



Preface

This material has been developed for the Respecting Patient Choices Program (RPC) as a component of the education materials for the training and development of staff to facilitate advance care planning with Aboriginal & Torres Strait Islander people. Mr Daryl Nayler, a Gundungurra Koori and former Aboriginal Health Development Officer at Austin Health is the author of this material and the Austin Health Ngarra Jarra Aboriginal Advisory Committee contributed to its development. This included a comprehensive consultation process with key people and patients.

This material is provided as resource for any health professionals working with Aboriginal & Torres Strait Islander people.

Advance Care Planning with Aboriginals and Torres Strait Islanders

Introduction

The task of writing a general framework for advance care planning that relates to all Aboriginal & Torres Strait Islander people is quite difficult. This is because discussions about end-of-life planning are sensitive and usually a 'no go' area for most Aboriginal & Torres Strait Islander people. This is coupled with the fact that many Aboriginal & Torres Strait Islander people have lost their trust in the institutions of government, including specifically Australian health services. Therefore many barriers exist between health care providers and Aboriginal & Torres Strait Islander people before even beginning a discussion about advance care planning.

Historically the lines of communication between Aboriginal & Torres Strait Islander people and the rest of Australia are distorted by mistrust and miscommunication. This is premised on a lack of respect by non-Aboriginal & Torres Strait Islander Australians for Aboriginal & Torres Strait Islander values and the discounting of these values by those non-Aboriginal & Torres Strait Islander Australians who have sought patronisingly and paternalistically to 'do good' to them.

This material is designed to support Respecting Patient Choices Consultants and associated medical and allied health professionals in the appropriate and relevant provision of 'common' cultural health care for Aboriginal & Torres Strait Islander patients and their families. It is intended only to be a general guide to established ways and is a guide to best practice that should be applied and interpreted in the context of each interaction.

Respecting Patient Choices Consultants bring a range of experiences and skills to the art of communicating this very sensitive issue of advance care planning. This chapter is designed to raise Aboriginal & Torres Strait Islander perspectives that will compliment the knowledge and skills that RPC consultants obtain to undertake advanced care planning with this group of people. Respecting Patient Choices Consultants respect the need to treat each interaction within its own individual context and this principle is whole-heartedly endorsed when engaging Aboriginal & Torres Strait Islander people.

There is no universal Aboriginal & Torres Strait Islander opinion or any given expert on advance care planning with Aboriginal & Torres Strait Islander people. The Aboriginal & Torres Strait Islander communities, clans and groups throughout Australia differ considerably, and there is usually no one right way to do things. To this end it is important that each person participating in advance care planning is considered on an individual basis.

It is highly recommended that health professionals secure the assistance and support from a local Hospital Aboriginal & Torres Strait Islander Liaison Officer where available. It is also possible to consider the use of local Aboriginal & Torres Strait Islander organisations and or Aboriginal & Torres Strait Islander community people to be involved where appropriate.

Prior to undertaking advance care planning with Aboriginal & Torres Strait Islander people it is important to have an understanding of the significant cultural issues that relate to them. Participation in a formal Aboriginal & Torres Strait Islander Cultural Awareness Program is recommended. Some health services already provide these types of cultural awareness programs.

All health professionals considering advance care planning with Aboriginal & Torres Strait Islander people should have access to, and read a resource developed by The National Palliative Care Program, called ***Providing culturally appropriate palliative care to Indigenous Australians***. This resource covers many important issues around culture and communication.

Copies of this resource can be obtained from the:

Rural Health and Palliative Care Branch
Department of Health and Ageing
GPO Box 9848
Canberra ACT 2601
Phone 1800 020 787
Website www.plliativecare.gov.au

The Austin Health Aboriginal Health Development Program and the Respecting Patient Choices Program, in collaboration with the Austin Health Aboriginal Advisory Committee and Austin Health Aboriginal Working Group, have undertaken to write this chapter. Many Aboriginal & Torres Strait Islander community stakeholders have been consulted in the development of this chapter and feedback has been gratefully received.

It is a great opportunity to provide a resource for support and advice to fellow Respecting Patient Choices Consultants, and I am delighted the Respecting Patient Choices Program is placing an emphasis on the Aboriginal & Torres Strait Islander community.

