

Australian Indigenous people and treatment decision-making at end-of-life

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Abstract

This article analyses Australian law and literature to identify the key cultural and legal considerations that can arise in medical treatment decision-making with Aboriginal and Torres Strait Islander peoples at the end-of-life. The authors explore how First Nation peoples' cultural values, connection to Country, family, and community, history, and health care experiences, intersect with end-of-life medical treatment laws, providing valuable insights for lawyers, policymakers and health practitioners.

Keywords

End-of-life, Aboriginal, Torres Strait Islander, medical treatment, health care, guardianship, consent, Indigenous

In Australia, health and wellbeing, and approaches to death, dying and decision-making for many Aboriginal and Torres

Strait Islander peoples (also respectfully referred to as First Nations People or Indigenous people¹) are intrinsically

¹'Aboriginal' refers to 'People who have cultural and ancestral lineage from mainland Australia (including Tasmania) preceding colonisation by the British': Marcia Langton, *The Welcome to Country Handbook: A Guide to Indigenous Australia* (Hardie Grant, 2023) 290 ('Welcome to Country Handbook'). 'Torres Strait Islander' refers to 'People who have cultural and ancestral lineage from the Torres Strait Islands preceding colonisation by the British': at 299. First Nations People and Indigenous people 'are generally acceptable when referring to Australia's original inhabitants': at 290.

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linked to diverse cultural values, customs and beliefs – including connection to Country,² family and community.³ These beliefs and connections, often particularly significant to people at the end-of-life, can influence decision-making about medical treatment, and shape interactions with health professionals and systems.⁴

Historical, social and economic factors, and health care inequities can also profoundly affect death, dying and decision-making for Indigenous people. Australia's colonisation and dispossession, and lengthy history of unjust laws, policies and practices against its First Nations People, has left a legacy of trauma, discrimination, and loss of culture, identity and connectedness.⁵ An ongoing impact of colonisation is the significant health inequalities⁶ that Indigenous people experience, including higher rates of mortality, life-limiting illness, burden of disease and disability than non-Indigenous Australians.⁷ At the end-of-life, systemic barriers including lack of palliative care services in some remote areas, late referrals to palliative care, lack of Culturally Safe and Responsive services, and institutional racism continue to impede Indigenous peoples' access to appropriate health care.⁸

Knowing and understanding this context, and how these factors intersect with health care and the law, is critical for medical treatment decision-making with Indigenous people and the delivery of Culturally Safe and Culturally Responsive care.⁹ It is also relevant to lawyers working in health care, guardianship and disability, and for policymakers developing health care policies and systems that support Indigenous people. Despite this, there has been little exploration of how Indigenous culture and health care experiences may influence medical treatment decision-making in the context of end-of-life law.

End-of-life law focuses on legal issues governing end-of-life decision-making, including advance care planning, decisions about withholding or withdrawing life-sustaining treatment, substitute decision-making, and regulation of palliative care.¹⁰ These laws aim to support provision of

health care consistent with a person's choices and values, to protect health professionals who act within the law, and to establish dispute resolution mechanisms.¹¹ All Australian states and territories have laws governing end-of-life decision-making.¹² Although similar, these laws differ across jurisdictions, and can be complex and difficult to understand.¹³

Few Australian legal cases consider end-of-life decision-making in the Indigenous cultural context. Further, guardianship and medical treatment legislation, state and territory health department policies, and health professional guidelines provide only limited guidance for legal and health professionals in relation to legal issues in this setting.

The authors have examined Australian law and literature to analyse how First Nations' culture, family and community relationships, history, and health care experiences intersect with and influence end-of-life decision-making. We then identified key legal concerns that may arise when caring for Indigenous people at the end-of-life. This informed the development of unique end-of-life law training for Australian health professionals.¹⁴

Our findings provide valuable insights for lawyers, policymakers and health practitioners, demonstrating how these professionals can engage in Culturally Safe and Culturally Responsive end-of-life decision-making with Indigenous people.

Method

Our analysis was undertaken as part of an Australian government-funded national training program, End of Life Law for Clinicians (ELLC).¹⁵ The training program, established in 2017, delivers online modules and workshops for medical practitioners, nurses, allied and other health professionals, and health professional students about Australian end-of-life decision-making laws. The training is also relevant and available to lawyers, policymakers and others.

²Country is defined as follows: 'Country with a capital "C" refers to the culturally defined homelands of Aboriginal and Torres Strait Islander people, for whom "Country" is a complex term, encompassing cultural practices, customs, law, place, language, spiritual beliefs, material sustenance, family and identity all in relation to the lands, waterways and seas to which people are connected.' See Bronwyn Carlson et al, *The Routledge Handbook of Australian Indigenous Peoples and Futures* (Routledge, 2023).

³Langton, *Welcome to Country Handbook* (n 1) 43.

⁴For discussion of how cultural beliefs, communication styles, and family and community relationships can shape interactions with health professionals and systems, see Indigenous Program of Experience in the Palliative Care Approach, *Cultural Considerations: Providing End-of-Life Care for Aboriginal Peoples and Torres Strait Islander Peoples* (Guidelines, 2020) ('IPEPA Cultural Considerations').

⁵Marcia Langton, *Welcome to Country Youth Edition: An Introduction to our First Peoples for Young Australians* (Hardie Grant Explore, 2019).

⁶Juanita Sherwood, 'Colonisation – It's bad for your health: The context of Aboriginal health' (2013) 46(1) *Contemporary Nurse* 28, 29.

