



# FINISHING UP BUSINESS

What we can learn from  
Australia's First Peoples  
about dying and death



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PM Glynn Institute  
Occasional Paper No.6

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GALARRWUY YUNUPINGU AM  
Gumatj leader and Australian of the Year 1978

# Finishing up business

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## STRENGTHS-BASED APPROACH

Australia has 65,000 years of traditional Aboriginal and Torres Strait Islander knowledge that remains undervalued when approaching issues in our contemporary society. The recent Australian bushfires put Indigenous knowledge back into the centre of the debate about land management. Ngiyampaa woman, Jessica Wegener, the co-chairperson of Firesticks acknowledges that “there’s a shift in mindset happening, and little bits of Indigenous knowledge are being embedded in Western practice. But it has to be applied holistically, not just in part”.<sup>1</sup> It took the horrors of the Australian bushfires to force this conversation to happen, and for decision-makers to be open to learning.

If the Australian community is committed to learning from Aboriginal and Torres Strait Islander cultures and peoples, we must first overcome the deficit discourse<sup>2</sup> and take a strengths-based approach. A strengths-based approach is based on the principle that Indigenous knowledge is valid and valuable. Determining how traditional and contemporary knowledge systems can work together and co-exist can benefit Indigenous peoples and the broader Australian community.

One such issue is the approach to dying and death. This is a sensitive subject across the broader population, and a taboo subject in Aboriginal and Torres Strait Islander communities. Yet we must discuss it in order both to design improved services and learn how the old ways and contemporary ways can work together. Designing services that respect and incorporate the views of Aboriginal and Torres Strait Islander peoples can benefit all Australians.

In 2020, the PM Glynn Institute considered an important public policy question in its report, *A snapshot of palliative care services in Australia*. This work examined the issue of equity in palliative care services. The premise of the report is that advocates of voluntary assisted dying argue that it should be about choice and autonomy. If this is true, then every Australian, including our First Australians, should have equitable access to palliative and end-of-life care in order for that choice to be real.

Building on this work, this paper seeks to better understand the attitudes of Aboriginal and Torres Strait Islander peoples towards dying and death. These attitudes might inform the debate our nation is continuing to have about end-of-life care, including voluntary assisted dying, and identify if, and how, these views are being considered.

## SPEAKING PUBLICLY

In a video released by Palliative Care Australia, *My Culture, My Kinship, My Country*, Yawuru man Jonathan Dodson-Jauncey, reminds viewers that until only recently dying was seen by many Aboriginal people as “sacred business and was only spoken about in our own circles . . . it’s obviously a sad time, we generally don’t speak openly about death and dying.” In addition to being sacred business, there is also the belief by some Indigenous Australians that discussing it will jinx them and someone will die.

Despite this, two of Australia’s prominent Indigenous politicians, Senator Patrick Dodson and the Hon. Ken Wyatt MP, provided speeches in 2019 when the Western Australian government introduced the *Voluntary Assisted Dying Bill 2019 (WA)*. There was a strikingly similar tone to the speeches given 25 years earlier, when the Northern Territory became the first jurisdiction to pass voluntary assisted dying legislation under the *Rights of the Terminally Ill Act 1995 (NT)*. Extracts from the parliamentary debate in 1995 clearly show Aboriginal communities were opposed to the Bill, arguing it was in conflict with traditional culture and practices. It is interesting to note there were two Members who voted on the Bill who identified as being Aboriginal. Despite both agreeing their constituents resolutely opposed the legislation, Wesley Lanhupuy, Member for Arnhem, voted in favour of the Bill, while Maurice Rioli, Member for Arafura, voted against the Bill. Lanhupuy acknowledged the opposition many Aboriginal people had to the legislation, but voted in favour of the Bill arguing he could not deny individuals the right to be assisted in dying should they wish to make this request.

The views of these politicians have provided rare public insights into the attitudes of Indigenous Australians towards this taboo subject. Culturally, Indigenous Australians are hesitant to talk about dying and death, and there is a risk that their views are not considered and that the broader discourse continues without understanding what we could learn from Australia’s Indigenous peoples.

Dodson and Wyatt have brought to our attention more recently the need to consider these views, and this paper seeks to better understand what these views are.