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Why do Advance Care Planning with Aboriginal & Torres Strait Islander people?

Aboriginal & Torres Strait Islander health is not improving. In comparison with other identified third world countries, Aboriginal & Torres Strait Islander people have the same level and in some cases worse scenarios across all indicators of health, social, and economic criteria. Aboriginal & Torres Strait Islander Australians die on average a great deal younger than the wider Australian community and have much higher rates of poor health outcomes.

For the Aboriginal & Torres Strait Islander community, death and funerals are commonplace and seem to be never ending. This relates to the deplorable health status of Aboriginal & Torres Strait Islander people in Australia and the high mortality rates. Death in the Aboriginal & Torres Strait Islander community is never settled and is an ongoing accumulation of shock, grief, trauma and sorry time, not only for the individual but also for the community. This is one reason why many Aboriginal & Torres Strait Islander people tend to be depressed and sometimes angry when they enter mainstream services such as hospitals. This is not a response to their individual situation, more a case of the ongoing grief and trauma issues within their life as an Aboriginal & Torres Strait Islander person and the aftermath of dealing with a host of other problems.

In Australia there are great disparities in the health system when it comes to health care for Aboriginal & Torres Strait Islander people compared to the non-Aboriginal & Torres Strait Islander population. The cluster of chronic illness such as diabetes, stroke, hypertension, heart and kidney disease is the greatest threat to their health since the arrival of European diseases over two centuries ago.

Aboriginal & Torres Strait Islander people have the lowest life expectancy of any minority in a first world country. Only 2.6 % of the Aboriginal & Torres Strait Islander population will pass the age of 65. Unexpected deaths in the Aboriginal & Torres Strait Islander community are common and it can be seen that advance care planning with this community would be of great assistance to patients with chronic illnesses and to families knowing that the end-of-life wishes for an Aboriginal & Torres Strait Islander person were being met.

Historic Overview to Aboriginal & Torres Strait Islander Culture, Social and Spiritual issues

Aboriginal people have lived in Australia since the beginning of time and believe their origins come directly out of the Dreamtime of the creative ancestors. The Dreamtime is a mythical era regarded as setting precedent for all human behaviour from that time on. It was the time when patterns of life were established and laws were laid down.

During the creation the ancestors had taken the form or shape of living species and the people identified themselves as having a relationship with other life forms. They did this through their totems and their life was in total harmony with the environment.

The Dreamtime is the all-important factor in the spiritual life of Aboriginal people. The Dreamtime was the sanction for everything in Aboriginal life, hunting grounds, social system, judgment and punishment, family and social relationships, art, myths, birth and death.

Aboriginal people do not have a religion. Aboriginal people across Australia have identified a number of all-father and all-mother spiritual figures. The name of the spiritual figures varies significantly from tribe to tribe and were normal people who could change into animals as told in the Dreamtime stories.

Each generation had a relationship with the ancestors, animals and nature because the ancestors had created spirits of every living species. Life was considered to be the result of spirit children and spirit animals being born or coming into life.

In the early colonisation era, Aboriginal & Torres Strait Islander people were brought under the 'control' of white British authority. It was believed that Aboriginal & Torres Strait Islander people had to be Christianised and civilised. Aboriginal & Torres Strait Islander people were forcibly removed to missions and reserves yet at the same time were denied citizenship of Australia.

Segregation on the basis of race excluded Aboriginal & Torres Strait Islander people from Australian society, public places and separated them away from the wider community e.g. hospitals with separate wards. They were not allowed to drink in the pubs, could not obtain social support and were refused enrolment in schools.

For Aboriginal & Torres Strait Islander people the assimilation policy has been absolutely devastating and has led to the destruction of identity and culture. Aboriginal & Torres Strait Islander people were removed from their environment where they would and were actively encouraged to forget language, history, culture, family, group and tribe. For early Australians, it justified dispossession and removal of children. The expectation of the Commonwealth was that all Aboriginal & Torres Strait Islander people would live like white Australians and that they would eventually be physically absorbed into the wider population and their culture would disappear.

Since colonisation huge adaptations have occurred to the time-honoured lifestyle of Aboriginal & Torres Strait Islander people. The outcome has resulted in the breakdown of traditional social, political and economic structures. Colonisation has created a new culture for Aboriginal & Torres Strait Islander people based on dependence, alienation and powerlessness.