⁷Eswaran Waran, Sharon Wallace and Jonathan Dodson-Jauncey, 'Failing to plan is planning to fail: Advance Care Directives and the Aboriginal people of the Top End' (2017) 206(9) *The Medical Journal of Australia* 377, 377.

⁸Shaouli Shahid et al, 'Improving palliative care outcomes for Aboriginal Australians: Service providers' perspectives' (2013) 12(26) *BMC Palliative Care* 1, 1–2; Hylda Wapau et al, 'Coming to town: Reaching agreement on a thorny issue' (2018) 26(6) *Australian Journal of Rural Health* 416, 416.

⁹In health care, Cultural Safety is 'the ongoing critical reflection of health professionals' knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible and responsive healthcare free of racism', while Culturally Responsive and Cultural Responsiveness describe how Culturally Safe care is provided: Indigenous Allied Health Australia, *Cultural Responsiveness in Action: An IAHA Framework* (2019).

¹⁰Lindy Willmott et al, 'Role of Law in End-of-Life Decision-Making: Perspectives of Patients, Substitute Decision-Makers and Families' (2021) 28(3) *Journal of Law and Medicine* 813, 813–4.

¹¹Ibid.

¹²Ben White et al, *Health Law in Australia* (Thomson Reuters, 4th ed, 2023) chs 13, 14, 15 ('HLIA').

¹³Ben White et al, 'Limitations in Health Professionals' Knowledge of End-of-Life Law: A Cross-Sectional Survey' (2021) *BMJ Supportive and Palliative Care* 3061: 8, 2.

¹⁴Ben White et al, 'End of Life Law For Clinicians' (Training Program, 2019) ('ELLC').

¹⁵The ELLC training program (<https://elc.edu.au/>) is funded by the Australian Government Department of Health and Aged Care as a National Palliative Care Project.

A new online module exploring end-of-life law when caring for Aboriginal and Torres Strait Islander peoples was developed by the ELLC training program. To support module development, we reviewed Australian case law, state and territory legislation, and literature (including searches of Google Scholar and PubMed) to identify and examine legal, cultural and health care considerations relevant to end-of-life and Indigenous people. Websites of health professional and palliative care organisations, health departments from all jurisdictions, and guardianship bodies were searched for relevant resources including end-of-life policies and guidelines. Reference lists of relevant literature were reviewed, and potentially relevant documents known to the authors were also considered.

The key considerations, themes and legal issues identified were categorised into various legal domains, drawing on a comprehensive mapping exercise previously undertaken by the ELLC training program.¹⁶ That mapping identified the following 11 (at times overlapping) domains: consent to treatment; decision-making capacity; withholding and withdrawing life-sustaining treatment; advance care planning; substitute decision-making; providing pain and symptom relief at the end-of-life; futile or non-beneficial treatment; emergency treatment; managing conflict/complaints and dispute resolution; children and end-of life decision-making; and voluntary assisted dying (VAD).

Findings

The following sections will discuss our key findings from the analysis of Australian legislation, case law and literature on end-of-life law and Aboriginal and Torres Strait Islander peoples.

Legislation

Human rights legislation in the Australian Capital Territory (ACT), Queensland and Victoria reinforces that First Nations People have distinct cultural and human rights.¹⁷ In these jurisdictions, public authorities, including hospitals and health services, must act consistently with these rights.¹⁸ Queensland law specifically recognises the right to health services.¹⁹

State and territory guardianship and medical treatment legislation provides a framework for medical treatment decision-making for a person with impaired decision-making capacity.²⁰ These laws apply to all people, regardless of cultural background, but provide only broad guidance for decision-making with Indigenous people.

The laws seek to preserve and maintain an Aboriginal and Torres Strait Islander person's cultural values, beliefs, customs, protocols and supportive relationships (for example, with family and community) when the person lacks capacity. Most state and territory legislation recognises that an individual's cultural and linguistic environment and values should be promoted, maintained and taken into account in decision-making for a person with impaired capacity.²¹ In Queensland and the ACT, the importance of maintaining the person's Aboriginal or Torres Strait Islander cultural and linguistic environment and values, including Aboriginal tradition or Island custom, is specifically recognised and must be considered.²²

In relation to communication, some legislation enables a person to receive assistance from an interpreter to make an Advance Care Directive.²³ Several jurisdictions also recognise that a finding of impaired decision-making capacity in someone should not be based on that person's inability to speak English, or engaging in or making decisions because of particular cultural or religious practices or beliefs.²⁴

¹⁶White et al, *ELLC* (n 14).

¹⁷These rights relate to cultural heritage, spiritual practices and beliefs; language, knowledge, and kinship ties; and the land, waters and resources to which Indigenous people are connected under traditional law and customs: *Human Rights Act 2004* (ACT) s 27 ('*Human Rights Act ACT*'); *Human Rights Act 2019* (Qld) Preamble (6), s 28 ('*Human Rights Act Qld*'); *Charter of Human Rights and Responsibilities 2006* (Vic) s 19 ('*Charter of Human Rights Vic*'). Although Tasmania's guardianship legislation does not recognise distinct cultural and human rights of First Nations People, it requires the human rights of a person recognised in the International Covenant on Economic, Social and Cultural Rights to be taken into account when giving effect to an Advance Care Directive: *Guardianship and Administration Act 1995* (Tas) ss 35B(e), (g)(i)-(iii) ('*Guardianship Act Tas*').

¹⁸*Human Rights Act ACT* (n 17) ss 40A(1), (3)(b)(iii), 40B(1); *Human Rights Act Qld* (n 17) ss 9, 10(3)(b)(i)-(iii); *Charter of Human Rights Vic* (n 17) s 4.

