would want?’ If we can't answer those two questions, then we're leaving our death in the hands of staff, in clinical hospitals, our families and friends, rather than ourselves. So we have to be able to answer those two questions. Who would we ask? And would they know what to say?’***

# 

# Executive Summary

To evaluate the first four years of the Victorian *Voluntary Assisted Dying Act 2017*, Karabena Consulting was engaged by the Centre for Evaluation and Research Evidence (CERE) to conduct culturally sensitive data collection with Aboriginal and Torres Strait Islander people. Focusing on experiences with death, dying, and voluntary assisted dying (VAD) accessibility, key questions addressed how VAD systems meet First Nations peoples' needs, barriers to compliance, and the safety and compassion of VAD processes. We interviewed 13 stakeholders, and data were analysed using Indigenous research methodologies including Dadirri and yarning. The findings significantly enhance understanding of the legislation’s impact on Victoria’s First Peoples.

The evaluation reveals that the current transactional and impersonal nature of end-of-life care does not align with the cultural values and needs of First Nations communities. It highlights the necessity for more culturally respectful and inclusive approaches, advocating for Aboriginal-led VAD processes to ensure appropriate practices and build trust. The importance of self-determination and autonomy in end-of-life decisions was raised, with a call to respect individual rights and wishes, which often conflict with medical interventions and are often denied because the family are ‘***not prepared to let someone go***’. Additionally, significant resource allocation gaps, particularly the absence of Aboriginal death and dying navigators and support personnel (death doulas), need addressing to improve accessibility and effectiveness of VAD services. Incorporating healing processes into end-of-life care is important for patients, their families, and communities to address past traumas and promote collective healing.

Focusing on quality of life and death, with comprehensive and respectful care options, is necessary for ensuring dignified and peaceful endings. Revitalising and integrating Aboriginal stories and traditions around death can help communities better understand and embrace end-of-life concepts. The narratives and language used by end-of-life practitioners, including palliative care professionals and those involved in the VAD process, are indispensable in shaping the experiences of individuals facing terminal illnesses. However, these narratives often focus on clinical efficiency and risk reduction, meeting legislative requirements rather than providing culturally sensitive care. The opportunity to engage in cultural practices is limited because VAD and end-of-life practitioners are not asking if people identify as Aboriginal and Torres Strait Islander consistently and have no cultural capacity to respond to ceremonial requirements over clinical processes at this point in time. A strong clinical focus can inadvertently create a cold and impersonal atmosphere, particularly for Aboriginal and Torres Strait Islander people who value relational and community-based approaches to care.

For many Aboriginal and Torres Strait Islander individuals, the process of seeking a VAD permit can be distressing and triggering, especially for those who have faced lifelong discrimination and are members of the Stolen Generations. The requirement to obtain permission from a non-Indigenous authority to end one's life evokes deep-seated trauma and feelings of disempowerment. As one participant noted, ‘***Imagine having to ask permission to die from the very system that once denied your right to live as an Aboriginal person***’. This statement encapsulates the pain and indignity felt by those who must navigate a system that has historically oppressed them.

The current end-of-life narratives and practices fail to acknowledge and accommodate the cultural needs and histories of Aboriginal and Torres Strait Islander peoples. The language of ‘permits’, of being clinically ‘assessed’, and strict adherence to legislation often neglects the importance of culturally caring practices that honour the individual's cultural identity and life experiences. These insights form the foundation for tailored recommendations that respect cultural values, enhance self-determination, ensure adequate resources, and promote holistic and dignified end-of-life care for Aboriginal and Torres Strait Islander peoples.

## Recommendations

To provide truly compassionate and respectful end-of-life care, these narratives must change. Practitioners could adopt a more culturally sensitive approach that prioritises relational care, community involvement, and the emotional and spiritual needs of the person. The following recommendations are categorised into short-term, medium-term, and long-term actions to ensure immediate, sustained, and future improvements in culturally sensitive end-of-life care.

### Short-term Actions (0-1 year)

*Inform people about their rights to VAD so people know to ask for this as an option.*

1. **Enhance Education and Awareness about VAD:** Develop and disseminate culturally tailored educational materials that explain VAD and the availability of this option. Use stories, case studies and testimonials from within the community to make the information more relatable and less intimidating.
2. **Train and Employ Aboriginal Health Workers in VAD Processes:** Invest in training for Aboriginal Health Workers to specialise in VAD processes, ensuring that they can advocate effectively for patients and guide them through the VAD process with understanding and respect for cultural values.
3. **Promote Open Conversations About Death and Dying:** Organise community forums and discussion groups to talk openly about death, dying and VAD. These should aim to reduce stigma and fear associated with talking about death and promote a more supportive environment for discussing end-of-life choices, as well as alerting people to the necessity of advance care planning.
4. **Inclusive Language Guidelines:** Develop and distribute guidelines for using inclusive and culturally sensitive language in end-of-life care communications and documentation.
5. **Community Consultations:** Conduct regular consultations with Aboriginal and Torres Strait Islander communities to gather input and feedback on VAD processes and ensure their voices are heard and respected.
6. **Cultural Safety Audits:** Perform audits of current VAD practices and environments to identify and address areas lacking cultural safety.

### Medium-term Actions (1-3 years)

*Develop a culturally competent workforce, who can facilitate ceremonial and clinical end-of-life practices.*

1. **Develop Cultural Safety Training for Health Care Providers:** Provide cultural safety training for all health care providers involved in end-of-life care, focusing on understanding and respecting Aboriginal cultural practices and values. This training should help providers recognise the importance of a holistic approach that includes physical, spiritual and community health.
2. **Establish Aboriginal-led Support Teams:** Create support teams consisting of Aboriginal Health Workers, spiritual advisors, and community Elders to assist patients and families through the VAD process. This team would ensure that all aspects of the patient's cultural, spiritual and emotional needs are met.
3. **Holistic Care Models:** Develop and implement holistic care models that integrate physical, emotional, spiritual and cultural aspects of end-of-life care.
4. **Advance Care Planning Workshops:** Organise workshops on advance care planning and VAD options, led by Aboriginal Elders and health professionals, to educate and empower communities.

### Long-term Actions (3-5 years)

*Work with services to ensure Aboriginal-centric end-of-life VAD can be delivered in line with Treaty aspirations for self-determination across a person’s entire life, including their death.*

1. **Advocate for Policy Changes to Support Culturally Safe VAD:** Work with policymakers to adapt VAD legislation and health care practices to be more inclusive and reflective of Aboriginal cultural practices and values. This could involve amendments that allow greater family involvement and community consultation in the decision-making process.
2. **Incorporate Traditional Practices and Rituals:** Encourage and facilitate the inclusion of traditional Aboriginal practices and rituals in the end-of-life care plan. This could include ceremonies, storytelling, or other culturally significant activities that honour the patient's life and heritage.
3. **Improve Access to Pain Management Resources:** Ensure that all patients have access to effective pain management options, including VAD if chosen. This involves training more health care providers in pain management techniques and ensuring that these resources are readily available in Aboriginal communities.
4. **Sustainable Funding:** Secure sustainable funding for Aboriginal-led VAD programs and initiatives to ensure their long-term viability and success.
5. **Regular Review and Feedback Mechanisms:** Implement a system for regular review and feedback involving community members to continuously improve the cultural appropriateness and effectiveness of VAD services offered to Aboriginal people.
6. **Research and Evaluation:** Conduct ongoing research and evaluation to monitor the effectiveness of implemented changes and continuously improve VAD services for Aboriginal and Torres Strait Islander communities.