Given the history of Aboriginal & Torres Strait Islander Australians a number of barriers to undertaking advance care planning are evident. Respecting Patient Choices Consultants need to be respectful of the cultural and historical differences and listen to the individual's perspective, especially about their future health care wishes. Respecting Patient Choices Consultants should not make assumptions of Aboriginal & Torres Strait Islander people and remember that each case is considered on an individual basis, without prejudice or judgment.

Cultural Identity – Who are Aboriginal & Torres Strait Islander people?

In modern urban Aboriginal society most Aboriginal & Torres Strait Islander people are of mixed origin reclaiming their heritage. In the urban context, Aboriginal & Torres Strait Islander people believe that their identity is based on their heritage. Today only a small minority of Aboriginal & Torres Strait Islander people live a traditional lifestyle in remote areas but many urbanized Aboriginal & Torres Strait Islander people have traditional beliefs. Traditional Aboriginal people tend to identify strongly with their tribal connections.

For the purposes of this work, Aboriginal and Torres Strait Islanders are; people, who have descended from an Aboriginal & Torres Strait Islander ancestor, identify as Aboriginal & Torres Strait Islander and are accepted as Aboriginal & Torres Strait Islander by the community in which they live. Aboriginal & Torres Strait Islander people may or may not claim that identity. RPC Consultants should not stereotype or have preconceived ideas of Aboriginal & Torres Strait Islander identity and need to ask the question: Are you of Aboriginal & Torres Strait Islander origin? They should not question a person's right to

identify as an Aboriginal & Torres Strait Islander person. This is not their role. It is the role of the local Aboriginal & Torres Strait Islander community.

Torres Strait Islanders

Torres Strait Islanders come from the islands of the Torres Strait between the tip of Cape York in Queensland and Papua New Guinea and have many cultural similarities with the people of Papua New Guinea and the Pacific.

Although they had long-standing contact with Australian Aboriginal people in the south and Melanesians to the north, the Torres Strait Islanders are a distinct people with their own culture and identity. Mainland Torres Strait Islanders experience problems with access and equity issues to health services similar to Aboriginal people

Language - Aboriginal & Torres Strait Islander versus Indigenous

Health professionals are asked to please use Aboriginal and or Torres Strait Islander when referring to Aboriginal & Torres Strait Islander people. The acronym ATSI describes Aboriginal & Torres Strait Islander people and is an acceptable abbreviation though preferably not used.

The literal translation of the word 'Aborigine' is: the people who were here from the beginning. It does not have the same meaning as 'indigenous' as this means originating in an area [Latin: indigena = in [in] + ginere [be born] in a particular place.

The use of the word indigenous to describe Australian Aborigines is not exclusive. In other words, anyone born in Australia is indigenous to this country. However many people say that Aboriginal & Torres Strait Islander people are indigenous to Australia. This appears to be based on the perception that this word combines Aboriginal & Torres Strait Islander together because it describes both Aboriginal & Torres Strait Islander people. But this is not the correct use of the word. All people who are born in Australia are indigenous to this country.

It is a requirement to gather data on Aboriginal & Torres Strait Islander status. The only sure way to get the answer is to ask the question "are you of Aboriginal and or Torres Strait Islander origin"? The question needs to be asked in a sensitive manner. It is not discriminatory to ask the question. Be aware that some Aboriginal & Torres Strait Islander people are suspicious about the collection and use of their data. Reinforce that the individual is protected via privacy legislation and the question needs to be asked as per legislative requirements.

Cultural Safety

In the late 1980s Maori nurses conceived the idea of "cultural safety" to improve nurses' delivery of health care. Cultural safety requires healthcare providers to reflect on their own cultural background and the nature of power relations in the provision of services to a minority culture by a dominant culture, so that the providers can work in a manner that is "culturally safe" for the patient/client (Gray et al, BMJ, 2003).

Health professionals need to acknowledge the beliefs and practices of people who differ from them in age, occupation or social class, ethnic background, sex, sexuality, religious belief, and disability. Health care providers do not need to research and understand other groups' beliefs and cultural practices; rather, they acknowledge their own culture as different from those of the people they serve, to ensure that they do not impose their beliefs on the minority communities. Cultural safety requires providers from the majority culture to

challenge their own stereotyped views of a minority culture. It promotes positive recognition of diversity.