¹⁹*Human Rights Act Qld* (n 17) Preamble (6), ss 27, 28(1), (2), 37.

²⁰*Guardianship and Management of Property Act 1991* (ACT) ('*Guardianship Act ACT*'); *Human Rights Act ACT* (n 17); *Mental Health Act 2015* (ACT); *Powers of Attorney Act 2006* (ACT) ('*Powers of Attorney Act ACT*'); *Guardianship Act 1987* (NSW) ('*Guardianship Act NSW*'); *Advance Personal Planning Act 2013* (NT) ('*Advance Personal Planning Act NT*'); *Guardianship of Adults Act 2016* (NT) ('*Guardianship Act NT*'); *Guardianship and Administration Act 2000* (Qld) ('*Guardianship Act Qld*'); *Human Rights Act Qld* (n 17); *Powers of Attorney Act 1998* (Qld) ('*Powers of Attorney Act Qld*'); *Advance Care Directives Act 2013* (SA) ('*Advance Care Directives Act SA*'); *Consent to Medical Treatment and Palliative Care Act 1995* (SA) ('*Consent and Palliative Care Act SA*'); *Guardianship and Administration Act 1993* (SA) ('*Guardianship Act SA*'); *Guardianship Act Tas* (n 17); *Charter of Human Rights Vic* (n 17); *Guardianship and Administration Act 2019* (Vic) ('*Guardianship Act Vic*'); *Medical Treatment Planning and Decisions Act 2016* (Vic) ('*Medical Treatment Planning and Decisions Act Vic*'); *Mental Health Act 2014* (Vic); *Guardianship and Administration Act 1990* (WA) ('*Guardianship Act WA*').

²¹*Powers of Attorney Act ACT* (n 20) sch 1.9(1); *Guardianship Act NSW* (n 20) ss 4(e), 14(2)(c), 28(2)(c); *Guardianship Act Qld* (n 20) s 11B(3) General Principle 5; *Powers of Attorney Act Qld* (n 20) s 6C General Principle 5; *Advance Care Directives Act SA* (n 20) s 10(e); *Guardianship Act Tas* (n 17) s 35B(e); *Guardianship Act Vic* (n 20) ss 4(c); *Medical Treatment Planning and Decisions Act Vic* (n 20) s 7(1)(c); *Guardianship Act WA* (n 20) s 51(2)(h).

²²*Powers of Attorney Act ACT* (n 20) sch 1.9(2); *Guardianship Act Qld* (n 20) s 11B(3) General Principle 5(2).

²³*Advance Care Directives Act SA* (n 20) s 14(1); *Guardianship Act Tas* (n 17) s 35J; *Medical Treatment Planning and Decisions Act Vic* (n 20) s 99.

²⁴*Guardianship Act ACT* (n 20) s 6A(b); *Powers of Attorney Act ACT* (n 20) s 91(1)(c); *Advance Personal Planning Act NT* (n 20) ss 6(5)(e), (f); *Guardianship Act NT* (n 20) ss 5(6)(e), (g); *Guardianship Act Tas* (n 17) s 35D(5)(g).

Health policies, guidelines and regulatory instruments

Health policies and guidelines vary between jurisdictions, and most do not provide specific guidance on end-of-life decision-making and Indigenous people.²⁵

In Queensland and New South Wales (NSW), some guidance is provided on obtaining consent to medical treatment, communication, and cultural considerations in delivering health care.²⁶ In Western Australia (WA), Queensland and NSW, there are also resources for health professionals caring for Indigenous people wanting to access VAD, but similar resources do not exist in the other states where VAD is operating.²⁷

Despite this, most health professional codes of conduct require health professionals to provide Culturally Safe and Culturally Responsive care, and to respect a person's diverse cultural practices and beliefs relating to death and dying.²⁸ National safety and quality standards for health services and aged care also require delivery of Culturally Safe and Culturally Responsive care.²⁹

Case law

We found very few Australian cases that focus on end-of-life decision-making for Indigenous peoples. Most do not consider the impact of the person's cultural values and beliefs or family relationships in decision-making. For example, the cases *Application of a Local Health District; Re a Patient Fay* [2016] NSWSC 624 and *Re PVM* [2000] QGAAT 1 concerned determinations of decision-making capacity, refusal of treatment and withholding of treatment. However, there was no discussion of the patients' Aboriginal cultural values, beliefs and practices in decision-making.

Some state and territory guardianship tribunals have considered the role of family and community; maintaining cultural, spiritual, and family connections; and returning to and connections with Country in applications for the appointment (or review of appointment) of a guardian or administrator for an Aboriginal and/or Torres Strait Islander person with impaired capacity.³⁰ These cases focus on whether there is a need for a guardian for broader health care, financial and personal decisions

(such as accommodation) rather than specific decisions about end-of-life treatment. However, they provide some guidance as to how tribunals may consider a person's culture and family relationships in determining guardianship applications.

There was brief consideration of an Aboriginal person's culture in relation to continuation of artificial nutrition and hydration in *Re Herrington* [2007] VSC 151. There, the hospital decided to cease artificial feeding and antibiotics and provide palliative care to an Aboriginal woman in a persistent vegetative state. The patient's partner and family applied for an order that continuing medical treatment was in her best interests. They believed she was responsive, and that food and drink should continue to be provided, in accordance with Aboriginal cultural values. The family also argued that 'Aboriginal culture involves caring for people who are unwell'.³¹

Williams J considered 'everything said about the cultural values of Aboriginal society' but accepted the unanimous medical evidence that continuing treatment would be futile, and may hasten death or cause unnecessary pain and suffering.³² The decision attracted some criticism for not giving sufficient weight or consideration to Aboriginal cultural values and human rights raised by the patient's family, or Aboriginal cultural rights (a requirement of the *Charter of Human Rights and Responsibilities Act 2006* (Vic)).³³

There was also discussion of cultural practices in decision-making in *Livermore v The New Children's Hospital Westmead* [2002] NSWADT 111. This case involved a claim of discrimination against the applicants during the time their infant child was in the respondent's care. Life-sustaining treatment was withdrawn from the child after an unsuccessful operation. The applicants alleged discrimination on the grounds of race and provision of goods or services in contravention of the *Anti-Discrimination Act 1977* (NSW).