Many Indigenous Australians remain opposed to any form of voluntary assisted dying, and there is an opportunity for deep listening, which is encouraged by Nauiyu Elder, and 2021 Senior Australian of the Year, Miriam-Rose Ungunmerr-Baumann. We are obliged to do this before Australian States continue to push forward legislation that enables voluntary assisted dying.

To begin this deep listening, it is important to understand there is much diversity in the cultural and spiritual beliefs and practices of contemporary Aboriginal and Torres Strait Islander people. These beliefs and practices differ from community to community, and are expressed in different ways based on the lived experiences of that community. Aboriginal beliefs have many similarities with Torres Strait Islander beliefs, with some differences. One person’s view does not represent some monolithic Indigenous experience.



## SORRY BUSINESS

Sorry business is commonly understood to be the period of cultural practice following the death of an Aboriginal or Torres Strait Islander person. Sorry business is an English expression that many Australians would have heard before, and have some knowledge of the practices undertaken at this time. For example, many Australians would know it is usually not appropriate to mention the deceased Indigenous person's name, and that sorry business usually involves a smoking ceremony to purify the house and cleanse it of bad spirits.<sup>3</sup> Often, there are large gatherings with members of the extended family regardless of whether they are related by blood.

The reason for these practices is explained in more detail by the Queensland Government health resource *Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying*:<sup>4</sup>

The name of the deceased is not mentioned for a long period of time, from several months to years. This is to ensure that the spirit is not held back or recalled to this world. A smoking ceremony is conducted. The smoking of the deceased person's belongings and residence also assists with encouraging the departure of the spirit. Some Aboriginal groups also practise means of identifying causes of death. These are practised by Elders who hold the cultural authority to do so, and the causes in question are usually of a spiritual nature. The ceremonies are likened to an autopsy of Western practice.

In debating the *Rights of the Terminally Ill Act 1995* (NT), Mr Rioli explained this important cultural practice, including returning to country:

They know when they are going to die and they wish to be at home with their family in their own country, on their own land, listening to and hearing the songs that give meaning, purpose and the strength to endure and to help the life spirit return to its place of origin so that everything will be right with the world.

## BEFORE THE SORRY BUSINESS

What happens *before* the sorry business is much less known by the broader Australian community, yet could provide important insights into dying and death. These views often have a basis in traditional knowledge, but due to colonisation, are usually practised by Aboriginal and Torres Strait Islander Australians with a contemporary expression.

Anecdotal evidence can be gathered from research undertaken by Federal, State and local health departments which have sought to better understand the perspectives of Aboriginal and Torres Strait Islander people on dying and death in order to inform service delivery.

These resources typically describe the process, but don't always try to explain the values that underpin the social norms and expectations of Indigenous Australians during this time. This is because Aboriginal and Torres Strait Islander Australians are diverse, and customary cultural and spiritual practices can differ between groups. In some areas of Australia, traditional practices have been lost altogether. A consequence is that the broader Australian community might have a small level of awareness of these practices, but is not in a position to reflect on these practices in a deeper and more meaningful way.

## FINISHING UP BUSINESS

End-of-life care typically refers to the twelve months prior to the death of a person. Palliative care specifically refers to the tailored care a person receives to assist with the effects of life-limiting illnesses.<sup>5</sup> While these terms are often used interchangeably, health professionals see them as distinctly different.

In Aboriginal and Torres Strait Islander communities, it is often said there is not a literal translation for palliative care or end-of-life care. In fact, the term 'end-of-life' can be confusing and frightening to many Indigenous Australians.

In much of the Australian community, death is often seen as final, as the permanent end of the life of a person. However, Aboriginal people believe they come from the land, and conversely, "when we go, we go back to the land and become the land again and that's something that's the belief of the people since time."<sup>6</sup> Aboriginal and Torres Strait Islander people usually view this period as preparation for the next stage of their spiritual journey, rather than a final end to life. For this reason, the period of dying and associated end-of-life care is sometimes called 'finishing up business.'<sup>7</sup> Referring to 'end-of-life' can cause concern for some Aboriginal and Torres Strait Islander communities as this implies the spirit will not return but become lost or disappear.