Cultural safety is a framework to deliver best practice for Aboriginal & Torres Strait Islander people, who often feel removed from and dominated by Western culture and mainstream health services. Cultural safety is measured as the level of comfort of Aboriginal & Torres Strait Islander people to use a mainstream health services and a feeling of acceptance at all levels; not being denied their heritage: It ensures that social and emotional well-being are taken into account. It is about meeting people's requests, making them feel valued, and being compassionate and welcoming. It starts with cultural awareness leading to cultural sensitivity, thus enabling a trustworthy environment for Aboriginal & Torres Strait Islander consumers and the health professionals who care for them.

It is an important framework for RPC consultants to embrace and allow the needs of the Aboriginal & Torres Strait Islander patient and families to be met. Cultural safety leads to empowerment for the patients to make the right decisions for themselves.

Advance Care Planning Points to Consider?

RPC consultant's need to remember that for Aboriginal & Torres Strait Islander people advance care planning is not common practice. Nearly all will choose to die at home or on their 'belonging place'. When Aboriginal & Torres Strait Islander people speak of their belonging place they are referring to their 'country'. That is, to a particular area of land where they and their ancestors were born, lived and died [genealogical links]. Most Aboriginal & Torres Strait Islander people today live in areas which are not their 'belonging place'. With this said, some Aboriginal & Torres Strait Islander people do not have strong attachments to the land they live in, as it is not their tribal connection.

- Some Aboriginal & Torres Strait Islander people will not see a necessity to draw up an end-of-life plan due to sensitivities around issues of death and a complacency that underpins Aboriginal & Torres Strait Islander society of 'why bother' or 'there is no need'. Remember that no one is an expert in Aboriginal & Torres Strait Islander interactions and the best way is to 'just do it'. Talk to each Aboriginal & Torres Strait Islander individual as you would anyone else about advance care planning. Use a Hospital Aboriginal Liaison Officer where possible and you can also use family members.
- Be mindful that confusion or conflict may occur over differing values that are held by the patient and you as a RPC consultant. Remember the cultural safety framework. You will need to deal with this by using communication techniques that empower the patient to develop a sense of personal responsibility.
- Remember that in general Aboriginal & Torres Strait Islander people see hospitals and other mainstream services as being run by white authority according to 'white' rules. Aboriginal & Torres Strait Islander patients approach such services with fear and apprehension. RPC consultants need to acknowledge this and help the patient be at ease within the setting.
- Consider respect and decency. This recognition must be the basis for mutual consideration that makes learning from each other and working together possible. It is about the RPC consultant being understanding and leaving attitudes, assumptions and negative values at the door. You will need to be culturally sensitive and develop communication techniques that build trust. For example you could start the conversation in a round about way, plant the seed, and observe if the idea is accepted. Do not be intrusive, as this will only cause tension. Come back at another time to continue the conversation. Respect the patients' right not to disclose or communicate.

- It may not be easy and, in some instances, it will be a challenge to work with Aboriginal & Torres Strait Islander patients. You may need to 'draw a line in the sand' and leave the information with them. In other cases they will not be interested at all and this will need to be respected. Aboriginal & Torres Strait Islander people have a philosophical view of life dealing with the way things are, not how they should be or could be.
- The last consideration is about cultural protocol and customs. As an example, men's and women's business still exists and the most important person to assist with this aspect is the Hospital Aboriginal Liaison Officer and family members.

How to approach Aboriginal & Torres Strait Islander patients

Each Aboriginal & Torres Strait Islander person is different and therefore should not be stereotyped. The first interaction will need to be applied and interpreted in the context of the patient's needs, and their acceptance and willingness to participate. Be honest and open and tell the patient why you are talking with them. Establish a commitment to the patient, build trust and be consistent. In saying this, understand that some Aboriginal & Torres Strait Islander people suffer low self-esteem and self-confidence and therefore will seek information in different ways. They may ask questions indirectly and not look you in the eye or, they may say nothing at all and just nod in agreement. They might agree to everything that is said just to get you out of there as soon as possible. You will need to continually ask the patient whether they have understood what you have explained and/or use the hospital Aboriginal Liaison Officer to present the information.