A central argument was that clinicians treated the applicant father differently and less favourably than the applicant mother because his appearance was Aboriginal. The applicants gave evidence that staff addressed the mother in preference to the father even though

Aboriginal culture required the man of the family to deal with major questions relating to the family. This would then be

²⁵Queensland Health, *Aboriginal and Torres Strait Islander Patient Care Guideline* (May 2014) ('Qld Aboriginal and Torres Strait Islander Patient Care Guideline'); Victoria Department of Health, *Victoria's End of Life and Palliative Care Framework* (2016); Government of WA, Department of Health, *Aboriginal End-of-Life and Palliative Care Framework* (2021).

²⁶NSW Health, *Consent to Medical and Healthcare Treatment Manual* (2020) s 4.8.5 ('NSW Consent to Treatment Manual'); Queensland Health, *Guide to Informed Decision-Making in Health Care* (2nd ed, 2017) s 5.3, 5.4 ('Qld Guide to Informed Decision-Making').

²⁷Government of WA, Department of Health, *Voluntary Assisted Dying in Western Australia: Information about Supporting Aboriginal People* (Information Sheet, 2021) ('VAD in WA: Supporting Aboriginal People'). Queensland Health and NSW Health provide similar information for health professionals.

²⁸Ahpra & National Boards, *Shared Code of Conduct* (29 June 2022); Medical Board Ahpra, *Good Medical Practice: A Code of Conduct for Doctors in Australia* (20 April 2021); Nursing and Midwifery Board Ahpra, *Code of Conduct for Nurses* (1 March 2018).

²⁹Australian Commission on Safety and Quality in Health Care, *NSQHS Standards User Guide for Aboriginal and Torres Strait Islander Health* (2017); Australian Aged Care Quality and Safety Commission, *Consumer Dignity and Choice: Standard 1* (2021); Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care* (2023) ('Safety and Quality National Consensus Statement').

³⁰QAI [2010] NSWGT 7; DZT [2022] NSWCATGD 7; *Re MC* [No.3] [2021] NTCAT 22; BSA [2014] QCAT 206; CDM [2010] QCAT 317; *Re RTB* [2023] SACAT 44; JL [2023] WASAT 20.

³¹*Re Herrington* [2007] VSC 151, [18] ('*Re Herrington*').

³²*Ibid* [23].

³³Thomas Faunce, 'Re Herrington: Aboriginality and the Quality of Human Rights Jurisprudence in End-of-Life Decisions by the Australian Judiciary' (2007) 15(2) *Journal of Law and Medicine* 201, 204-5.

related back to the family so that each member can have some input in the decision-making process.³⁴

By showing preference in addressing the mother, the father 'was humiliated and shamed within his cultural framework'.³⁵ The Tribunal ultimately concluded there was no discrimination by the respondent.

Re Herrington and Livermore provide useful guidance for lawyers and health practitioners about cultural considerations that may arise in the context of decision-making with Indigenous patients, families and communities at the end-of-life.

Due to the recency of the operationalisation of VAD laws in Australia, there are very few reported decisions relating to VAD. To date, no reported cases have involved consideration of Indigenous cultural values, beliefs or decision-making practices. *Wake v Northern Territory of Australia* (1996) 109 NTR 1 involved a constitutional challenge to the validity of the now-repealed *Rights of the Terminally Ill Act 1995* (NT), which permitted voluntary euthanasia in the Northern Territory (NT) between 1996 and 1997. The plaintiffs included an Aboriginal Uniting Church Minister, the Reverend Djiniyini Gondarra. One of the key arguments was that the Act violated an inalienable right to life and was therefore invalid. This case was decided on constitutional law grounds, and the judgment did not discuss end-of-life decision-making, or Aboriginal and/or Torres Strait Islander cultural values or beliefs.

Literature review

The literature revealed that end-of-life legal concerns for Indigenous people arise primarily within two domains: consent to treatment and approaches to decision-making. Six other domains – advance care planning, withholding or withdrawing life-sustaining treatment, futile and non-beneficial treatment, managing conflict, administering pain and symptom relief, and VAD – were also identified (these will be referred to as treatment decisions). Across all domains, two core themes emerged about approaches to end-of-life decision-making: first, the importance of clear, honest and Culturally Safe and Respectful communication with patients, families, and community; and second, for some Indigenous people, the role of collective decision-making with family and community.

There is significant diversity among First Nations People, and different preferences, beliefs and values about end-of-life decisions and medical treatment. Accordingly, the

findings presented below may not apply to everyone. It is important to discuss with every patient (and, with consent, their family or community) their preferences, and identify individual needs.

Consent to medical treatment and communication

Consent to treatment is valid when it is given freely and voluntarily, a person has decision-making capacity, and it applies to the circumstances.³⁶ Decision-making capacity is presumed unless a person is unable to comprehend, retain, use and weigh the relevant information.³⁷ The literature reported additional factors relevant to obtaining consent from Indigenous people (see [Figure 1](#), on the following page).

