

# 1 Introduction .....

These Practice Principles, which were developed through extensive consultation with palliative care providers and Aboriginal and Torres Strait Islander people and their communities, acknowledge that each palliative care patient has unique cultural requirements that influence the care provided.

These Practice Principles aim to assist palliative care services and personnel to meet the cultural needs of Aboriginal and Torres Strait Islander patients, their families and communities. Recognising that palliative care is provided within a context of organisational and personal practice, the principles are supported by organisational and personal strategies for reflecting on practice.

Although these principles and strategies have been developed specifically to support palliative care which is culturally appropriate to Aboriginal and Torres Strait Islander peoples, they may also apply to culturally appropriate palliative care for people from other cultures.

## Cultural safety

The notion of cultural safety is a key theme of the Practice Principles. It extends beyond cultural awareness and cultural sensitivity, allowing palliative care personnel to reflect on:

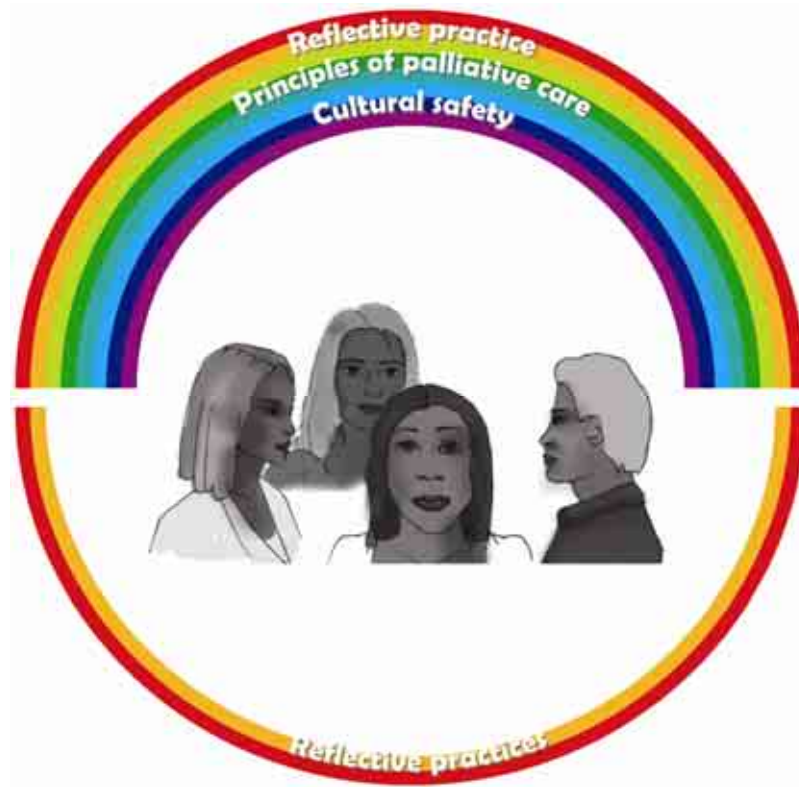
- their own culture and values
- the culture and values of their organisation
- how these influence the care provided
- how practice can be improved
- the perception of the care experience by the Indigenous Australian, their family and community.

In considering these Practice Principles and supporting information, the following are key themes:

- valuing difference
- avoiding assumptions
- communication.



They underpin the concept of cultural safety within the framework of these Practice Principles.



#### **Cultural safety in a palliative care context**

Originating in New Zealand, cultural safety<sup>1</sup> can be explained as practice which respects, supports and empowers the cultural identity and wellbeing of an individual. It is based on the palliative care practitioner understanding their own culture and the power relationship between the practitioner, the patient and/or their family and their community.

Cultural safety relates to the values, attitudes and beliefs of the individual practitioner, and to the organisational culture and values of palliative care services. Unsafe cultural practice comprises any action which diminishes, demeans or disempowers the cultural identity and wellbeing of an individual.

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<sup>1</sup> This explanation of cultural safety is based on the Nursing Council of New Zealand definition as explained in the 'Guidelines for Cultural Safety, the Treaty of Waitangi, and Maori Health in Nursing and Midwifery Education and Practice', Nursing Council of New Zealand, March 2002.

## **Diversity of Aboriginal and Torres Strait Islander cultures**

Aboriginal and Torres Strait Islander peoples are not a homogenous group. Like the many nations of Europe, Aboriginal and Torres Strait Islander peoples comprise a large number of diverse, culturally different communities. Each community has its own unique customs, cultural beliefs and associated ceremonies.

