

# Failing to plan is planning to fail: advance care directives and the Aboriginal people of the Top End

Advance care directives can enable Aboriginal people to fulfil their end-of-life wishes to die in their community

**T**he United Kingdom's great wartime Prime Minister, Sir Winston Churchill, once said "he who fails to plan is planning to fail". These prescient words resonate for advanced care planning and end-of-life decision making.

Advance care directives (ACDs) are used in all Australian states and territories, but take different forms and names. In the Northern Territory, they are known as advance personal plans (APPs).<sup>1</sup> An APP allows not only for advanced consent decisions in relation to life support and palliative care, but also the appointment of a substitute decision maker. The powers of the substitute decision maker under the *Advance Personal Planning Act 2013* can include health and financial matters.<sup>1</sup>

ACDs have a valuable role for Aboriginal and Torres Strait Islander (respectfully referred to hereafter as Aboriginal) Australians for two important reasons. First, Aboriginal people suffer from higher rates of life-limiting conditions and burden of disability approaching end of life.<sup>2</sup> Second, because of their strong connections to land and community, Aboriginal people from rural and remote regions have a strong preference to "die at home connected to land and family".<sup>3</sup> McGrath outlined a fear of dying away from home for Aboriginal patients from remote communities and outstations, who were relocated to tertiary facilities often hundreds of kilometres away.<sup>3</sup> Early discussion of end-of-life preferences, with the use of an ACD, could play an important part in preventing unnecessary displacement of patients by allowing those who wish to die in their community to do so.

Nevertheless, the sparse research in this area suggests that advanced care planning is not common place for most Aboriginal people.<sup>2,4</sup> Some of the reasons for this include the taboo of death talk, communication barriers, presence of multiple clinicians (with no single professional taking on the responsibility for initiation of discussion), uncertainty in prognosis, availability of family (often limited by distance), scarcity of Aboriginal health practitioners, and the formal, structured approach of an ACD. Regardless, Sinclair and colleagues demonstrated acceptance for ACDs in their qualitative study of Aboriginal people in the Great Southern region of Western Australia.<sup>2</sup> Their patients outlined the potential for the ACD to ameliorate family disputes. The authors called for an increased role for the family, use of Aboriginal health practitioners, and a whole-of-community approach in implementing ACDs.<sup>2</sup>

The NT APP is a formal, structured document, which necessitates English language proficiency and health literacy. Previous authors have suggested that these characteristics make ACDs an ineffective document for many Aboriginal patients.<sup>2</sup> Despite the nature of the population of the NT and the Royal Darwin Hospital (RDH), its Aboriginal health practitioners are not required to undertake training in the use of the APP as part of their curriculum. It is these same individuals who have been delegated the task of helping Aboriginal patients to complete their ACDs.<sup>2</sup> In a Canadian context, Kelly and Minty have called for less formal documentation of aboriginal patients' wishes.<sup>5</sup> A culturally appropriate, less formal document that allows for immediate and future planning may also be most pertinent in an Australian context. However, this carries with it the peril of operating outside the legal protections afforded by the APP. Perhaps, an option for the NT is the creation of an educational document to help inform Aboriginal people about APPs. Similar documents exist in other states, such as *Advance care yarning* in South Australia.<sup>6</sup> The cultural diversity among the Aboriginal peoples of Australia behoves the development of such a document in the NT.

To further examine ACDs for the Aboriginal people of the Top End, especially in the context of life-limiting illness, Territory Palliative Care, Program of Experience in the Palliative Approach (PEPA) and the Aboriginal Medical Services Alliance Northern Territory plan to conduct focus groups with key stakeholders in the NT. Focus group sessions will be run in conjunction with PEPA workshops over the next 12 months. Focus groups will be scheduled in Darwin, Alice Springs, Katherine, Tiwi Island, Gove, Wadeye, Maningrida and Groote Eylandt. Key issues to be examined include the applicability of the current APP for Aboriginal people, education of Aboriginal health practitioners, the utility of a Top End-specific educational document, and the suitability of a less formal document such as a personal portfolio. Funding is being sought for the focus groups and creation of a culturally appropriate education document. In the interim, a steering committee has been created by the RDH to consider the key issues.

**Competing interests:** Eswaran Waran is a member of the RDH steering committee on ACDs and the Aboriginal people of the Top End.

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References are available online at [www.mja.com.au](http://www.mja.com.au).

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