Clear, honest and respectful communication between health care providers, patients and families, and strong relationships based on trust and rapport underpins end-of-life decision-making with Aboriginal or Torres Strait Islander peoples. Good communication and rapport with patients and families allows the person's values and cultural beliefs associated with dying to be explored and understood, and their preferences followed (for example, returning to and dying on Country or involving family and community in decision-making).³⁸ It also enables accurate determinations of decision-making capacity, and effective consent and decision-making processes.

Aboriginal and Torres Strait Islander health practitioners and health workers play a significant role in supporting communication, obtaining consent, and decision-making. These health professionals coordinate and provide specialised, holistic, Culturally Safe and Culturally Responsive health services to Indigenous people at the end-of-life.³⁹ Aboriginal and Torres Strait Islander health workers provide essential emotional, social and cultural support to patients with a life-limiting illness and their families.⁴⁰ They are an important conduit between the individual, family and clinical team in hospital and health services, and the community, understanding language (verbal and non-verbal) of the people they care for, as well as Indigenous cultural beliefs and knowledge.⁴¹

Other relevant factors include support for communication, including interpreters, setting aside more time for yarning (conversations), and the importance of kinship and culture in decision-making.⁴²

In many Aboriginal communities, child rearing practices are communal, often involving extended family.⁴³ Treatment decisions for children may be a shared responsibility of the child's parents, extended family and community members, and the child's biological parents.⁴⁴ In Torres

³⁴*Livermore v The New Children's Hospital Westmead* [2002] NSWADT 111, 24.

³⁵*Ibid* 25.

³⁶White et al, *HLIA* (n 12) ch 5.

³⁷*Ibid*.

³⁸Ivan Lin, Charmaine Green and Dawn Bessarab, "'Yarn with me': Applying Clinical Yarning to Improve Clinician–Patient Communication in Aboriginal Health Care' (2016) 22(5) *Australia Journal of Primary Health* 377, 377.

³⁹National Aboriginal and Torres Strait Islander Health Worker Association, *The importance of Aboriginal and/or Torres Strait Islander Health Workers and Health Practitioners in Australia's health system* (Statement, August 2019) 1.

⁴⁰*Qld Aboriginal and Torres Strait Islander Patient Care Guideline* (n 25).

⁴¹Pat McGrath et al, 'The case for Aboriginal Health Workers in palliative care' (2007) 3(3) *Australian Health Review* 430, 437.

⁴²Lin, Green and Bessarab (n 38) 378.

⁴³Simone Sherriff and Josephine D Gwynn, 'Yarning Together: Toward targeted, co-designed parenting programs for Aboriginal Australians' (2024) 220(6) *Medical Journal of Australia* 313, 313.

⁴⁴*NSW Consent to Treatment Manual* (n 26) s 8.8.



Figure 1. Diagram of considerations for medical treatment discussions with Indigenous people.

Strait Islander cultures, consent to medical treatment may be the responsibility of the child's cultural parents in accordance with Ailan Kastom traditional adoption and child rearing practice.⁴⁵

At the end-of-life, advance care planning processes may be undertaken to determine a person's values and preferences about treatment if they lose decision-making capacity in the future.⁴⁶ Many First Nations People may prefer to communicate about the end-of-life through advance care yarning.⁴⁷ This approach, embodying traditional yarning practices, involves people connecting, storytelling, and sharing information.⁴⁸ In the end-of-life context, yarning supports discussions about treatment and care preferences and needs, and cultural and spiritual values and beliefs. If the person desires, it can include formally documenting these in an Advance Care Directive or other planning documents (but this is less common among Indigenous than non-Indigenous people).⁴⁹ For many Indigenous people the terms 'death' and 'dying' may not be appropriate, therefore care should be taken to use the person's preferred

terminology in advance care planning and other end-of-life conversations.⁵⁰

Collective decision-making

In First Nations Peoples' kinship systems and Lore, the individual, family, and community are innately linked.⁵¹ Connection to family, community and Country is also fundamental to Indigenous peoples' health and wellbeing.⁵² While medical treatment laws in Australia generally focus on individual autonomy, some Indigenous people may prefer collective decision-making, a cultural approach involving collaborative and consultative decision-making with family, Elders and/or community.⁵³

The critical role of family and community in supporting decision-making was a core theme that arose throughout our analysis. A health care decision may consider the needs of family and community and therefore a patient may seek input from others before deciding.⁵⁴ Patients may identify the 'right person' within their family or community for involvement in the decision-making process if this is a cultural protocol.⁵⁵ Decisions

⁴⁵Queensland government, *Legal Recognition of Torres Strait Islander Traditional Child Rearing Practice* (Web Page, 6 September 2021) <https://www.qld.gov.au/firstnations/family-social-support/torres-strait-islander-traditional-child-rearing-practice>.

⁴⁶*Safety and Quality National Consensus Statement* (n 29).

⁴⁷Lin, Green and Bessarab (n 38) 378.

⁴⁸*Ibid.*

⁴⁹*Ibid* 381.

⁵⁰Alternative phrases that may be preferred include *finishing up, passing away, passed on, gone, returning to spirit, sick person, not going to get better, unwell, into the Dreaming/returning to the Dreaming*: Gwandalan National Palliative Care Project, 'eLearning Modules', *Part 1: Introduction to Aboriginal and Torres Strait Islander Palliative Care* (2021) <https://gwandalanpalliativecare.com.au/elearning-modules/>.

⁵¹Langton, *Welcome to Country Handbook* (n 1) 89.

⁵²Lowitja Institute, *Links between Aboriginal and Torres Strait Islander Culture and Wellbeing: What the evidence says* (Report, November 2018).