Rather than referring to death, it is common to speak of the person 'passing' and that they have 'gone back', signaling they have returned to the land. The 2018 *Life Journeys: Death and Sorry Business* report captured this sentiment from an elder in New South Wales who described a circular relationship to death. Rather than death being the end, it is a change of state.<sup>8</sup>

## THE COMPLEXITIES OF CARE

There is a strong preference towards the close involvement of family during end-of-life care, both in terms of the family being present to spend time with the person, and having family

involved in the decision-making that supports a person's care.<sup>9</sup> This is based on the Aboriginal kinship system that is a complex and dynamic force that binds Aboriginal people together.<sup>10</sup> The *Little Red Yellow Black Book* describes kinship as “the glue that holds Aboriginal and Torres Strait Islander societies together. It locates all Aboriginal and Torres Strait Islander peoples in networks of belonging and webs of relationships that incorporate people, places, plants, animals and ancestors.”

There are practical steps that can be taken to accommodate family groups, especially during the time immediately before the person passes. For example, patients who are hospitalised for palliative care could be provided with a larger private room so family groups can be with the person, or special consideration can be given to hospital visiting hours to ensure family who have travelled long distances can have time with the person before their passing.<sup>11</sup>

Providing the right care can be highly complex. This is highlighted in the 2006 report, *The biggest worry: Research findings on pain management for Aboriginal peoples in Northern Territory, Australia*. The report outlined the difficulties in assessing pain as patients who have a leadership role in a community may not want to appear weak. There are complex cultural relationships that determine who can be involved in making care decisions, and who can discuss or be informed of the dying person's status. There was a strong fear that people looking after the dying family member can be judged on how that person was cared for. This could elicit 'pay back' if other family members believe pain medication contributed to the death of that person, or the person was not looked after appropriately in any way.

While there is a strong sense of obligation and commitment from the family during this time, there is also a fear of getting it wrong and causing family disputes.

## KNOWLEDGE HOLDERS

Aboriginal culture is the oldest continuous culture in the world, dating back 65,000 years ago. The foundations of Aboriginal culture can be found in a time called the Dreaming:

These ancestral spirits made rules and created the lore to govern the land, the waterways, and their people, animal and plant life . . . Each lore connected all elements of life on earth and, if life on earth was to continue, the lores would need to be followed. Ceremonies ensure that vital components of the lores and The Dreaming stay intact. They provide a time and place where all people in a language group and community work together to maintain and ensure the ongoing survival of spiritual and cultural beliefs . . . members of the language group had, and continue to have, the responsibility of ensuring that these stories and knowledges are correctly remembered and passed on, and that rituals and ceremonies are correctly performed to do this . . . Passing on specific lores and knowledges through ceremonies has ensured their protection for all people within the community.<sup>12</sup>

Torres Strait Islander Australians have a strong relationship to the stars. Similar to the Dreaming, Torres Strait Islander peoples form a sense of their identity through a concept based on the *Tagai*:

The people throughout the Torres Strait are united by their connection to the Tagai. The Tagai consists of stories which are the cornerstone of Torres Strait Islanders' spiritual beliefs. These stories focus on the stars and identify Torres Strait Islanders as sea people who share a common way of life. The instructions of the Tagai provide order in the world, ensuring that everything has a place.<sup>13</sup>

Survival of this knowledge is far greater than one person or one family. These ceremonies are one way to show respect during the time the person is finishing up. This respect is centred on their connectedness: to country, to kin, to knowledge, to memory – to what they share with their people and culture, not just who they are alone. Ceremonies, including at the time of death, are important for many communities in the transmission of this cultural knowledge and passing on these beliefs and practices.

In Western cultures, the elderly are typically seen through an economic lens, usually as a burden, and are undervalued socially and culturally. As a case in point, the 2021 Intergenerational Report identified Australia's ageing population as the greatest demographic challenge, citing the reduction in the number of working-age people relative to the number of older Australians as presenting long-term economic and fiscal challenges.

Yet, Indigenous communities in Australia have traditionally used a more positive framework, where older people are valued for their contribution in “transmitting culture, maintaining language and kin relations and fostering strong community ties.”<sup>14</sup> The Australian Institute of Health and Welfare acknowledges the elderly are highly respected for their contributions to family life in Aboriginal communities, particularly in helping children to understand the practical aspects of life and society. This distinction does not imply there is a different level of grief experienced when the person passes away, but that the Elders are valued as knowledge holders and when they pass this is an important time for the transmission of this knowledge.