For many Aboriginal and Torres Strait Islander people with strong traditional connections, traditional knowledge and customs guide everyday living. For others, where there has been a significant loss of culture or where the person is of mixed descent, cultural requirements will reflect influences from both Aboriginal and Torres Strait Islander culture and mainstream culture.

Aboriginal and Torres Strait Islander cultures are not static or uniform. Like all cultures, they are continually changing and adapting depending on the influences on the person or the community.

However, the concept of community, the central place of land and family obligations are common underpinning values within and across Aboriginal and Torres Strait Islander communities throughout Australia. Family extends to distant relations, with obligations and responsibilities to all members and others within the community. 'Family' members may not be related according to the 'mainstream' notion of blood relatives, but be related through traditional kinship or cultural groupings.



## **Aboriginal and Torres Strait Islander people use of palliative care**

Statistics from palliative care services and research within Aboriginal and Torres Strait Islander communities and health services indicate that very few Aboriginal and Torres Strait Islander people are accessing palliative care support. With some notable exceptions this occurs throughout Australia, even in areas where there are significant Aboriginal and Torres Strait Islander communities.

Terminally ill Aboriginal and Torres Strait Islander people are being supported by family, their community and/or Aboriginal and Torres Strait Islander primary health care services or community services. These services may not be funded to provide palliative care and staff providing the care may not necessarily be trained in this specialised area.

## **Aboriginal and Torres Strait Islander mortality and morbidity and their implications for palliative care**

Aboriginal and Torres Strait Islander people across Australia have significantly lower life expectancies than mainstream Australians. Late diagnosis of disease is common, with many Aboriginal and Torres Strait Islander people entering the terminal phase of disease before it is diagnosed. This has implications for palliative care provision.

It has been highlighted in many reports that more Aboriginal and Torres Strait Islander people are dying from renal failure, circulatory diseases, respiratory disease, injury, poorly managed diabetes and AIDS, than from cancer. The needs of Aboriginal and Torres Strait Islander people who suffer from a non-malignant disease as well as malignant disease also need to be addressed by palliative care. Palliative care provision is needed by Aboriginal and Torres Strait Islander people of all ages for a range of non-cancer diseases which are terminal but which are not necessarily recognised as such by health systems until the terminal phase of the illness.

Many Aboriginal and Torres Strait Islander people express a desire to die in their own communities (Sullivan 2003). This is more important to them than the physical treatment of their disease. Flexible models of palliative care which allow people the choice to return to their place of birth need to be developed. This will involve working in partnership with primary community health services, families and communities.