## Conclusion

These recommendations aim to enhance the support for Aboriginal and Torres Strait Islander peoples in accessing VAD. By addressing educational needs, enhancing cultural safety, establishing supportive structures, advocating for policy changes, incorporating traditional practices, improving pain management resources, and ensuring regular community feedback, we can create a more inclusive and respectful end-of-life care system. This approach will help mitigate the distress and trauma experienced by those who have faced discrimination, such as members of the Stolen Generations, ensuring their end-of-life journey is dignified and culturally appropriate.

# Introduction and Methodology

To comprehensively evaluate the first four years of the Victorian *Voluntary Assisted Dying Act 2017* (the Act), the Centre for Evaluation and Research Evidence (CERE) engaged Karabena Consulting, a Torres Strait Islander woman-owned and led organisation. Karabena Consulting was tasked with leading culturally sensitive data collection with Aboriginal and Torres Strait Islander people and service providers. With a deep understanding of cultural nuances, and because of the recent work supporting Aboriginal and Torres Strait Islander people through their cancer journey, Karabena Consulting completed consultations focused on Aboriginal and Torres Strait Islander people’s experiences of death and dying, and the accessibility of voluntary assisted dying (VAD). Our consultations focused on the following questions:

1. To what extent do VAD systems, processes, and practices meet the needs of First Nations communities?
2. What were the barriers and enablers to First Nations compliance, understanding, and operation of the Act?
3. To what extent were VAD systems, processes and practices timely, safe and compassionate for First Nations communities?

The outcomes will significantly contribute to the evidence on the appropriateness, effectiveness, and impact of the Act's operations for Victoria’s First Peoples. We interviewed 13 stakeholders using semi-structured, open-ended questions, maintaining confidentiality and respecting cultural sensitivities. We developed flyers and reached out to individuals we had engaged through projects related to culturally safe cancer care, as well as members of the community who had experienced the loss of loved ones. We spoke with men and women both online and face-to-face, including those whose family members, partners and children had passed away in hospitals, palliative care facilities, and at home. Most people's experiences were framed by a hospital context. We also spoke with family members caring for parents who wanted a 'self-determined death' and wished to die at home. Additionally, we engaged staff working in palliative care, funeral homes, pharmacists, and Statewide VAD Care Navigators.

As a result of the VAD workshop with Elders at a community organisation, these professionals have been invited to conduct a workshop on advance care planning and VAD options. These are important, though rarely discussed, educational programs needed in the community. Thus, the project achieved both evaluation outcomes and community education outcomes.

In large part, these outcomes can be attributed to the use of Indigenous research methodologies, including Dadirri (deep listening) and yarning (informal two-way conversation). These methods ensure the integrity, respect and safety of Aboriginal and Torres Strait Islander people throughout the consultation process. Data from interviews were audio-recorded, transcribed, and analysed using inductive thematic analysis techniques.

# Experiences of Death and Dying

The experiences of death and dying among First Nations peoples are deeply influenced by cultural, spiritual and historical contexts. This section explores the various dimensions of end-of-life care for Aboriginal and Torres Strait Islander communities, highlighting the importance of culturally sensitive practices, the role of family and community, and the need for healing and dignity in end-of-life processes. By integrating quotes from stakeholders, we aim to provide a nuanced understanding of how VAD can be approached in a way that honours the values and traditions of First Nations peoples. This exploration highlights the necessity for an enabling environment that respects individual autonomy, promotes informed decision making, and addresses the complex emotional and cultural layers involved in end-of-life care.

## End-of-life care disparities

Disparities exist in access to both end-of-life care and resources, influenced by geographical location and socioeconomic status. Achieving equitable support for all individuals necessitates addressing systemic barriers to ensure universal access to comprehensive care options.

## Trauma and colonisation

There are lingering effects of trauma and colonisation on Aboriginal and Torres Strait Islander communities' experiences of death and dying. There needs to be acknowledgment and redress of historical injustices while advocating for culturally sensitive end-of-life care practices that respect Aboriginal and Torres Strait Islander perspectives and traditions.

## Role of family and community

Our evaluation found that for Aboriginal and Torres Strait Islander people, within the context of VAD, families and communities have not been allowed to be part of the process of having open communication, understanding, and respect for individual choices within familial and cultural contexts. Stakeholders noted that a major reason why there is a low uptake of VAD among Aboriginal and Torres Strait Islander people is because these conversations are not happening early enough.

One participant expressed, ***‘I think we all need to be on the right page and have the best interests of the patient at heart. And then I don't think we can go wrong, to be honest, if we're on the same page, but thinking about the best possible care for that patient’****.*

Another shared, ***‘Sometimes us the living ones hold on to the person that's passing so they know that that person is hanging on and until they're okay, they're not going to go. So I think with voluntary assisted dying, I think that it's not just about the person that is about to pass, it's about everyone around them and they need to be able to understand it and give their permission for that person to pass as well. And then I think it’s a much easier passage for them to do what they need. So I'm all for it, to be honest. I'd never ever want to see, I've seen a few people… when [they] passed in so much pain, so I think that when, you know, if you’re still of the right mind, well then you need to be able to make that decision’****.*

## Cultural beliefs, spirituality and religious influences

Cultural and religious backgrounds among Aboriginal and Torres Strait Islander communities significantly influence their attitudes towards VAD. Stakeholders noted spirituality is important in how individuals and communities perceive and handle end-of-life decisions rather than systemic processes or practices. The community argued it needs to reclaim spirituality to cope with the fear surrounding death, particularly when considering VAD.

One participant emphasised, ***‘I think people need to understand that when you are passing, your loved ones that are in spirit will be there to help you cross over as well. And I think a lot of people are scared of that, those ideas and those sorts of things, but it is really, really something that's real’****.*

Another reflected on cultural traditions: ***‘For a really long time, like going back to when I was a kid, there was this notion that Dad had, that when your time is up, you accept it. And, and I think that acceptance helped us when he was dying because we knew he knew his time was up and could accept it. I was reading a story about Dad’s great-great-grandmother recently, and she'd said that when an old person in the area that she came from knew they were close to death, they would go and lie down next to where they were going to be buried. It was just that acceptance and that's something that Dad had.’***

Additionally, another participant discussed the importance of spiritual guides: ***‘Maybe there’s a journeyman somewhere in the culture who comes in and says, listen I’m going to help you mob go through this journey. And they take them out of the bush and sit out there knowing time’s getting near.’***

The integration of cultural beliefs and practices into end-of-life care is important. One participant mentioned, ***‘I think there's a medical way of doing things and then I also think we've got our spiritual way of doing things that can be blended in a really beautiful, safe way and a really… one for everyone to have the healing. Because when spirit leaves, there's a part of us that dies and grieves and goes with them and vice versa. So I think it can help and by talking or whether there's smoking or there's music or conversation, something that will change that for everyone to help, but I really think it's, you got to talk about it early’.***

## Stakeholder insights on choice and control

Our evaluation highlighted the importance of choice and control in end-of-life care from an Aboriginal and Torres Strait Islander perspective. Participants suggested the need for expanded options and choices, including natural and alternative methods.

