

*Providing culturally appropriate palliative care to
Aboriginal and Torres Strait Islander peoples*

Practice Principles




*Providing culturally appropriate palliative care
to Aboriginal and Torres Strait Islander peoples*

Practice Principles



Prepared for the Australian Government Department of Health and Ageing
by Mungabareena Aboriginal Corporation, Wodonga Institute of TAFE,
and Mercy Health Service Albury (Palliative Care)





© Commonwealth of Australia 2004

ISBN 0 642 82371 5

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part (including artwork or artwork components) may be reproduced by any process without prior written permission from the Commonwealth available from the Department of Communications, Information Technology and the Arts. Requests and inquiries concerning reproduction and rights should be addressed to the Manager, Copyright Services, Info Access, GPO Box 1920, Canberra ACT 2601.

Additional copies of these Practice Principles can be obtained from the

Rural Health and Palliative Care Branch
Australian Government Department of Health and Ageing
GPO Box 9848
Canberra ACT 2601

Phone 1800 020 787
Facsimile 02 6289 9295
Website www.palliativecare.gov.au

Disclaimer: The opinions expressed in this document are those of the authors and are not necessarily those of the Australian Government Department of Health and Ageing

Publication Approval Number 3371



Acknowledgements

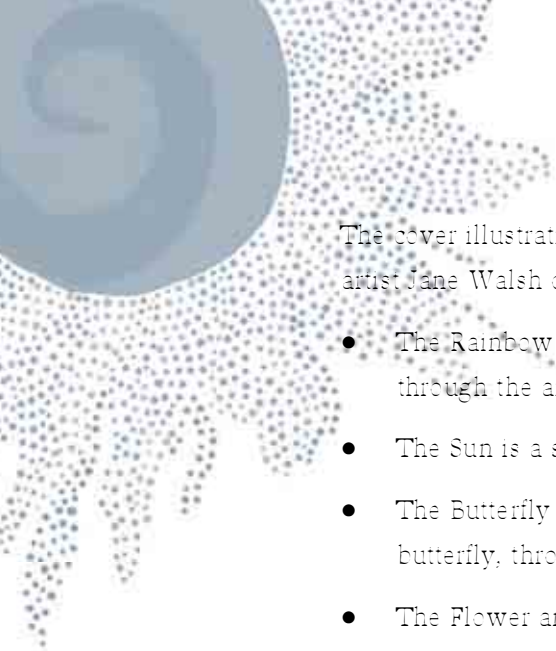
The production of these Practice Principles was funded as part of the National Palliative Care Strategy by the Australian Government Department of Health and Ageing's National Palliative Care Program. They were produced by Mungabareena Aboriginal Corporation, Wodonga Institute of TAFE, and Mercy Health Service Albury (Palliative Care).

The project team would like to thank and acknowledge:

- all Aboriginal health services, medical services and community organisations who provided advice and feedback
- all palliative care service providers who provided advice and feedback
- all individuals, including Elders and Indigenous Australian community leaders, medical and allied health professionals, Indigenous Australian community members and members of the general public for their support of the project
- members of federal, state and local government health and community services departments
- our reviewers and Reference Group — Indigenous Australian community leaders and experienced palliative care practitioners. They provided specific feedback and were an invaluable source of advice and information
- our Indigenous Australian and palliative care consultation facilitators
- the National Indigenous Palliative Care Needs Study conducted by Kate Sullivan and Associates
- and particularly the members of our Steering Committee. We thank them for their guidance, advice and dedication to this project.

The project team comprised Ruth Brooks and subsequently Jenny Butler (Manager), Pam Griffin (Elder and Project Cultural Manager), Pauline Heath (Clinical Nurse Consultant), Kerry Strauch (Project Coordinator, writer and instructional designer), Karen Giltrap (writer and instructional designer), Carmen Denniss and Jason Murray (cultural advisors), Jane Dewildt (editor), Jane Walsh (cover artwork), Bernadette Mullins (illustrator), Tammie Müller (desktop publisher and design), Chris Hartles (web site design and development), Jason Cartwright (CD-ROM development), Professor Ian Anderson (research), Dr Jeannie Devitt (research) and Mayssa Powell (administrator).