## The impact of past policies and practices

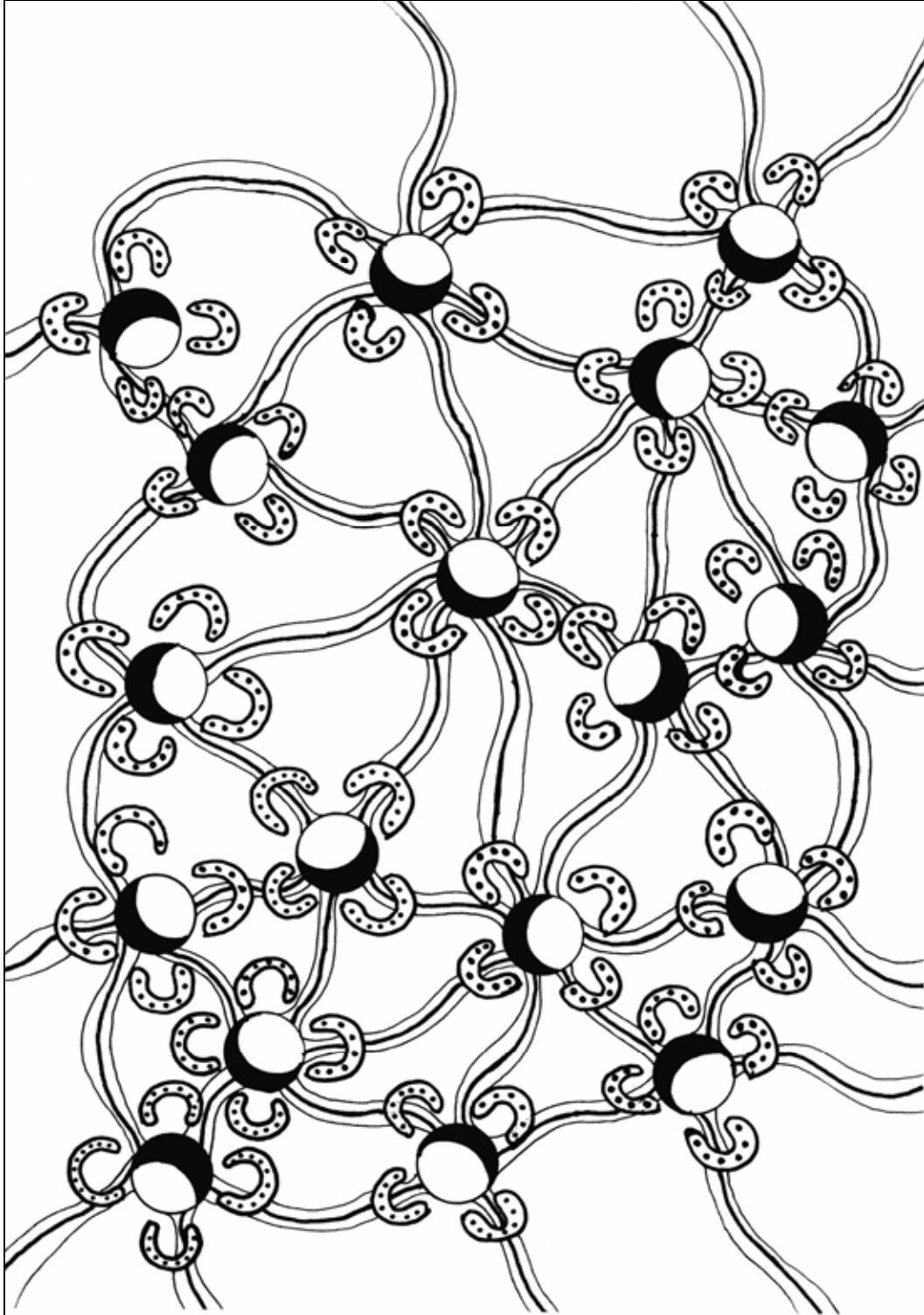
The past experiences of Aboriginal and Torres Strait Islander peoples may act as barriers to accessing mainstream services. Past government policies such as forced relocation from traditional lands, the taking of mixed race children (the stolen generations), and a lack of rights and decision making power have contributed to a breakdown of Aboriginal and Torres Strait Islander culture.

These events and the results of the policies are still very vivid in the minds of many Aboriginal and Torres Strait Islander people. Consequently, many have little trust in mainstream services — including health services.

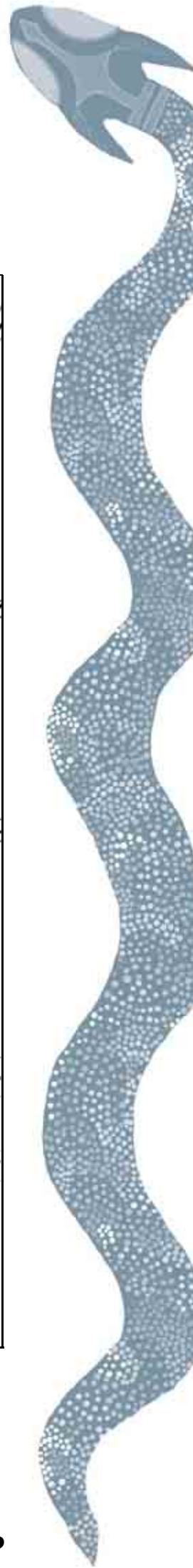
**‘Palliative care services need a basic understanding of the diversity of Indigenous culture. Cultural, socio-economic, emotional, historical and political factors, which potentially make the experience of death and dying different for Indigenous Australians, should be considered by service providers to provide accessible and relevant palliative care.’**

(Wagstaff 1997)

## The web of care



Artist: Jane Johnson, Pen on Paper



The elements of the design, *The Web of Care*, represent different focuses within palliative care.



The circles represent the individual who requires palliative care. There are two parts to each individual:

- Black relates to the body.
- White is for the spirit.



These shapes represent the immediate family of the individual.

- The dots within refer to their extended family.



The three lines connecting each individual and family are all different aspects of connection.

- The line on the left relates to palliative care networks and organisations.
- The thick middle line refers to the land.
- The line on the right considers the part that community plays in palliative care.

These three lines all weave together to form a web of support to both the person and their family.

(Jane Johnson 2003, reproduced with permission)

## Use of terms

**Aboriginal Medical Service (AMS)** — These are community-controlled organisations which provide services to maintain and improve the physical, social and emotional wellbeing of the Aboriginal and Torres Strait Islander community. They vary in the services they offer depending on their size, the expressed needs of the community and resource levels.