One participant pointed out, ***‘People are not knowing [the] choice. They’re not even knowing [the] choice about how to bury someone differently… and some people have got all these different ways of thinking about it. I just noticed being a part of the funeral service… people don't know that they have [a] choice’.***

Another reflected on personal autonomy, ***‘I thought about it. I don’t know if I want to donate my organs now… and you know that’s pushed into people a lot about donating organs and you’re doing a better thing, but how do you keep intact about your own spirituality? We shouldn’t be made to sort of feel guilty about we’re going to take our organs with us, we should be able to make it, it’s just a whole part of the package. How do we want to go? If we’re making decisions about giving up our organs, we need to talk a bit more about that as well… That could be the time to go, what about voluntary death? That should be brought up in there… It’s about the person, not what we can get from you when you’re gone, it’s actually how do I go in a peaceful manner? And I need to be in control about that’.***

Our evaluation revealed the need to prioritise cultural safety and respect for diverse traditions and beliefs in end-of-life care, particularly from an Aboriginal and Torres Strait Islander viewpoint. Equitable support and the integration of cultural practices are critical for ensuring comprehensive and respectful care experiences for all.

## Improving VAD service experience for First Nations people

Some stakeholders believe that creating an enabling environment that facilitates informed decision making is key for First Nations people seeking advice, support or information about this particular way of dying. They suggested it would be beneficial for individuals at the end of their lives to have a dedicated professional to guide these discussions while respecting the autonomy and cultural values of the person involved. These meetings would allow family members to come together, understand the wishes of their loved ones, and determine how they can support them. This approach helps address any potential misconceptions or concerns, ensuring that the individual’s decisions are respected and supported. Additionally, it addresses the cultural and emotional complexities involved in discussing end-of-life decisions, especially in communities where stoicism and resilience are highly valued traits.

One stakeholder stated, ***‘Someone should have a conversation with them, even though it's going to be their decision’.***

Another shared, ***‘VAD needs to be an option. You know, it's like it can be really hard, but when we [Aboriginal Hospital Liaison] go into an appointment with a patient and it's not looking great for them … and the doctors want to cure or they want to do their thing. A couple of times when I've been in appointments and the doctor said, ‘you can do this or you can do this, these are the side effects of this treatment, these are the side effects of this one’, and I've actually turned around and said to the patient, ‘the other option is always that you could do nothing’. Because doctors, they just don't say that and a lot of mob will just go along with it because that's what the doctor said. And it's a shame job if you question them. And I think that there needs to be, you know, more widely known that you don't have to do what the doctor says’.***

## Healing trauma

It is key to incorporate healing into end-of-life processes, not only for the patient but also for those surrounding them. Witnessing loved ones' suffering and navigating the health care system is traumatic. The opportunity to have open dialogue and support to address past traumas and promote healing in end-of-life care is required.

One participant mentioned, ***‘It’s also healing. If we had such traumatic lives, it still can be a part of the healing process if we can control how we go. If we can make our families feel good and make them feel fine, you know, it's OK, I know what's happening and this is what I want, and all I want is to be assisted in how to go and that shouldn't be a real medical trauma’.***

Another noted*,* ***‘If we talk about it as in healing, it’s not just that person that is about to pass. It’s everyone that’s involved with that person’.***

A further reflection was, ***‘I think it is truly about that healing side of things because, you know, you hear a lot, especially men will say ‘I’m not scared about dying’… but when it comes to the nitty gritty, [people] are scared of being scared of passing which is really understandable. You know, no one really wants to die to be honest. But if that healing process has started, where they are able to start their healing process about passing away, I think that plays a big part in it too. So I think that, you know, there needs to be that work done with people that may be able to use this VAD. And I think that's really important to be able to have that, I suppose, that pre-passing but then after the passing as well, there needs to be a lot of work done as well’.***

## Quality of life and death

We need to focus on the quality of life and death, so that people can have peaceful and dignified endings. It is necessary to have comprehensive end-of-life care options that prioritise individual preferences and values, ensuring that individuals can die with comfort and respect.

One stakeholder observed, ***‘We do have our elderly people who are older and frail but then actually diagnostically have [nothing] wrong with them, and then they still can't access [care]. I've been almost like everybody else, but I've been pretty fit and strong my life. And it's not ever something that I would have contemplated until, until I got what I've got’.***

Another shared, ***‘…Watching people not have quality of life… we need to be in control of how we die’.***

A particularly heartfelt account was, ***‘[The nurse] had been giving her… some drug to assist with there not being pain when you are in the last week or so of dying. But she was still breathing but she wasn't there. And she was like skeletal. It was terrible. It was like she was frozen in time. And all you could hear was this gurgling noise, which was her dying, which was fucking awful. I think, if it's possible for assistance when you're like that, just do it’.***

Our evaluation shows the need to promote cultural safety and respect for diverse traditions and beliefs in end-of-life care, particularly from an Aboriginal and Torres Strait Islander viewpoint. Equitable support and the integration of cultural practices are required for ensuring comprehensive and respectful care experiences for all.

# Implications for VAD and First Peoples in Victoria

In considering the Act and other legislation in Victoria, it is vital to prioritise cultural perspectives in end-of-life care for Aboriginal and Torres Strait Islander peoples. Cultural safety must be ensured, respecting diverse traditions and beliefs surrounding death. Stakeholders argued for expanded options and choices in end-of-life care, including natural and alternative methods.

Creating an enabling environment that facilitates informed decision making is needed. Dedicated professionals should guide these discussions, respecting the autonomy and cultural values of the individuals involved. This approach allows family members to come together, understand their loved ones' wishes and support them, addressing potential misconceptions or concerns and ensuring that the individual's decisions are respected and supported.

Healing should be incorporated into end-of-life processes, not only for the patient but also for those surrounding them. Witnessing loved ones' suffering and navigating the health care system can be traumatic, so open dialogue and support to address past traumas and promote healing in end-of-life care are important. Focusing on quality of life and death is needed to ensure individuals can have peaceful and dignified endings. Comprehensive end-of-life care options should prioritise individual preferences and values, allowing individuals to die with comfort and respect.

Challenges in navigating end-of-life care include access to appropriate services, managing pain and symptoms, and addressing individual preferences and needs. Improved support systems are needed to address these challenges. Additionally, revitalising and teaching Aboriginal stories and traditions around death, which are rich with lessons about life’s responsibilities and the cycle of life, would help communities understand and integrate the concept of death more widely.