⁵³Ian Olver et al, 'Communicating cancer and its treatment to Australian Aboriginal and Torres Strait Islander patients with cancer: A qualitative study' (2022) 30(1) *Supportive Care in Cancer* 431; Tossy Baadjo Nangala, Gracie Mosquito Nangala and Brian McCoy, 'Who Makes Decisions for the Unconscious Aboriginal Patient?' (2008) 32(1) *Aboriginal & Islander Health Worker Journal* 6.

⁵⁴*Qld Guide to Informed Decision-Making* (n 26) 68.

⁵⁵*IPEPA Cultural Considerations* (n 4) 15.

may become shared decisions, made within family contexts and within a wide network of supportive relationships and responsibilities. They are not decisions of one Person: the partner, the parent or the child.⁵⁶

However, decision-making preferences vary among individuals, with some Indigenous people preferring to make decisions independently.

Decisions may be influenced by traditions, cultural protocols, kinship, and family dynamics. For example, decision-making may be led by a certain person, such as the eldest person in the family,⁵⁷ or Elders or others within kinship groups may be consulted.⁵⁸ The decision-maker recognised by guardianship and medical treatment laws may not be the same as the cultural decision-maker, based on cultural Lore and protocols.⁵⁹ Some decisions may only be made by male or female family members if considered Men's or Women's business.⁶⁰

Some jurisdictions' guardianship and medical treatment legislation (and health policies) support a person's choice to involve family or community in decision-making, as well as to decide independently. For example, in the ACT, South Australia and Tasmania, a person's wish to involve family and relatives in decision-making, and to make decisions collaboratively with family and community, is recognised.⁶¹ Queensland's legislation acknowledges and respects the role of families and significant persons in the adult's life to support the adult to make decisions.⁶² In all jurisdictions, a person's decision to involve or not involve family or community in decision-making should be respected.⁶³

State and territory guardianship and medical treatment legislation provides a framework for treatment decisions to be made by a 'default' decision-maker if a person does not

have capacity and there is no Advance Care Directive or appointed decision-maker.⁶⁴ In all states and territories except the NT and Victoria, a person's close relative or friend can be a default decision-maker.⁶⁵ This could be an Indigenous person's extended family, friends and community representatives.⁶⁶ In Queensland and SA, relatives under Aboriginal tradition, Torres Strait Islander custom, or Aboriginal or Torres Strait Islander kinship rules are recognised as default decision-makers.⁶⁷ In SA, this includes an adult legally married to a person in accordance with Aboriginal tradition.⁶⁸ There may be more than one possible default decision-maker, which may be the case if the person has many family members under kinship protocols.⁶⁹

Queensland has further provisions relating specifically to Indigenous people. For example, whether a potential guardian is compatible with the person, ie whether they have appropriate cultural or social knowledge or experience, is a consideration the tribunal must take into account when appointing a guardian for the adult.⁷⁰ Another example is that, in order to be a statutory health attorney (default decision-maker), a person must be 'culturally appropriate' to exercise decision-making power.⁷¹

In the NT, a person related to the adult in accordance with Aboriginal customary law or tradition may be an 'interested person' and consulted by a decision-maker when determining what is in the adult's best interests.⁷²

In clinical practice, when there are multiple family members involved in decision-making and the person does not have capacity, decisions are generally reached through shared decision-making at family meetings. This involves the person's clinical team bringing together close and extended family, Elders and possibly other community members to discuss and decide about the person's care and treatment.⁷³ Including Aboriginal and Torres Strait Islander health care

⁵⁶Tossy Baadjo Nangala, Gracie Mosquito Nangala and McCoy (n 53).

⁵⁷Office of the Public Advocate Queensland, *Research Insights: Aboriginal and Torres Strait Islander Queenslanders with Impaired Decision-Making Capacity* (Report, 2013) 2.

⁵⁸Ibid; Tossy Baadjo Nangala, Gracie Mosquito Nangala and McCoy (n 53).

⁵⁹See, eg, Tossy Baadjo Nangala, Gracie Mosquito Nangala and McCoy (n 53). The authors explain who has decision-making responsibilities and who should be consulted about significant treatment decisions, in accordance with communities' kinship relationships and cultural norms and values.

⁶⁰Bronwyn Fredericks, Mick Adams and Odette Best, 'Indigenous gendered health perspectives' in Odette Best and Bronwyn Fredericks (eds), *Yatdjuligin: Aboriginal and Torres Strait Islander Nursing and Midwifery Care* (Cambridge University Press, 2021) 105.

⁶¹*Powers of Attorney Act ACT* (n 20) s 1.1(2); *Advance Care Directives Act SA* (n 20) s 10(e); *Guardianship Act Tas* (n 17) s 35B(e); *Medical Treatment Planning and Decisions Act Vic* (n 20) s 7(1)(f)(v).

⁶²*Guardianship Act Qld* (n 20) s 11B(3) General Principle 4(3); *Powers of Attorney Act Qld* (n 20) s 6C General Principle 4.

⁶³NSW Health, *End-of-life Care and Decision-Making* (8 April 2021).

⁶⁴White et al, *HLLA* (n 12) ch 7.

⁶⁵In September 2023 the NT Parliament passed the *Health Care Decision Making Act 2023* (NT) ('*Health Care Decision Making Act NT*') (yet to commence) which will introduce default decision-makers.