In terms of language, there is a distinction between Aboriginal and Torres Strait elders, and those who are elderly. Elders are not chronologically old, but are custodians of cultural knowledge and law. When an Elder is approaching the end of their life, this will be an important time for their family and community.

## CULTURES ARE DYNAMIC

Culture refers to a common understanding by a group of people about their way of life, and the values, customs and social behaviours underpinning this.<sup>15</sup> This does not mean every

individual who identifies as an Aboriginal or Torres Strait Islander Australian will hold the same beliefs.

Cultures are not static. Aboriginal and Torres Strait Islander cultures have adapted dramatically since the arrival of Europeans.<sup>16</sup> The beliefs of Indigenous peoples in Australia have adapted to the changing circumstances in which they live,<sup>17</sup> and the approach to dying and death is a case in point.

One example is the use of self-harm during grieving known as ‘sorry cuts’. These cuts are used to let the blood flow and bring a release of pain.<sup>18</sup> While sorry cuts are still used in some parts of Australia, they are less frequent.

Despite the changing circumstances, the sources of received wisdom that underpin Aboriginal and Torres Strait Islander cultures continue to play a fundamental role in how community members are cared for leading into, during, and after their passing. Specifically, the nature of the kinship system and the circular relationship with death guide who can care and where that care should ideally occur.

## AUTONOMY OR COMMON HUMANITY?

We have never been more connected via smart devices, yet at the same time, it could be argued we have never been more disconnected from our social networks and peers, and even our families. Many sociologists, politicians and commentators have observed how our communities are becoming increasingly atomised, dominated by self-sufficiency and individualism.

Advocates of assisted dying argue in favour of individualism and for the autonomy of the patient to be respected. They argue the state does not have the right to “diminish the individual’s autonomy in choosing assisted dying, as it does no harm to others” and that “opponents to assisted dying will not be affected by a change in law, but those who want assisted dying are adversely affected by the current situation.”<sup>19</sup>

Individualistic autonomy has advantages when it comes to patients being free to make decisions about their bodies and their care. However, it also has limitations. Humans are relational beings whose sense of identity and interests are shaped by our connections to others.<sup>20</sup> Senator Patrick Dodson directly challenges the right to individualistic autonomy, arguing that our connectedness as a society means the decision by one person can and will impact our common humanity:

If we give one person the right to make that decision – that is, to assist in committing suicide – we as a whole are affected. If we give one family that right, we as a whole are

affected. If we give one state or territory that right, we as a country are affected. If we give one nation the right to determine life, our common humanity is affected . . . The quality of life for individuals and for our communities are intertwined, not limited to the wellbeing of an individual. We are fundamentally responsible for honouring our fellow human beings. We are called to carry responsibilities, to exercise duties and to honour those who are in need, who are ill, who are elderly, who are dependent and those of the next generation to value life with love, respect and responsibility. This is true of family members and unknown individuals.<sup>21</sup>

This view is also supported by the Chair of the National Aboriginal and Torres Strait Islanders Catholic Council, John Lochowiak, who has stated:

If that sense of accompaniment is now bypassed or delegated to a doctor having euthanasia discussions with a patient, without any reference to the community, then it is going to seriously weaken the connectedness of the community.

## TOGETHERNESS

For many Aboriginal and Torres Strait Islander people, the ceremonies around death are extremely important and are usually prioritised over all other activities.<sup>22</sup>

Naiyiu Elder, Miriam-Rose Ungunmerr-Baumann, says that “when a relation dies, we wait a long time with the sorrow. We own our grief and allow it to heal slowly.” Punjima woman from north-west Western Australia, Aunty Margaret Parker, also reflects on the cultural practices when someone passes:

when we have someone passed away in our families and not even our own close families, the family belongs to us all, you know. The whole community gets together and shares that sorrow within the whole community . . . We have to cry, in sorrow, share our grief by crying and that’s how we break that [grief], by sharing together as a community. This is an important aspect of our culture. And this is how we are brought up.<sup>23</sup>