By addressing these considerations and incorporating them into the operationalisation of the Act and other legislation, we can ensure that end-of-life care for Aboriginal and Torres Strait Islander peoples in Victoria is respectful, dignified and culturally appropriate.

# Project Findings – Emerging Themes

## VAD systems, processes and practices

**To what extent do VAD systems, processes and practices appropriately meet the needs of First Nations communities?**

### Transactional end-of-life care

Aboriginal stakeholders were of the view that the current VAD systems, processes and practices do not fit well with the cultural values of First Nations communities. They pointed out that the current approach to end-of-life care is too transactional/business-like and impersonal. It does not respect the cultural and personal connections that are important in Aboriginal traditions. For them, the VAD practices do not create a safe and welcoming space for Aboriginal people, often ignoring the important role of community during this critical time. A stakeholder recalled:

***‘...it's still very transactional, which is the Western consciousness. It's incredibly, you know, transactional and linear… everything was medical. There was no sense of relationships or so, for me, that is not culturally safe. Because you have to have those around you that journey through that with you. Despite the compassion and the understanding. I don't consider that very cultural now.’***

Our evaluation shows a clear need to change how end-of-life care that may potentially lead to engaging in VAD is handled to make sure it respects and includes the cultural needs of Aboriginal communities.

### Aboriginal-led VAD processes

A prominent theme from the discussions was that the VAD systems, processes and practices are insufficient because they lack Aboriginal leadership. Our evaluation revealed that Aboriginal communities strongly believe that VAD processes should be led by Aboriginal people, especially for First Nations Victorians seeking access to VAD. They argued that this leadership is required to ensure the practices are culturally respectful and appropriately tailored to meet their specific needs.

***‘If [we] are going to improve the services for First Nations Victorians who are trying to seek access to voluntary assisted dying, I would like to be guided by someone with skills within Aboriginal Health [workers] to be able to feel comfortable to have conversations.’***

This approach would help in building trust and making the services more accessible and relevant to Aboriginal communities.

### Self-determination, autonomy and dignity

Another key theme that emerged is the lack of self-determination and autonomy within these systems. Stakeholders raised the importance of respecting individual rights and the self-determination of Aboriginal people in making end-of-life decisions. They expressed a strong desire to have their end-of-life wishes respected as most times there are tensions between medical intervention and the personal desires of the patients and their families, particularly concerning powers of attorney.

***‘...People that are watching you make these decisions gasped at the reality that you're making a choice and what happens if the issue of a power of attorney is present and other people have to make choices, but the individual had already made their choice known’***

In another instance, a stakeholder expressed: ***‘It's about honouring the individual in our lives, respecting their wishes, and celebrating their life as they requested.’***

Others highlighted the importance of genuinely listening to what the community wants: ***‘I think it’s about that real authentic voice of listening to what mob really want.’*** Additionally, the sentiment was shared that when individuals are mentally capable, they should have the right to decide their own end-of-life timing and manner: ***‘If you're in the right mind and you've said your goodbyes, it's really that person's right to say, this is my time now.’***

***‘It's absolutely dreadful, because [this] is all about trying to get control at the end of life. But when you go through the assessment process, you actually relinquish all control, [because] you need to be assessed by two doctors, and they need to apply for [a permit] to find that you're eligible when they get the [permit]. So you're at the mercy of others.’***

Our evaluation also found that it is important to consider the difference between self-determined death, where community members maintain control over their end-of-life experience without formal assistance, and VAD, which involves legal and medical processes.

***‘[People discuss] how your burial is going to be, or your after-death experience is going to be, what about how you want to die? That is not on the table. How many of our families actually do suicide themselves? Which is, in that sense, it’s a terrible word for that. To me, I think that suicide is a violent thing. This is not violent, is it?’***

For Aboriginal communities, having control over their own end-of-life process, including the timing and manner of death is important.

### Resource allocation

Stakeholders shared their experiences regarding the availability and support of VAD doctors, navigators, hospital coordinators and pharmacists. They noted that the limited information on VAD among Aboriginal people, combined with the resource constraints of these professionals, hampers the effectiveness of VAD systems in meeting the needs of First Nations communities. Our evaluation found that there is a notable absence of support within the current system, suggesting that there are no dedicated personnel available to guide or support Aboriginal people and their families through the process of VAD. A stakeholder expressed a concern that, within the context of resource allocation, the establishment of such roles has not been prioritised particularly in regional areas.

***‘…We don't have those [Aboriginal] navigators. We don't have people that can walk beside us or anything like that, because that's just another resource and there's other more, more important resources to have in your hospital. No one came near us. No one really came to us and asked, what support do we need?’***

One stakeholder suggested: ***‘I think [we] should have as many or intermediaries [including] Indigenous health workers who might want to train in this area.’***

## Discussion

The evaluation has highlighted several critical issues and implications for recommendations concerning VAD systems, processes and practices for Aboriginal and Torres Strait Islander peoples in Victoria. Firstly, the current transactional and impersonal nature of end-of-life care does not align with the cultural values and needs of First Nations communities, indicating a need for more culturally respectful and inclusive approaches. There is a strong call for Aboriginal-led VAD processes to ensure culturally appropriate practices and to build trust within the community. The importance of self-determination and autonomy in end-of-life decisions was raised, with stakeholders highlighting the need to respect individual rights and wishes, often in tension with medical interventions.

Additionally, significant resource allocation gaps, especially the absence of Aboriginal navigators and support personnel, must be addressed to improve accessibility and effectiveness of VAD services. Incorporating healing processes into end-of-life care is key, not only for patients but also for their families and communities, to address past traumas and promote collective healing. Promoting quality of life and death, with comprehensive and respectful care options, is required for ensuring dignified and peaceful endings. Lastly, revitalising and integrating Aboriginal stories and traditions around death can help communities better understand and embrace end-of-life concepts. These findings highlight the need for tailored recommendations that respect cultural values, enhance self-determination, ensure adequate resources, and promote holistic and dignified end-of-life care for Aboriginal and Torres Strait Islander peoples.

## Barriers and enablers

As part of the evaluation, Aboriginal stakeholders were asked to identify the barriers and enablers to First Nations compliance, understanding, and operation of the Voluntary Assisted Dying (VAD) Act. Their insights provide a comprehensive view of the factors that either hinder or facilitate the effective implementation and uptake of the Act within Aboriginal and Torres Strait Islander communities.

### Lack of resources and information

Our evaluation found that there are key concerns around the scarcity of accessible information and support, particularly surrounding VAD. Stakeholders noted that there is a need for improved communication, education, resources and advocacy to empower individuals in making informed decisions about their end-of-life care. Some stakeholders also mentioned that the only term they are familiar with is ‘euthanasia’ rather than VAD.