⁶⁶*Powers of Attorney Act ACT* (n 20) s 1.9(2); *Guardianship Act NSW* (n 20) s 3E(1) (definition of 'close friend or relative'); *Guardianship Act Qld* (n 20) ss 11B(3) General Principle 4, General Principle 5(2); *Consent and Palliative Care Act SA* (n 20) ss 14(1) (definition of 'person responsible'), (2); *Guardianship Act Tas* (n 17) s 35B(e); *Guardianship Act WA* (n 20) s 44.

⁶⁷*Guardianship Act Qld* (n 20) ss 11B General Principle 4, 11B(f); *Powers of Attorney Act Qld* (n 20) s 63(5)(b); *Consent and Palliative Care Act SA* (n 20) ss 14(1) (definition of 'prescribed relative' and 'person responsible'), 14(2); *Guardianship Act SA* (n 20) ss 3(1) (definition of 'prescribed relative' and 'person responsible'), 33(1)(e)(i).

⁶⁸*Guardianship Act SA* (n 20) s 3(5).

⁶⁹The NT's *Health Care Decision Making Act NT* (n 65) will allow for the default decision-maker to be a relative of the adult who is considered by Aboriginal or other customary law or tradition to be the appropriate person to be the decision maker: at s 13(c).

⁷⁰*Guardianship Act Qld* (n 20) s 15(1)(d).

⁷¹*Powers of Attorney Act Qld* (n 20) s 63(1).

⁷²*Guardianship Act NT* (n 20) ss 4(5)(b), 7(1)(j) (definition of 'relative').

⁷³*IPEPA Cultural Considerations* (n 4) 25.

professionals in meetings (with the family's consent) can facilitate decision-making and obtaining consent.⁷⁴

Treatment decisions

Issues relating to withholding or withdrawing life-sustaining treatment, futile or non-beneficial treatment, administering pain and symptom relief, and VAD also arose in the literature.

For many Indigenous people, decisions about withholding (not starting) or withdrawing (stopping) life-sustaining treatment may be influenced by the person's cultural, spiritual and religious beliefs, and connection to Country, family and community.⁷⁵ For example, a person may refuse life-prolonging treatment and/or transfer to hospital or care facilities in order to pass away on Country or remain close to community.⁷⁶ A related challenge is provision of treatment that is unnecessary or unlikely to benefit the person. Although the law does not require health professionals to provide treatment that is futile or non-beneficial, research indicates that such treatment is often provided at the end-of-life.⁷⁷ For Indigenous people, non-beneficial treatment can result in unnecessary hospital admissions, false hope of recovery, or deterioration preventing the person from returning home to pass away.⁷⁸ Such outcomes can cause considerable emotional and spiritual distress to the person and family.⁷⁹

Considerations relating to administering pain and symptom relief were also identified. These include beliefs among some Indigenous people that suffering is a necessary part of sickness and death, uncertainty about pain medication and fear of addiction.⁸⁰ Concerns that strong pain relief may prevent a person from communicating, spending time with family, or passing on traditional knowledge were also raised.⁸¹ These factors may lead to the refusal of pain and symptom relief at the end-of-life.

In some communities, fear of payback (practices of punishment or retaliation under cultural Lore) may arise,⁸² where a dying person's community feel the person was poisoned or their death was hastened by care providers.⁸³

Blame may be directed at family members or health professionals administering the medication.⁸⁴ This may make health professionals reluctant to provide pain relief.⁸⁵ Clear communication about pain relief can reduce this fear and dispel myths.

VAD was identified as an area relevant to First Nations People. At the time of writing, VAD is operating in all states.⁸⁶ Reports of some states' VAD regulatory Boards indicate that people who identify as Aboriginal and/or Torres Strait Islander have applied to access VAD.⁸⁷

As with the general Australian population, there are diverse attitudes and beliefs regarding VAD among First Nations People. For all people, personal values and beliefs, including cultural, spiritual and religious beliefs, guide decision-making at the end-of-life,⁸⁸ including decisions about accessing VAD.⁸⁹ While a person may involve family and others in discussions about VAD, each state's laws require the decision to access VAD to be made autonomously and voluntarily by the person, and only if they have decision-making capacity.⁹⁰ An Indigenous person's family or community cannot choose VAD for a person.⁹¹ Where required, interpreters can provide communication support to assist a person to access VAD.⁹²

Online training module

The online training module *Aboriginal and/or Torres Strait Islander Peoples and end of life law* was launched in September 2022 as part of the ELLC training program.⁹³ It is self-directed, interactive and includes case studies.

In addition to legal analysis, consultation was undertaken with Aboriginal and Torres Strait Islander palliative care and health professional stakeholders to inform the module. The consultation included participation in a National Yarning Circle comprising representatives from key Indigenous health professional bodies. These stakeholders provided invaluable knowledge, stories and perspectives about end-of-life and palliative care to support identification of

⁷⁴Shahid et al (n 8).

⁷⁵Re Herrington (n 31).

⁷⁶Wapau et al (n 8) 416.

⁷⁷Lindy Willmott et al, 'Reasons Doctors Provide Futile Treatment at the End of Life: A Qualitative Study' (2016) 42(8) *Journal of Medical Ethics* 496, 500-501.

⁷⁸Craig Sinclair et al, 'A public health approach to promoting advance care planning to Aboriginal people in regional communities' (2014) 22(1) *The Australian Journal of Rural Health* 23, 23-24.

⁷⁹Pam McGrath and Emma Phillips, 'Western Notions of Informed Consent and Indigenous Cultures: Australian Findings at the Interface' (2008) 5(1) *Journal of Bioethical Inquiry* 21, 27.

⁸⁰Ian Maddocks and Robert Rayner, 'Issues in Palliative Care for Indigenous Communities' (2003) 179(6) *Medical Journal of Australia* S17, S18.