The Walpiri people in the Tanami Desert in the Northern Territory attend sorry camps during sorry business. At the women’s camps, the ritual of co-wailing is practised. This type of wailing signifies *marlpa* (meaning ‘company’) which is about larger groups of women rather than one-to-one companionship for the purpose of harmony, connectedness and relationship responsibility.<sup>24</sup>

Their wails and tears are absorbed into everybody else’s wails and tears, not to negate their validity but to express *marlpa*, company. In the sorry camps other women wail after one of the central mourning women starts her wails, not only because they are reminded of their shared loss, but also to remind the bereaved woman that she is not alone.<sup>25</sup>

These examples of Aboriginal cultural practices highlight the shared need to express grief and to accompany those who are grieving; to give grief voice as part of healing. They are important reminders to reflect about the way we “manage” grief in the broader Australian community – including the time we are prepared to give to this – and the need to draw strength from those around you when someone important passes away.

## THE WAY WE DIE IS CHANGING

One argument put forward in support of voluntary assisted dying laws is the way people are dying is changing, and our approach to dying and death must change too. There is no doubt that a larger proportion of end-of-life care is occurring in institutions such as hospitals and residential aged care facilities, and it is becoming more highly medicalised.

A 2014 Grattan Institute report, *Dying Well*, identified the fact that many people know when they are likely to die in the relatively near future, as most have chronic diseases and disabilities. The report also stated that around half of Australians die in hospital, and about a third in residential care with impersonal, lingering and lonely deaths, feeling disempowered. The report identifies the fact that “in the last year of life, many experience a disconnected, confusing and distressing array of services, interventions and relationships with health professionals.”

As we have seen, Indigenous Australians remind us that dying does not need to be like this; that it is a journey which we do not set out on alone. In Western societies and in Aboriginal and Torres Strait Islander communities, most people want to die with dignity, surrounded by those who love them.

## LIFE IS PRECIOUS

There have been significant improvements in age-standardised mortality rates of Indigenous Australians. However, death rates for Indigenous Australians are amongst the highest in the world, and the gap between Indigenous and non-Indigenous life expectancies has not narrowed.

Circulatory disease and cancer remain the two leading causes of death amongst Indigenous peoples in Australia. For Indigenous Australians aged 44 years and under, the leading cause of death was due to external factors including suicide, injury and poisoning.<sup>26</sup>

According to the *Closing the Gap Report 2020*, in 2015–17, life expectancy at birth for Indigenous males was 71.6 years compared to non-Indigenous males who are expected to live to 80.2 years (8.6 years longer). For remote and very remote Indigenous males this gap is even larger, with life expectancy at birth dropping to just 65.9 years.

The life expectancy at birth for Indigenous females is 75.6 years compared to non-Indigenous females who are expected to live to 83.4 years (7.8 years longer). For remote and very remote Indigenous females, the life expectancy at birth was just 69.6 years.

A total of 988 palliative care-related hospitalisations for Indigenous Australians were reported in 2011–12, with the majority (96%) occurring in public hospitals. There were more hospitalisations for Indigenous males than females. The number of palliative care-related hospitalisations in public hospitals per 10,000 population is twice as high for Indigenous Australians as for 'Other Australians' (34.6 and 19.5, respectively).

While the way Australians are dying might be changing, the heavy burden of disease and premature death weighs heavily on Aboriginal and Torres Strait Islander peoples. Anangu Pitjantjatjarra woman, Melissa Thompson, opposes voluntary assisted dying on the grounds that “the last thing we all, Aboriginal people, need is another avenue to death.” When life is taken away prematurely, it becomes more precious. This view is directly expressed by Aboriginal man Ralph Madigan, who is also a Deacon in the Diocese of Cairns: “We’ve had family that have died from sicknesses, and much in pain, but we wouldn’t dream of having euthanasia. Life is important, life is precious.” In arguing against voluntary assisted dying, Ken Wyatt MP also expressed this view: “I am opposed to the legislation, and I strongly believe that all life is sacrosanct and should be protected.”<sup>27</sup> Aboriginal people have also expressed real horror at the belief “we would just euthanise people because we didn’t want them to suffer.”<sup>28</sup>

Guugu Yimithirr man, Noel Pearson, voiced his opinion on the issue of Voluntary Assisted Dying in *The Australian* on 18 September 2021. Though not overtly advocating for an Aboriginal perspective, nonetheless, he spoke as an Aboriginal man. Pearson argues that opponents of assisted dying are not unaffected by pain and suffering themselves and on the part of their loved ones, but that public policy should not be a question of emotion. Pearson puts forward two powerful questions which must not go unanswered. Firstly, does your individual freedom include the freedom to choose death? And secondly, what does it avail our society if we gain the world and lose our souls?