The cover illustration and artwork design of this document was painted by Aboriginal artist Jane Walsh of Victoria. According to Jane:

- The Rainbow Serpent is a myth of how the land was formed and this is shown through the array of colours.
- The Sun is a symbol of life, with which we greet each day with appreciation.
- The Butterfly represents our expectation to bloom in life. It is as delicate as a butterfly, through which we become aware of how fragile life can be.
- The Flower and the Rainbow are nature's creations to beautify what we have in life and to accept the outcome of reality.

The *Maybe soon* poem was written by Jane Johnson, a member of Mungabareena Aboriginal Corporation. It has been used with full permission.



Maybe soon

Maybe soon yeah doctor? you can send me home,
Back to my family, and my land, too long we've been apart.
I know that you all have worked hard for me.
For though you want to, I know you just cannot understand.
For try hard as I can, I can't explain this longing in my heart.

Maybe soon I will start that journey
Along my dreaming track,
I have to go home now, to say my good-byes,
Cos' when I go, I won't be coming back.

Maybe soon when I go home,
My family will come around.
We can cry our grief together,
Out on the ceremony ground.

Maybe soon now brother, when you just want to cry,
Don't name your baby something silly when I die.
I was so glad that you named her after me.
Maybe when I go, you might call her 'Pretty Sky'.

Maybe soon now sister, you will moun for me.
You will weep and never say my name again.
And later on, from time to time, you will remember me and laugh.
All our funny times will help you smile, and take away your pain.

Maybe soon the singing will start, out on the ceremony ground,
My uncles singing low, and my aunties singing high,
My sisters clapping sticks, and my nephews playing didg.
And everyone is stomping now sending dust flying all around.
Oh what a send off, you really make me proud.

Maybe now I'm going, time has come for me to pass,
I can hear the crying and the wailing all around.
I can hear all the music, and feet stomping in the dust.
But yet I feel no sorrow, I no longer feel the pain,
Only freedom now, and lots and lots of joy.
I start to live my dreaming now, as I've longed for all my life.
I will start that final journey now at last...

Jane Johnson, May 2002 (with permission)





Foreword

Palliative care providers throughout Australia and the Australian Government Department of Health and Ageing have recognised that palliative care provision needs to be more culturally appropriate to meet the needs of Aboriginal and Torres Strait Islander palliative patients, their families and communities.

Contrary to popular belief, Aboriginal and Torres Strait Islander culture is not a single culture. Rather it comprises a number of different cultures which share some common values and beliefs.

The diverse cultures of Aboriginal and Torres Strait Islander peoples, the influence of European cultures and religions, and other social and environmental factors all contribute to the broad range and diversity of cultural beliefs and requirements of Aboriginal and Torres Strait Islander peoples. There is no single formula or set of practices which can be applied to meet these needs.

These Practice Principles have been developed to provide a framework for palliative care service providers to examine their own policies and practice in relation to the requirements of Aboriginal and Torres Strait Islander peoples.

The Practice Principles are based on a holistic approach to palliative care, responding to the spiritual, emotional, social, psychological, physical and economic needs of the Aboriginal and Torres Strait Islander patient.

The importance of family and community and their role in decision-making and care support is acknowledged and incorporated.

The Practice Principles aim to support palliative care service providers to be inclusive in developing locally appropriate policies and practices to meet the needs of their Aboriginal and Torres Strait Islander patients, families and communities.



Contents

| | |
|--|-----------|
| Introduction..... | 1 |
| Cultural safety | 3 |
| Diversity of Aboriginal and Torres Strait Islander cultures | 5 |
| Aboriginal and Torres Strait Islander people use of palliative care..... | 6 |
| Aboriginal and Torres Strait Islander mortality and morbidity and their implications for palliative care | 7 |
| The impact of past policies and practices | 8 |
| The web of care..... | 9 |
| Use of terms..... | 11 |
| Icons | 14 |
| | |
| The Practice Principles and implementation strategies | 15 |
| Implementing Practice Principle 1: Involving Aboriginal and Torres Strait Islander people | 18 |
| <i>Organisational strategies</i> | <i>18</i> |
| <i>Personal strategies.....</i> | <i>19</i> |
| Implementing Practice Principle 2: Communication | 21 |
| <i>Organisational strategies</i> | <i>21</i> |
| <i>Personal strategies.....</i> | <i>21</i> |
| Implementing Practice Principle 3: Training..... | 23 |
| <i>Organisational strategies</i> | <i>23</i> |
| <i>Personal strategies.....</i> | <i>23</i> |
| | |
| Factors influencing implementation | 25 |
| Factors influencing the involvement of Aboriginal and Torres Strait Islander people | 28 |
| <i>Recognising cultural diversity.....</i> | <i>29</i> |
| <i>Acknowledging Aboriginal and Torres Strait Islander peoples' identity (disclosure/non-disclosure of Aboriginal and Torres Strait Islander status)</i> | <i>31</i> |
| <i>Choice of place of death.....</i> | <i>33</i> |
| <i>Family and kinship relationships.....</i> | <i>35</i> |
| <i>Caregivers.....</i> | <i>36</i> |
| <i>Culturally appropriate consent.....</i> | <i>37</i> |
| <i>Ceremonies and practices.....</i> | <i>38</i> |
| <i>Treatment environments.....</i> | <i>40</i> |