⁸¹Pam McGrath, "'The Biggest Worry...': Research Findings on Pain Management for Aboriginal Peoples in the Northern Territory, Australia' (2006) 6(3) *Rural and Remote Health* 549, 560-1.

⁸²Mark Finnane, "'Payback', Customary Law and Criminal Law in Colonised Australia' (2001) 29(4) *International Journal of the Sociology of Law* 293, 293.

⁸³Eswaran Waran et al, "'Finishing up" on Country: Challenges and Compromises' (2016) 46(9) *Internal Medicine Journal* 1108, 1109.

⁸⁴Sinclair et al (n 78) 25.

⁸⁵McGrath (n 81) 556.

⁸⁶Katherine Waller et al, 'Voluntary Assisted Dying in Australia: A Comparative and Critical Analysis of State Laws' (2023) 46(4) *UNSW Law Journal* 1, 2-3. Currently VAD is not lawful in the ACT or NT.

⁸⁷Queensland Voluntary Assisted Dying Review Board, *Annual Report 2022-2023* (Report, 29 August 2023) 18; Safer Care Victoria, *Annual Report: July 2022 to June 2023* (Report, June 2023) 17; Voluntary Assisted Dying Board Western Australia, *Annual Report 2021-22* (Report, 16 November 2022) 17.

⁸⁸NSW Health, *NSW Voluntary Assisted Dying Clinical Practice Handbook* (9 October 2023) 40 ('NSW VAD Handbook').

⁸⁹Sophie Lewis et al, 'First Nations' Perspectives in Law-Making About Voluntary Assisted Dying' (2022) 29(4) *Journal of Law and Medicine* 1168, 1177-8.

⁹⁰VAD in WA: *Supporting Aboriginal People* (n 27) 2.

⁹¹NSW VAD Handbook (n 88).

⁹²Voluntary Assisted Dying Act 2022 (NSW) s 183; Voluntary Assisted Dying Act 2021 (Qld) s 157; Voluntary Assisted Dying Act 2021 (SA) s 7; End-of-Life Choices (Voluntary Assisted Dying) Act 2021 (Tas) s 15(3); Voluntary Assisted Dying Act 2017 (Vic) s 115; Voluntary Assisted Dying Act 2019 (WA) s 162.

⁹³White et al, ELLC (n 14).



Figure 2. Main artwork.



Figure 3. ELLC Indigenous logo. (Designed by Isaac Simon and Daniel Richards, Kit Kreative).

relevant cultural, health and legal considerations. Non-Indigenous health professionals with experience caring for Indigenous people were also consulted.

All stakeholders shared perspectives on the challenges that First Nations People may experience in end-of-life decision-making, and stories of decision-making involving Indigenous patients, families and community. Three Indigenous professionals with expertise in nursing, health and palliative care (including co-author Eliza Munro) were integral in identifying these challenges and concerns, providing knowledge, facilitating connections with Indigenous stakeholders, guiding module development, and undertaking review.

An Aboriginal artist worked with a graphic designer to design a unique logo and artwork for the module (Figures 1, 2 and 3). The artwork demonstrates the importance of cultural law and Lore in the Indigenous setting. It depicts the flow of information through community back and forth to understand practices and protocols, and how they relate to mainstream non-Indigenous law.

The module is novel in several respects. It examines significant historical, socio-economic, cultural, and health care considerations relating to Aboriginal and Torres Strait Islander peoples. This enables the cultural, historical and social context in which the law operates to be understood and acknowledged. Further, consultation with key Indigenous stakeholders enabled Aboriginal and Torres Strait Islander knowledge and perspectives to directly inform the development of accurate, relevant, Culturally Safe and Culturally Responsive module content, and realistic case studies based on actual experiences and clinical cases. Finally, the module comprehensively addresses Australian

end-of-life decision-making laws relevant to the experiences of First Nations People.

Conclusion

End-of-life decision-making for many Aboriginal and Torres Strait Islander peoples can be shaped by diverse cultural values, beliefs and customs. Connection to Country, kinship, Lore, spirituality and religion may have a profound impact on treatment preferences. However, some Indigenous people continue to face significant barriers to accessing health care, arising from a range of historical, socio-economic and systemic factors, which can also impact end-of-life decision-making.

We undertook a novel analysis to determine the key legal considerations at end-of-life when caring for Aboriginal and Torres Strait Islander peoples. These processes highlighted consent to treatment, collective and substitute decision-making, and end-of-life treatment decisions including withholding and withdrawing life-sustaining treatment, provision of pain and symptom relief, as well as VAD, as key areas relevant to Indigenous people.

Two central themes – the importance of clear, honest and Culturally Safe and Respectful communication, together with the role of collective decision-making at the end-of-life – emerged throughout the analysis. Effective communication and trusting relationships between health professionals and Indigenous people is critical to obtaining consent, capacity determination, treatment decision-making, resolving conflict and delivering end-of-life care that reflects the person's preferences and values. Some Indigenous people may prefer to make end-of-life decisions collectively, where decision-making occurs collaboratively with family and community.

This analysis has important implications for legal and health professionals, and for policymakers. For each of these groups, understanding the cultural, historical, social and health factors influencing end-of-life decision-making with First Nations People can support delivery of health and legal services and systems that are culturally aware, safe and responsive.⁹⁴ This can also reduce existing barriers to accessing palliative and end-of-life care for many Indigenous people. We also suggest there may be value in education for Indigenous communities on the core themes and domains discussed in this article, to support enhanced knowledge and awareness of the law and legal rights at the end-of-life.

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⁹⁴Lewis et al (n 89) 1181–2.

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