**Aboriginal and Torres Strait organisation** — This is an organisation controlled (managed/governed) by an Aboriginal and Torres Strait Islander community. It may or may not be directly associated with health and/or medical service provision.

**Aboriginal Health Worker (AHW)** — This term includes Indigenous Health Worker or Torres Strait Islander Health Worker. People undertaking these roles are of Aboriginal and Torres Strait Islander descent. They provide health support to Aboriginal and Torres Strait Islander communities. Aboriginal Health Workers may be employed by palliative care services, mainstream health organisations, Aboriginal Medical Services or Aboriginal and Torres Strait Islander organisations. They may be employed within a wide range of health disciplines, including aged care, mental health, maternal health, disability support and patient care in acute care facilities.

**Aboriginal Liaison Officer (ALO)** — This term includes Indigenous Liaison Officer or Torres Strait Islander Liaison Officer. A key component of an Aboriginal Liaison Officer's role is to support communication between Indigenous Australian communities and peoples and mainstream communities and organisations. Aboriginal Liaison Officers may be employed by Aboriginal and Torres Strait Islander organisations, mainstream health services, local government, government departments and instrumentalities, schools, other education providers, enterprises and businesses.



**Community** — This term refers to the local Aboriginal and Torres Strait Islander community or to the Aboriginal and Torres Strait Islander community of the patient's birthplace.

**Cultural safety** — The definition and principles of cultural safety referred to in this document draw on the 'Guidelines for Cultural Safety, the Treaty of Waitangi and Maori Health in Nursing and Midwifery Education and Practice' of the Nursing Council of New Zealand, March 2002. Although developed for the New Zealand context, the universal nature of the cultural safety definition and principles make them relevant to the provision of palliative care to Aboriginal and Torres Strait Islander peoples.

Within the context of these principles, cultural safety is the influence of personal and organisational culture and values on the provision of palliative care.

**Mainstream** — This refers to personnel and/or services who cater to all members of Australian communities, regardless of ethnic background. Where mainstream is used in these principles in a historical context, it refers to Anglo-Saxon culture, people and cultural values.

**Palliative care** — 'Palliative care is care provided for a person with an active, progressive, far advanced disease with little or no prospect of cure and for whom the primary treatment goal is quality of life. This is evidenced by an interdisciplinary assessment and/or management of the physical, psychological, emotional and spiritual needs of the person; and a grief and bereavement support service for the person and their carers/family.' (Palliative Care Australia) In these principles it refers to a holistic approach to care provision, supporting the spiritual, cultural, emotional, social, psychological and physical needs of the patient and/or their family. It is provided through a team-based approach, working with Aboriginal and Torres Strait Islander personnel and organisations as identified by the patient and/or their family.

**Principles of Palliative Care** — This term refers to the principles and values set out as core values in the *Standards for Palliative Care* (1999) developed by Palliative Care Australia. For these Practice Principles, Standard 5.1 is particularly applicable: 'The palliative care service meets the cultural needs of the patient and family and reflects the cultural diversity of the community it serves'.

**Provider** — This term refers to the organisation or individual personnel providing palliative care support. Personnel may be staff or volunteers of a palliative care service, or personnel providing palliative care support through another organisation (for example, home and community carers, aged care or acute care personnel). Personnel may also be those providing informal palliative care support on their own behalf (for example, friends of the patient) or through another organisation (for example, an Aboriginal and Torres Strait Islander organisation).

**Reflective practice** — This is reflecting on provision of care as a means of continually improving practice. It encompasses technical reflection (rational, deductive thinking about clinical procedures), practical reflection (interpretation of experience for description and explanation of human interaction) and emancipatory reflection (critical review of practice in relation to power relationships and constraints) (Taylor 2000).



## Icons

The following icons have been used in this document:



This icon indicates an issue which has **implications for the provision of palliative care** to Aboriginal and Torres Strait Islander patients and their families. Factors which may need to be considered in care planning and provision are identified and in some cases potential strategies are presented.



This icon indicates a **case study** which illustrates how an issue can impact on palliative care provision or on the patient and/or their family. All case studies are based either on anecdotal 'stories' told to the project team by palliative care personnel or Aboriginal and Torres Strait Islander people, or have been drawn from published literature. Except where they have been drawn from published literature, the case studies have been carefully de-identified to respect the confidentiality and protect the privacy of the contributors.