| | |
|---|-----------|
| <i>Models of care provision</i> | 42 |
| <i>Post-death requirements and support</i> | 45 |
| <i>Loss and grief support</i> | 47 |
| <i>Funerals</i> | 49 |
| <i>Advocacy by an Aboriginal and Torres Strait Islander person</i> | 51 |
| <i>Inclusion at each stage of care</i> | 53 |
| <i>Consideration of shared care models of care provision</i> | 57 |
| <i>Supporting the Aboriginal and Torres Strait Islander family</i> | 58 |
| <i>Developing support strategies for Aboriginal and Torres Strait Islander staff</i> | 60 |
| <i>Aboriginal and Torres Strait Islander participation at policy development level</i> | 63 |
| Factors influencing communication | 64 |
| <i>Using appropriate language</i> | 65 |
| <i>Appropriate non-verbal communication and attire</i> | 66 |
| <i>Considering gender issues, location and environment</i> | 67 |
| <i>Presence of a support person</i> | 67 |
| <i>Using appropriate communication strategies</i> | 68 |
| <i>Providing sufficient information to the person and their family to make informed choices</i> | 70 |
| Factors influencing training | 72 |
| <i>Aboriginal and Torres Strait Islander cultural safety training</i> | 73 |
| <i>Principles and concepts of palliative care training</i> | 74 |

| | |
|---------------------------|-----------|
| Bibliography | 77 |
|---------------------------|-----------|

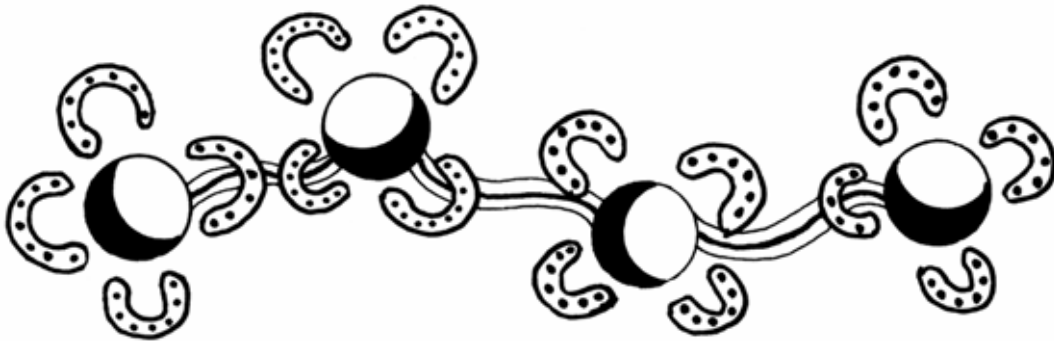
| | |
|---|-----------|
| Practice Principles feedback sheet | 77 |
|---|-----------|