***‘So the question then becomes one of what is the wish of that person in terms of do I want to continue my life journey and put up with the suffering until the end and have a natural death for whatever reason, or would I prefer to actually set a date. I'm out of here, get everything organised. Say goodbye to everyone, and then off we go. And that's where the voluntary assisted dying stuff comes into it. I think the challenge with that though, is people understanding what the [I'll use this term loosely] administrative process is.’***

One critical insight from the consultations is the importance of broadening the scope of information beyond the patients to include their families and friends. This approach helps to ensure that the entire support network understands the available end-of-life options and the rights of the person considering VAD. As one stakeholder noted, ***‘I think [what is needed is] a better understanding for everyone, not just the person that's passing. If we could have more information for people that when they go in and not just for them, but for their family and friends as well, I think that goes a long way to helping people and putting people at peace because ultimately that's what we're trying to do… if we can overcome that fear with peace and love, then I think it goes a long way. It’s about having more information readily available for people’.***

Stakeholders pointed out the gaps in the community's knowledge and resources concerning VAD, which is often cast as a sensitive and taboo topic. This deficiency in accessible information obstructs the initiation of meaningful discussions about end-of-life options, preventing individuals and their families from engaging fully and openly in these crucial conversations.

***‘…it's really like a taboo topic in our community, we don't talk about this.’***

Other stakeholders raised the notion that the scarcity of resources extended to online searches and health care settings, where information was either outdated or non-existent, and the need for approval from multiple health care providers posed additional barriers.

### Regulatory restrictions on health professionals

Feedback from Aboriginal stakeholders highlighted the regulatory limitations faced by health professionals, including Aboriginal Health Workers, regarding discussions on VAD. Current regulations strictly prohibit these professionals from initiating conversations about VAD with patients. This includes the prohibition of distributing written materials on the subject; the patient must be the one to initiate any discussion related to VAD.

***‘Health professionals etc. are not permitted to initiate VAD discussions with a patient, including giving a patient written information. The person needs to initiate that. Even then it can be very challenging.’***

***‘…In Victoria, no one can raise VAD with a person. And so it's a real disadvantage [to] people because the clinicians will have an end of life conversation about options, but it's actually not equity, because they're giving them options except for VAD.’***

This situation creates a disparity in the health care system, as health professionals can discuss various end-of-life options with their patients, except VAD. This restriction is seen as a significant barrier, denying patients a comprehensive understanding of all available options, which is essential for making informed decisions about their end-of-life care.

### Limited health conditions eligible for VAD access

During consultations with Aboriginal stakeholders on the implementation of the Act, a key issue that emerged was the restrictive eligibility criteria for accessing VAD. Stakeholders expressed concerns that these criteria are too narrow, effectively excluding individuals with certain health conditions, such as dementia or mental health issues. Specifically, the current requirement that a person must have a life expectancy of six months or less means that those suffering primarily from mental health conditions, without a terminal diagnosis, are unable to utilise VAD. This limitation has raised significant concerns about the accessibility and fairness of the Act.

***‘Dementia is a huge issue. Some people have what appears to be a good quality of life living with dementia, they remain pleasantly confused enjoying their life until the dementia progresses, until they decline and have a peaceful ending. However, there are some that are agitated, tormented and their quality of life is severely adversely impacted with no relief. Palliative sedation can ease physical and psychological distress at the end of life, however some people want VAD before the end of life.’***

Furthermore, stakeholders highlighted that in cases where an individual experiences mental anguish or suicidal ideation alongside a physical illness, the current procedure involves the coordinating medical practitioner seeking a specialist opinion, such as from a psychiatrist. While this step is relevant for a thorough evaluation of an individual's mental health status, the approach also inhibits the need for broader considerations in the eligibility criteria, to ensure that all aspects of a person’s health, both mental and physical, are appropriately addressed in the decision-making process.

### Reluctance from family

Family and community play a pivotal role in navigating end-of-life care. Decisions about end-of-life care frequently involve family conflict. A point highlighted by Aboriginal stakeholders is the reluctance from family members to First Nations compliance, understanding, and operation of the Act. We found that this hesitation can stem from a variety of factors such as denial and unwillingness to engage with the process, leading to potential conflicts. A stakeholder noted,***‘there will be some people within the family who will absolutely not accept it, will put them on life support, and say, “don't turn them off because we don't want them to die”’.***

In the same vein, one stakeholder recalled:

***‘She [my sister] was on machines. But the husband and the kids were still holding on but the poor woman was in pain. So it would have been helpful for her to be able to have this choice.’***

***‘You've got people that are in palliative care, and their family members refuse to let them go.’***

Our evaluation found that families often insist on treatment and refuse to discuss alternative options, creating a pervasive sense of denial that is deeply saddening.

### Cultural acceptance and stigma

Our evaluation found that within Aboriginal communities, there are ongoing challenges and taboos associated with death, including the reluctance to openly discuss end-of-life preferences and the stigma associated with choices like VAD.

***‘I think mob's so scared to talk about death. I think that unknown, as spiritual as we are, there's still that fear. I think we've got to get okay with going, okay I want to be cremated, I want to be buried, I want my ashes spread out here or whatever. But I think there's got to be that one person in family that you do have that conversation with…’***

### VAD health care professionals database

In discussions with Aboriginal stakeholders about the implementation of the Act, a key enabler identified was the creation of a registry of Aboriginal health care professionals who support VAD. This registry would serve an important role by allowing individuals to make informed decisions when selecting medical practitioners (particularly those who identify as Aboriginal and/or Torres Strait Islander). The goal is to ensure that people receive support from compassionate health care professionals who respect and facilitate their end-of-life choices, thereby upholding the dignity of their final wishes.

***‘...We have a register, for donating our organs and all that kind, which is really interesting, because they're our wishes and we put them on our licence. Nothing's really said about that. But once you start talking about being assisted to die, it goes against the grain.’***

Such a measure would not only promote autonomy but also protect against undue influence during these sensitive decisions.

### Modifying VAD services for better access

A supportive measure identified was the need to modify or adapt the VAD services to improve accessibility for those in need. This change would not only provide relief but also a sense of security to those considering VAD, knowing that it remains an available option, thus protecting their right to choose their own end-of-life journey.

***‘I truly hope that the VAD service is modified to improve access to those wanting it, even if it’s just easier to access the information. Some people may never go through with it, but just knowing they can is a safeguard.’***

This adaptation ensures that the dignity of choice is both respected and facilitated, offering peace of mind to those considering their future. As a stakeholder stated, ***‘there was someone who wanted to know about VAD, and they had the script, but they never ever used it. Just knowing it was there as an option was enough’.***

### Effective pain management

Aboriginal stakeholders discussed the importance of effective pain management for terminally ill patients. This aspect is considered a key enabler for improving compliance and understanding of the Act, as well as enhancing the quality of life during the final stages of illness.

***‘I don't think [he] thought he had an option of going, “can I get out of this quicker because I'm in so much pain?” And by the time he got to that point, there was nothing that could help him with pain. Because he was in so much pain… and I think people need to know that [VAD] is a choice, that you can ask.’***

One stakeholder shared the painful experience of a relative, including the severity of his suffering. They recounted, ***‘...In those last few days, if he [could have] been able to pass away, he would have because he was in that much pain and he was suffering that much. We heard him on the phone and he was just crying in pain and that's not [him]’.***

This testimony shows the impact that effective pain management has on end-of-life experiences and how integral it is to the dignity and quality of life of terminally ill individuals. The ability to alleviate severe pain not only transforms the final days for the patient but also deeply affects their loved ones. When patients are made aware of VAD as an available option, it offers a meaningful choice to those enduring unbearable pain, providing a pathway to alleviate suffering and uphold the dignity of those nearing the end of life.