Do:

- Respect Aboriginal and Torres Strait Islander cultural protocol, practices and customs eg men and women's business, death.
- Respect Aboriginal and Torres Strait Islander decision-making processes. For most Aboriginal and Torres Strait Islander people, having the family involved is extremely important. Some Aboriginal and Torres Strait Islander patients will very much want this, some will not. This is another reason why RPC consultants will need to exercise their own judgement and expertise.
- Remember that the Aboriginal and Torres Strait Islander family can include an extensive range of relatives and not necessarily of blood connection. This is a value system in the Aboriginal and Torres Strait Islander community of sharing and caring regardless if you are blood related or not.

Don't

- Do not use medical jargon or expect Aboriginal and Torres Strait Islander people to understand written information.
- Do not have preconceived ideas of Aboriginal and Torres Strait Islander identity. They come in all sizes, shapes and colours. Many mainstream people have romantic ideas of Aboriginal and Torres Strait Islander identity. Many Aboriginal and Torres Strait Islander people are expected to be confused, cynical and hard to work with. This is not necessarily the case.
- Do not film, photograph or depict Aboriginal and Torres Strait Islander business where it is likely to cause offence.

Step-by-Step Guide for Advance Care Planning

- Use the hospital Aboriginal Liaison Officer as the vehicle to initiate the first conversation. Do not assume the Aboriginal & Torres Strait Islander Hospital Liaison is the expert. They are excellent advisors and can warn against a course of action but may not necessarily be wanted by the patient. Again, this needs to be considered on an individual basis. Recognition of Aboriginal & Torres Strait Islander people's choice of spokesperson or cultural broker is important to respect and should not be questioned.
- Think about using the terms 'Aunty' or 'Uncle' for older Aboriginal & Torres Strait Islander people, however first ask the patient's permission if this is acceptable. In nearly all instances most will be happy with this, as it is a term of endearment. It can be a powerful way to establish trust quickly.
- In order to establish the particular traditions, customs and cultural values, you will need to speak with Next-of-Kin. The hospital Aboriginal Liaison Officer can help with this.
- Do not exclude family. Help them to also understand the information. Accept the communal nature of Aboriginal & Torres Strait Islander culture and the need for the family to be involved.
- Do not assume the person is able to understand the information you are presenting. In many cases Aboriginal & Torres Strait Islander people have not completed schooling and have literacy issues and or they may speak a traditional language. Use the patient's family and the hospital Aboriginal Liaison Officer to assist with this.
- Empower the patient by allowing them to make decisions for themselves by giving them ownership of the information and choices to be made. At all times it must be the patient's choice with the family's wishes respected.
- Follow up with the patient – do not make it a one off visit. Take the time to chat and have a cuppa.
- Make the patient feel comfortable within the setting – a simple Aboriginal & Torres Strait Islander poster, painting, access to Aboriginal radio etc can make all the difference.

Given the nature and complexities of dealing with Aboriginal & Torres Strait Islander interactions it is strongly suggested that Aboriginal & Torres Strait Islander cultural awareness training be seen as very important and necessary. Effective Aboriginal & Torres Strait Islander cultural awareness training will develop appreciation and an understanding of

key issues of their identity, culture, society, attitudes and factors impacting on their health both from a pre-colonisation and modern-day perspective. Local Aboriginal & Torres Strait Islander training providers to fully grasp the context of local issues should provide this training.

Death and Dying

Unfortunately, given the nature of Aboriginal & Torres Strait Islander death rates and the many funerals that happen within Aboriginal & Torres Strait Islander communities, death is a familiar event. Be aware that for family, visiting the sick and dying is very important to Aboriginal & Torres Strait Islander people. The patient will usually want the presence of family and community friends. Often, relatives will have travelled long distances and made great sacrifices in order to be present. They will be grateful for permission to sit silently with a patient during rest time and at night.

The Aboriginal Liaison Officer is also a crucial support for the patient and families during a time when death is imminent. In terms of protocol, the hospital Aboriginal Liaison Officer should be the person to make contact with the patient's family and community friends.