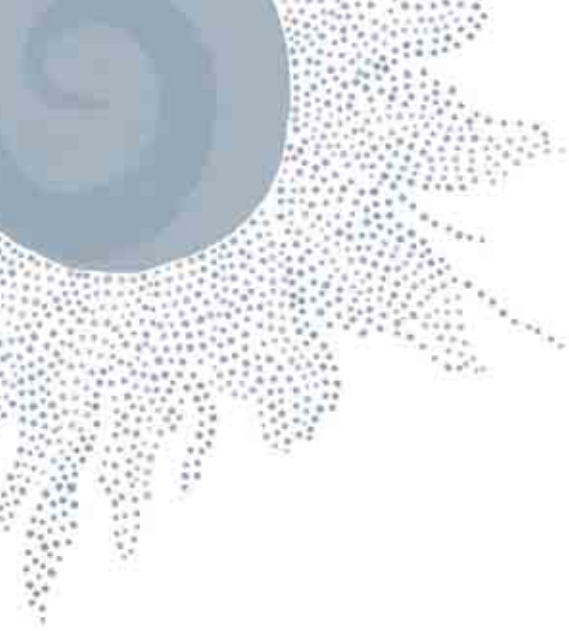


Section 1



Introduction





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:

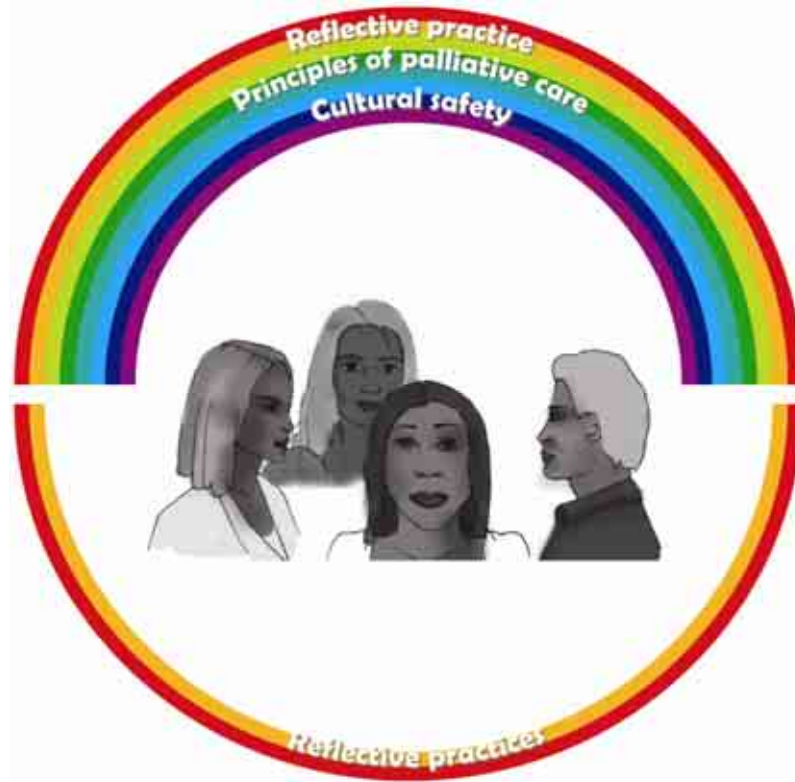
- their own culture and values
- the culture and values of their organisation
- how these influence the care provided
- how practice can be improved
- the perception of the care experience by the Indigenous Australian, their family and community.

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 safety¹ 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.