### Advance care plan

One key enabler to First Nations compliance, understanding, and operation of the Act is advance care planning. Despite the availability of services like palliative care, many people often avoid engaging in advance care planning. This highlights the need for proactive discussions about end-of-life preferences.

Stakeholders noted that many Aboriginal people find themselves in difficult end-of-life situations. In these moments, making informed decisions can be challenging and often someone else must step in, particularly regarding pain management, where death might be a possible outcome.

One stakeholder shared a story about her sister who was in end-of-life care for cancer. She expressed that when her sister had been able to speak and engage in discussions earlier, an advance care plan, including the opportunity to access VAD, would have significantly helped. This experience shows the importance of having these conversations early, while individuals are still capable of making their own decisions.

For many Aboriginal individuals and families, discussing death is uncomfortable, yet necessary. One person noted, ***‘A lot of people don't like to talk about passing, which is understandable, but the conversation needs to happen much earlier’.***

***‘Mum and Dad had been very upfront about their wishes over quite a number of years. They'd already prepaid their funerals, so they already had that in hand, and what they wanted to do in terms of resuscitation, they'd been very open about that, and what they wanted to do with their bodies once they'd passed. That had been a conversation we'd had for a long time. That conversation helped us through the experience of Dad dying.’***

A request for VAD in an advance care plan helps to have a structure to have those important conversations with those that we love and those around us. These conversations become part of the last wishes – the pain management experience an individual wants to have, designating who will communicate on one’s behalf to other family members etc. This clarity helps to spell everything out, leaving nothing unsaid. One stakeholder considered this ***‘an act of love towards the family and community and that by planning ahead, you remove the burden of making difficult decisions from your loved ones, alleviating them from the guilt and stress of those choices’****.*

Early conversations about advance care planning can ensure that people are prepared and can work through their preferences for end-of-life care and facilitate better compliance, access and understanding of the Act for First Nations people.

### The language and practices of end-of-life care

The narratives and language used by end-of-life practitioners, including palliative care professionals and those involved in the VAD process, play a role in shaping the experiences of individuals facing terminal illnesses. However, these narratives often lean towards clinical efficiency and risk reduction, focusing on meeting legislative requirements rather than providing culturally sensitive care. This clinical focus can inadvertently create a cold and impersonal atmosphere, particularly for Aboriginal and Torres Strait Islander people who value relational and community-based approaches to care.

**The impact on Aboriginal and Torres Strait Islander peoples**

For many Aboriginal and Torres Strait Islander individuals, the process of seeking a VAD permit can be distressing and triggering, especially for those who have faced lifelong discrimination and are members of the Stolen Generations. The requirement to obtain permission from a non-Indigenous authority to end one's life evokes deep-seated trauma and feelings of disempowerment. As one participant emotionally noted, ***‘Imagine having to ask permission to die from the very system that once denied your right to live as an Aboriginal person’***.This statement encapsulates the pain and indignity felt by those who must navigate a system that has historically oppressed them.

By shifting the narrative from one of clinical compliance to one of cultural care and compassion, end-of-life practitioners can help alleviate the trauma and distress experienced by Aboriginal and Torres Strait Islander peoples. This change is needed to ensure that the end-of-life journey is as dignified and respectful as possible, honouring the individual's life and cultural heritage.

## Impact of VAD systems, processes and practices

**To what extent were VAD systems, processes and practises timely, safe and compassionate for First Nations communities?**

### Support from health workers

It is evident from our evaluation that there is a low uptake of VAD by Aboriginal people. One reason stakeholders believed VAD systems, processes and practices might not have been timely, safe and compassionate for Aboriginal people is the inadequate training and support from health care workers.

A stakeholder recounted how an elderly family member, in the final stages of life, was moved from palliative care to a rehabilitation ward—an environment ill-suited for end-of-life care, characterised by minimal intervention and support. Family members were dismayed and in shock from watching their loved one through this phase. Another stakeholder recalled:

***‘…my own father was in an Aboriginal ACF. The week he passed I got a call from the ACF saying he had a choking episode and was very unwell. I did tell the staff he most likely aspirated and got Pneumonia and to keep him comfortable and he was not for hospital. The staff ignored me and sent him to hospital. My Dad had [always] expressed he never wanted to be kept alive if his quality of life would be impacted adversely. He passed away 1 week later, and we were by his side to ensure he got the care he needed.’***

The stakeholder pondered whether a more proactive approach to discussing VAD might have alleviated some of the trauma experienced by both the patient and his family.

In contrast, a stakeholder described how the health care system and the VAD processes provided safe, timely and compassionate support. They recounted the case of a young man in his thirties who was in the palliative care ward and chose to pursue VAD. He insisted on receiving the procedure at a hospital closer to his home. The staff facilitated this request, arranging for his transfer to a nearby palliative care ward. Throughout the process, he obtained all necessary consents from various doctors within the hospital. Similarly, one of our stakeholders recalled:

***‘During COVID we had a palliative patient from Western Australia who had been over here for about 10 years. She was having treatment that whole time and then it came near the end. It was really hard to get anyone back to WA but we made it happen. It was tough, but we did it.’***

These examples highlight the mixed impact of the VAD systems and processes in terms of being safe, timely and compassionate for First Nations people.

### Self-harm due to lack of opportunities

Aboriginal stakeholders are of the view that because of the lengthy and time-consuming process, the current VAD systems and processes are putting Aboriginal people at risk of self-harm. We found that there is a distressing tendency within the Aboriginal communities to resort to self-harm or suicide due to perceived prolonged suffering, especially when they feel that all other avenues (including VAD) for relief are closed to them. Stakeholders noted that the VAD process, which involves a lengthy and complex permit-assessment procedure, stringent eligibility criteria, and the need for approval from two doctors, often feels burdensome and inaccessible.

***‘VAD has got to be easier than suicide. You know, at least you can bring people along with you on a journey rather than just do it quietly by yourself at a great deal of risk.’***

***‘It's knowing that it is an option or a choice that I can make, rather than it not being there. The other option to VAD is suicide. In VAD you're letting your loved ones know this is your choice, and I would like to use this whereas suicide ... people do it alone, for the most part.’***

A stakeholder reported observing several distressing cases where Aboriginal individuals diagnosed with dementia or suffering from long-term, treatment-resistant mental health conditions like depression and schizophrenia expressed a wish to die. These individuals often resorted to severe self-harm before being admitted for care. Tragically, in one instance, the stakeholder stated an individual took their own life shortly after being discharged.