Pearson argues that voluntary assisted dying laws are being passed by Parliaments, without the public fully understanding the meaning of the profound changes at stake:

I would go so far as to say it is not even a matter of conscience. Or religion. It is a matter of fundamental philosophy. About the history and nature of human society and the meaning of human life and death . . . And the question facing the parliament was whether it was now time to abandon a principle that was more ancient and more common than perhaps any other: that the choice to die was not one that society ever sanctioned.



## CEREMONIES AROUND DEATH

John Lochowiak has strongly argued that euthanasia is culturally unacceptable given the ceremonies around death.<sup>29</sup> This is especially important when an Elder is 'finishing up' and the family and community must ensure their knowledge is passed on through ceremonies. This involves giving the right stories to the right person.<sup>30</sup>

Perhaps the most eloquent explanation of the significance of these ceremonies is explained by Galarrwuy Yunupingu who wrote when his father passed away:

He was the most senior man in the community – in our world – such that his passing called many, many people of great seniority and experience to his side, to sit with the family while he died.

As we sang to his mind, to his head and to his ears, all the songs he loved and had taught us, we made the way and set up the direction for his spirit. Our song cycle, so important to our lives, is particularly important to individuals at the moment of their dying. It means a lot to their past, present and future. The future is already in the song cycle, and it takes senior ceremonial people, with great knowledge and love, to relate that to the dying person. Ordinary people cannot understand this or comprehend the critical importance of the event. Normally there is no hope in finding a place in the spirit home if there is no song. The songline sends you on a course so that your spirit arrives at its rightful destination . . .<sup>31</sup>

On his deathbed, as his spirit started its journey to Badu, the spirit land, my father handed me his clapsticks and his authority. My senior family members saw the passing and told of it throughout the clan nations.<sup>32</sup>

This period before death is vitally important. Even administering pain medication can be seen to interfere with this process, and there is concern that Elders would be leaving without passing on the knowledge.<sup>33</sup>

## IMPACT OF COLONISATION

The Christian belief that only God should create life or destroy it is based on the commandment "thou shalt not kill" (Exodus 20:1-17). During colonisation, Christian missionaries introduced these beliefs to Indigenous peoples. It could be argued this has greatly influenced Indigenous people's opposition to voluntary assisted dying.

Torres Strait Islander woman Rose Elu, has argued against voluntary assisted dying:

because of the strength and wisdom of our faith, we feel that when the time comes for someone to depart, that is in God's hands . . . It would be very difficult for the people to

understand why you would do this, why you would take action to cause someone to die. It is not our way.<sup>34</sup>

Similarly, John Baptist Pupangamrirr from Bathurst Island expressed the view that:

if a person wants to die it is up to the person to die themselves. But if I am a doctor and I give a person a right to kill themselves, if I support the person in killing themselves, then I am a murderer too. It makes me a murderer too. You cannot agree to this sort of thing. Killing is wrong. It is against the Law.<sup>35</sup>

This may be seen as an acquiescence by Indigenous peoples to the views of the missionaries and colonisers. However, this shallowly dismisses the thousands of years of cultural practice that occurred before the arrival of Europeans. It also neglects the complex way in which different cultures interact, and how beliefs about the preciousness of life and meaningfulness of death are shared across cultures and faith traditions.

During the 1995 debate on the *Rights of the Terminally Ill Act 1995* (NT), Chips Macknoilty was engaged by the Northern Territory government to run an Aboriginal Reference Group and later ran 21 information sessions across the Northern Territory. Macknoilty submitted that it was traditional religion and Law that was the overwhelmingly dominant factor influencing Aboriginal people's rejection of the legislation, as the rejection was just as strong in communities not heavily influenced by the Christian churches.<sup>36</sup>

The Meriam people of the Torres Strait believe bright meteors (*Maier*) represent the spirit of the person who has passed on. Meriam elder Ron Day explains that "when someone dies, when you see a falling star or Maier, you always hear a sound in that direction. It's like they received him and the drums go boom". Maier existed pre-colonisation, and continues today demonstrating that the influence of Christianity has not extinguished these traditions.<sup>37</sup>

## ARE INDIGENOUS INSIGHTS BEING CONSIDERED?

Palliative care is becoming more commonly discussed, as is the way Indigenous Australians want to be cared for as they approach their finishing up business. An advanced care plan can document a person's beliefs, values and preferences in order to guide care decisions. Advanced care plans are becoming more common amongst Indigenous people. These plans can support a person's choices and ensure they are cared for in a culturally appropriate way.