To most Aboriginal & Torres Strait Islander people, death is a sincere time of sorrow and fear. It can be a time of great superstition and some Aboriginal & Torres Strait Islander people may take a great amount of care and respect to ensure that a deceased spirit cannot harm living people. They also strive to ensure that the spirit can find its way to the 'Sky Camp'. In some parts of Australia the Aborigines still believe that a deceased person's spirit went to live in the sky.

When a family member dies, Aboriginal people spend 'Sorry Time' with their family members and grieve with them. Sorry time is very important Aboriginal business with no set finish time. It is very individual.

Wailing or crying is a common occurrence among the mourners who may paint their bodies with pipe clay, red ochre or charcoal when a relative or friend dies. Some Aboriginal people beat themselves and cut themselves.

Family members may insist the room where the deceased passed away will need to be *smoked* to cleanse it. Other Aboriginal & Torres Strait Islander patients within the facility may have unease staying until this ceremony is performed. As with most Australians, Aboriginal & Torres Strait Islander family and perhaps 'extended family' will want to see the deceased. This enables the 'family' to express their grief and say their goodbyes. The hospital Aboriginal Liaison Officer should facilitate viewing the body.

The family will normally make arrangements to choose a funeral service, perhaps with the local Aboriginal & Torres Strait Islander organisation that may provide a specific funeral program. In some instances due to financial constraints hospital social workers will need to become involved to assist the family to access financial and counselling supports. In the case of sudden, traumatic or unexpected death, arrangements for debriefing the family and community members should be facilitated through the hospital Aboriginal Liaison Officer. This is imperative, especially when the death is a suicide.

If an autopsy is expected, it should be discussed with the family by the Aboriginal Liaison Officer. In general most Aboriginal & Torres Strait Islander people will not want the deceased to have an autopsy. Their rights of objecting to an autopsy will need to be explained in terms of legal process. The hospital Aboriginal Liaison Officer should do this with, perhaps, the support of a trained grief counsellor or social worker. Ultimately, autopsies are influenced by Australian laws relating to coronial inquiry and may leave the family with no choice. The hospital Aboriginal Liaison Officer should communicate this. In general, depending on

cultural influences - organ donation will be unacceptable within the Aboriginal & Torres Strait Islander community.

Burial

For some Aboriginal & Torres Strait Islander people, burial on the deceased persons 'belonging place' is the most important requirement. The impact of western values, particularly in relationship with the interaction of Christian Missionaries has influenced modern Aboriginal & Torres Strait Islander funeral practice. Many Aboriginal & Torres Strait Islander people are very religious in the mainstream religions and therefore practice the beliefs like other Australians. In general, Aboriginal & Torres Strait Islander people will follow customs associated with Christian beliefs and influences relating to burial. However Aboriginal & Torres Strait Islander mourners and their services may complement western funerals with aspects of their culture. For example, before the funeral all the adults may meet at one place to decide what is going to happen at the funeral. Didgeridoo, song and dance may be performed, caskets may be decorated with Aboriginal & Torres Strait Islander art design and lowering of the Aboriginal and or Torres Strait Islander flag will occur.

At nearly all Aboriginal & Torres Strait Islander funerals a large Aboriginal & Torres Strait Islander community turnout will happen as a sign of respect to the deceased and family. Usually cremation is not the preferred burial practice for Aboriginal & Torres Strait Islander people as burial is important in terms of a connection to belonging place.

In traditional life, the burial customs of Aboriginal & Torres Strait Islander people varied around the country e.g. buried or cremated. Both forms involved a mourning ceremony and or funeral dance. The belief in a person-spirit led Aboriginal people to take great precautions in the burial of the deceased. Sometimes the deceased was placed in a sitting position because the people believed that a person's spirit 'jumped up' into the sky. In other parts of the country people were buried on their sides facing north, east, south or west. This was based on the belief that birth was the result of a spirit-child entering a woman's body and after death, the spirit would return to the place where it lived before being born.

In some areas a deceased person was buried in a possum rug along with their possessions such as weapons, utensils or tools. Relatives and friends often sat beside the grave of deceased person, but this was related to their superstitious beliefs. Sitting beside a grave, sometimes shaded with a hut or covering to provide shelter for the mourner or mourners, ensures that the deceased person's spirit has gone to the 'sky camp' or its 'spirit place'.

After the mourning period is completed, a deceased person's first name is never mentioned again.

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