### VAD medication and administration

Our evaluation found the current VAD process, systems and practices in terms of VAD medication and administration appear to be safe, timely and compassionate. Currently, support personnel like pharmacists visit patients in their homes, ensuring comfort and familiarity for the patients. The entire process is patient driven. Pharmacists can stay during medication administration and typically provide information, respecting patients' autonomy and decision making. One stakeholder noted:

***‘There are always two pharmacists that go out and visit these patients. The whole process is driven by patients. So at no point in time we make contact or make initial contact with the patients or the family members. We can only go out and visit these patients when they call us.’***

Moreover, we found that the operational framework of the VAD service includes detailed procedures for pharmacist visits, prescription handling and patient support. Protocols ensure patient safety, with options for medication storage and administration discussed with patients.

***‘In terms of storage, the legal requirement is that the substance needs to be kept in the lockbox that we supply [a steel box with a key]. If we have any concerns, say family members, or friends accessing the medication when it's kept at home. We will most likely not leave it there.’***

In terms of training, support personnel undergo comprehensive training and adapt their approach based on cultural considerations. Team debriefs, individual reflections, and access to mental health professionals help manage vicarious trauma and maintain wellbeing. They also undertake training on difficult conversations, cultural awareness, psychological first aid, as well as grief and bereavement support. Although patients have the option of having a support person (family or friends), support personnel prioritise maintaining confidentiality and discretion during the visits.

# Recommendations

To enhance the understanding and accessibility of VAD for Aboriginal and Torres Strait Islander peoples, we have developed a comprehensive program of actionable recommendations. These recommendations are categorised into short-term (0-12 months), medium-term (1-2 years), and long-term (3-5 years) actions to ensure immediate, sustained and future improvements in culturally sensitive end-of-life care. The proposed measures aim to address educational needs, enhance cultural safety, establish supportive structures, advocate for policy changes, incorporate traditional practices, improve pain management resources, and ensure regular community feedback. By implementing these recommendations, we can create a more inclusive, respectful and supportive system for Aboriginal and Torres Strait Islander peoples considering VAD, ensuring their end-of-life journey is dignified and culturally appropriate.

## Short-term Actions (0-1 year)

### Enhance Community Education and Awareness about VAD

Develop and disseminate culturally tailored community educational materials that explain VAD, focusing on pain management and the availability of this option. Use stories, case studies, and testimonials from within the community to make the information more relatable and less intimidating.

### Train and Employ Aboriginal Health Workers in VAD Processes

Invest in training for Aboriginal Health Workers to specialise in VAD processes, ensuring that they can advocate effectively for patients and guide them through the VAD process with understanding and respect for cultural values.

### Promote Open Conversations About Death and Dying

Organise community forums and discussion groups to talk openly about death, dying and VAD. These should aim to reduce stigma and fear associated with talking about death and foster a more supportive environment for discussing end-of-life choices.

## Medium-term Actions (1-3 years)

### Establish Aboriginal-led Support Teams

Create support teams consisting of Aboriginal Health Workers, spiritual advisors, and community Elders to assist patients and families through the VAD process. This team would ensure that all aspects of the patient's cultural, spiritual and emotional needs are met.

### Advance Care Planning Workshops

Organise workshops on advance care planning and VAD options, led by Aboriginal Elders and health professionals, to educate and empower communities.

## Long-term Actions (3-5 years)

### Advocate for Policy Changes to Support Culturally Safe VAD

Work with policymakers to adapt VAD legislation and health care practices to be more inclusive and reflective of Aboriginal cultural practices and values. This could involve amendments that allow greater family involvement and community consultation in the decision-making process.

### Regular Review and Feedback Mechanisms

Implement a system for regular review and feedback involving community members to continuously improve the cultural appropriateness and effectiveness of VAD services offered to Aboriginal people.

### Research and Evaluation

Conduct ongoing research and evaluation to monitor the effectiveness of implemented changes and continuously improve VAD services for Aboriginal and Torres Strait Islander communities.

## Broader recommendations relating to palliative care

### Inclusive Language Guidelines

Develop and distribute guidelines for using inclusive and culturally sensitive language in end-of-life care communications and documentation.

### Community Consultations

Conduct regular consultations with Aboriginal and Torres Strait Islander communities to gather input and feedback on VAD processes and ensure their voices are heard and respected.

### Cultural Safety Audits

Perform audits of current VAD practices and environments to identify and address areas lacking cultural safety.

### Develop Cultural Safety Training for Health Care Providers

Provide cultural safety training for all health care providers involved in end-of-life care, focusing on understanding and respecting Aboriginal cultural practices and values. This training should help providers recognise the importance of a holistic approach that includes physical, spiritual and community health.

### Holistic Care Models

Develop and implement holistic care models that integrate physical, emotional, spiritual and cultural aspects of end-of-life care.

### Incorporate Traditional Practices and Rituals

Encourage and facilitate the inclusion of traditional Aboriginal practices and rituals in the end-of-life care plan. This could include ceremonies, storytelling, or other culturally significant activities that honour the patient's life and heritage.

### Improve Access to Pain Management Resources

Ensure that all patients have access to effective pain management options. This involves training more health care providers in pain management techniques and ensuring that these resources are readily available in Aboriginal communities.

### Sustainable Funding

Secure sustainable funding for Aboriginal-led VAD programs and initiatives to ensure their long-term viability and success.

# Conclusion

These recommendations aim to enhance the support for Aboriginal and Torres Strait Islander peoples in accessing VAD. By addressing educational needs, enhancing cultural safety, establishing supportive structures, advocating for policy changes, incorporating traditional practices, improving pain management resources, and ensuring regular community feedback, we can create a more inclusive and respectful end-of-life care system. This approach will help mitigate the profound distress and trauma experienced by those who have faced discrimination and are part of the Stolen Generations, ensuring their end-of-life journey is dignified and culturally appropriate.