The issue of voluntary assisted dying has been debated at both a state and territory level, and at a national level. Rarely has the deep cultural opposition to voluntary assisted dying by Aboriginal and Torres Strait Islander peoples been documented, discussed and considered in great detail. When Indigenous views are considered, they are typically reduced to a problem

about misinformation leading to a fear of doctors and making people fearful of accessing care.<sup>38</sup> When Indigenous people have spoken out, it appears to be a values-based opposition to assisted dying. Yet, in the recent debates, jurisdictions have dismissed these views.

In 2015, the Victorian Legislative Council referred the issue of end-of-life choices to the Standing Committee on Legal and Social Issues. The final report was 444 pages long and considered the arguments for and against legalising assisted dying, but did not consider the cultural reasons that form the basis for Indigenous opposition to this concept. Instead, the report recommended the need to “highlight the benefits of palliative care to Aboriginal and culturally and linguistically diverse Victorians.”<sup>39</sup> This was a missed opportunity for the broader Australian community to engage more deeply and undertake deep listening. It dismissed Indigenous people’s views, and focused instead on how an information campaign could correct their thinking.

## SO WHAT CAN WE LEARN?

It is important to recognise that Aboriginal and Torres Strait Islander cultures are complex and diverse. While there are many common beliefs and practices, there is also diversity in these beliefs, practices, and lived experiences. This complexity is present in all facets of Indigenous policy and service delivery, especially in healthcare and never more so than in end-of-life care or finishing up business.

It is clear that there is some informative anecdotal evidence around Aboriginal and Torres Strait Islander people’s beliefs about dying and death, but it lacks the depth required to truly inform the broader Australian community. It is hoped that this paper will begin to help promote increased discussion of these insights. They remind us and teach us about many important things, including some things we have forgotten or can lose sight of too easily, including:

- we should respect and value elderly people as sources of knowledge fundamental to the transmission of culture, and for their role as carers of kin;
- dying is a special time for passing on wisdom, healing relationships, and caring for others;
- it is important to respect the wishes of the dying person, including through culturally appropriate palliative care and advanced care plans, so that they can remain alert and aware and able to attend to finishing up business;
- people should not die alone in impersonal environments, but be able to go home where they feel the most connected and prepared for the next stage of their journey;
- no one should die alone; just as we need our people around us as we live, we need them with us when we die – and they need to be with us at this time too;

- time needs to be given to finishing up business, and time needs to be given to sorry business; just as the dying person needs to be accompanied – to know they are not alone – so do those who grieve;
- our death is our own, but it affects others. Our life and our death are both anchored in the people around us; we cannot make choices as autonomous individuals that affect our common humanity;
- death is not the end. It is the beginning of another journey, a continuation of life beyond this life;
- life is precious, even when there is suffering.

Over time, Aboriginal and Torres Strait Islander people have raised their voices to draw attention to the opposition to assisted dying, particularly in the Northern Territory. More recently, Dodson and Wyatt have brought to our attention the need to protect our common humanity and the sanctity of life.

Dying and death are difficult issues to deal with, but we cannot allow our discomfort to prevent us from hearing the perspectives of the oldest continuous cultures in the world, and being open to learning from these views.

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“In the broad sense, we are part of a common humanity. If we give one person the right to make that decision – that is, to assist in committing suicide – we as a whole are affected. If we give one family that right, we as a whole are affected. If we give one state or territory that right, we as a country are affected. If we give one nation the right to determine life, our common humanity is affected.”

SENATOR PATRICK DODSON

## ***Finishing up business: What we can learn from Australia's First Peoples about dying and death***

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Robert Moore, *Broom Pines*, 2016 (detail).

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