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# Appendices

## Appendix 1: Quotes and Themes

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| **Themes** | **Quotes** |
| **Role of Family and Community** | *‘I think we all need to be on the right page and have the best interests of the patient at heart. And then I don't think we can go wrong, to be honest, if we're on the same page, but thinking about the best possible care for that patient.’*  *‘Sometimes us as the living ones hold on to the person that's passing so they know that that person is hanging on and until they're okay, they're not going to go. So I think with voluntary assisted dying, I think that it's not just about the person that is about to pass, it's about everyone around them and they need to be able to understand it and give their permission for that person to pass as well. And then I think it’s a much easier passage for them to do what they need. So I'm all for it, to be honest. I'd never ever want to see, I've seen a few people… when [they] passed in so much pain, so I think that when, you know, if you’re still of the right mind, well then you need to be able to make that decision.’*  *‘Until we get that balance right where, you know, the people that we're leaving are okay with it, then I think that the VAD, I think patients will be more looking for that, if you like.’*  *‘For a really long time, like going back to when I was a kid, there was this notion that Dad had, that when your time is up, you accept it. And, and I think that acceptance helped us when he was dying because we knew he knew his time was up and could accept it. I was reading a story about Dad’s great-great-grandmother recently, and she'd said that when an old person in the area that she came from knew they were close to death, they would go and lie down next to where they were going to be buried. It was just that acceptance and that's something that Dad had.’* |
| **Cultural Beliefs, Spirituality and Religious Influences** | *‘Maybe there’s a journeyman somewhere in the culture who comes in and says, listen I’m going to help you mob go through this journey. And they take them out the bush and sit out there knowing time’s getting near.’*  *‘I think people need to understand that when you are passing, your loved ones that are in spirit will be there to help you cross over as well. And I think a lot of people are scared of that, those ideas and those sort of things, but it is really, really something that's real.’*  *‘How can we get back to our own spirituality here? How do we be in a situation where we can make our own decision?... Isn’t that part of that whole process of colonisation that we were made Christians? Isn’t this part of decolonisation as well?... and so we have that decision making about our life. You should be able to have our decisions about life and about death.’*  *‘We dream a lot … we see our old fellas in our dreams and we know they’re coming. We’ve gotta get some of these guys to see that they’re coming and they’re coming to take you with them and they’re coming to take you home. You need to have that in the language.’*  *‘I really think from what I’ve learned working in the funeral service… there was always a conflict when [death occurred] in a hospital. If someone was at home, there’d be a different story of the experience of them passing… and I really feel that those that pass at home pass a lot easier than what they would in the hospital.’*  *‘I thought about it. I don’t know if I want to donate my organs now… and you know that’s pushed in to people a lot about donating organs and you’re doing a better thing, but how do you keep intact about your own spirituality? We shouldn’t be made to sort of feel guilty about we’re going to take our organs with us, we should be able to make, it’s just a whole part of the package. How do we want to go? If we’re making decisions about giving up our organs, we need to talk a bit more about that as well… That could be the time to go, what about voluntary death? That should be brought up in there… It’s about the person, not what we can get from you when you’re gone, it’s actually how do I go in a peaceful manner? And I need to be in control about that.’* |
| **Cultural Perspectives in Death and Dying** | *‘I just don’t think there was enough support from the hospital. I don’t think they have enough understanding of our culture.’*  *‘I think there's a medical way of doing things and then I also think we've got our spiritual way of doing things that can be blended in a really beautiful, safe way and a really… one for everyone to have the healing. Because when spirit leaves, there's a part of us that dies and grieves and goes with them and vice versa. So I think it can help and by talking or whether there's smoking or there's music or conversation, something that will change that for everyone to help, but I really think it's, you got to talk about it early.’*  *‘People are not knowing choice. They’re not even knowing choice about how to bury someone differently… and some people have got all these different ways of thinking about it. I just noticed being a part of the funeral service… people don't know that they have choice.’*  *‘More and more people are being cremated but families are not happy about that either.’*  *‘I had to go and get Nanny Lorna. She’s an experienced Elder in births and deaths, the celebration and the passing and I said, ‘oh you gotta help me here, Aunty, you gotta help me get my sister home’ because I thought, culturally something might be able to help her. And she was lovely. She kind of brought a bit of calmness … she said, ‘just let her go now, just let her go’. Like that resonated for us, ‘you’ve got to let her go now, accept that you’ve got to let her go’. And I think that once that occurred for us, we were all in a better space.’* |
| **Improving VAD Service Experience for First Nations** | *‘... Someone should have a conversation with them, even though it's going to be their decision.’*  *‘VAD needs to be an option. You know, it's like it can be really hard, but when we [Aboriginal Hospital Liaison] go into an appointment with a patient and it's not looking great for them … and the doctors want to cure or they want to do their thing. A couple of times when I've been in appointments and the doctor said, ‘you can do this or you can do this, these are the side effect of this treatment, these are the side effects of this one, and I've actually turned around and said to the patient, ‘the other option is always that you could do nothing’. Because doctors they just don't say that and a lot of mob will just go along with it because that's what the doctor said. And it's a shame job if you question them. And I think that there needs to be, you know, more widely known that you don't have to do what the doctor says.’* |
| **Healing Trauma** | *‘It’s also healing. If we had such traumatic lives, it still can be a part of the healing process if we can control how we go. If we can make our families feel good and make them feel fine, you know, it's OK, I know what's happening and this is what I want and all I want is to be assisted in how to go and that shouldn't be a real medical trauma.’*  *‘If we talk about it as in healing, it’s not just that person that is about to pass. It’s everyone that’s involved with that person.’*  *‘I think it is truly about that healing side of things because, you know, you hear a lot, especially men will say “I’m not scared about dying”… but when it comes to the nitty gritty, [people] are scared of being scared of passing which is really understandable. You know, no one really wants to die to be honest. But if that healing process has started, where they are able to start their healing process about passing away, I think that plays a big part in it too. So I think that, you know, there needs to be that work done with people that may be able to use this VAD. And I think that's really important to be able to have that, I suppose, that pre-passing but then after the passing as well, there needs to be a lot of work done as well.’* |
| **Quality of Life and Death** | *‘We do have our elderly people who are older and frail but then actually diagnostically have [nothing] wrong with them, and then they still can't access…’*  *‘I've been almost like everybody else, but I've been pretty fit and strong my life. And it's not ever something that I would have contemplated until, until I got what I've got.’*  *‘…Watching people not have quality of life… we need to be in control of how we die.’*  *‘[The nurse] had been giving her… some drug to assist with there not being pain when you are in the last week or so of dying. But she was still breathing but she wasn't there. And she was like skeletal. It was terrible. It was like she was frozen in time. And all you could hear was this gurgling noise, which was her dying, which was fucking awful. I think, if it's possible for assistance when you're like that, just do it.’* |
| **Navigating End-of-life Care** | *‘The other thing too, as we know, before this voluntary assisted dying stuff came in, there were people that were saying, I really want to get out of here. And then you had this unfortunate situation of them asking their loved one or a partner or whatever, or their doctor say, look, I really, really, really, really want to go, I don't want to be here anymore. Because I just, I need to move on and sort of end my life journey here. It's about the dignity of death. Is that person wanting to, or able to have a dignified death?’*  *‘When my sister died, after three days of being in the most awful pain, I know the doctor knew what we were saying and you know what … they probably do it anyway. They’re doing this, they’re just not calling it VAD.’*  *‘If Mum fell over and she was never about to walk again or done some real damage, what capacity does she have to actually have assisted dying? She doesn't want to lay in bed and have people come visit her. It would be terrible for everybody. So at what point can you do that? So, you know, my Mum could be a real candidate. She should have that choice. But how do you go about getting that choice?’* |
| **Life-Death-Life** | *[We] never spoke about death [this way]. Never did we speak about death [this way]. We just spoke about living.’*  *‘I don’t think anybody has thoughts about assisted dying.’*  *‘No one really mentions it [VAD], but then it's that whole thing. People don't mention cancer if they can help it, which I think is part of the reason why so many people come to us when they’re already palliative.’*  *‘I think that we just need to be able to talk about it [VAD]. And we need to make sure that we've got the right resources and we need some training.’*  *‘It's like the legislation’s there but the practice isn't.’*  *‘Some people will not acknowledge that death is a part of life's journey. And then might not be prepared for those left behind and what will happen to them in terms of, okay you know, this person's dead now. Some people want to hang on to life for as long as possible, even though you know, their health is challenging for them. And then, in terms of dying, I mean, it comes back to in part whether that person is focusing on quality of life or longevity.’* |

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