¹ 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

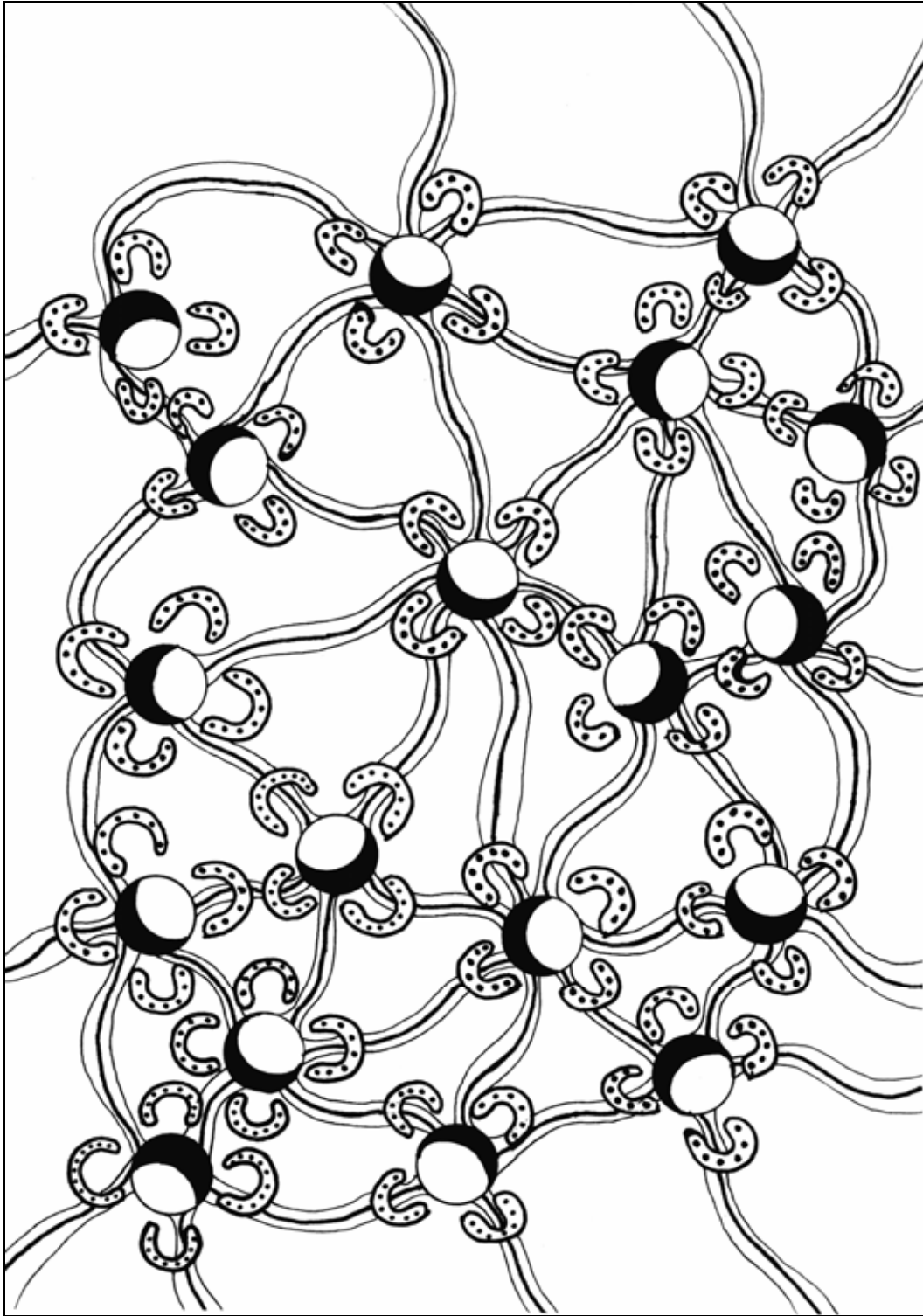
The past experiences of Aboriginal and Torres Strait Islander peoples may act as barriers to accessing mainstream services. Past government policies such as forced relocation from traditional lands, the taking of mixed race children (the stolen generations), and a lack of rights and decision making power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



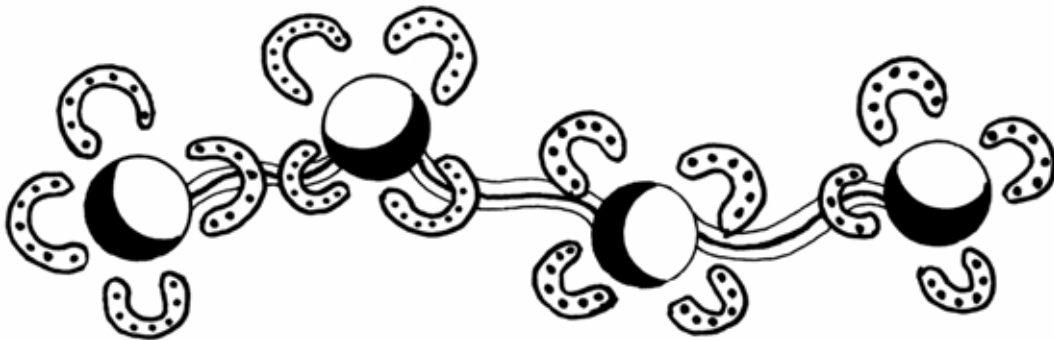
This icon indicates an issue which has **implications for the provision of palliative care** to Aboriginal and Torres Strait Islander patients and their families. Factors which may need to be considered in care planning and provision are identified and in some cases potential strategies are presented.

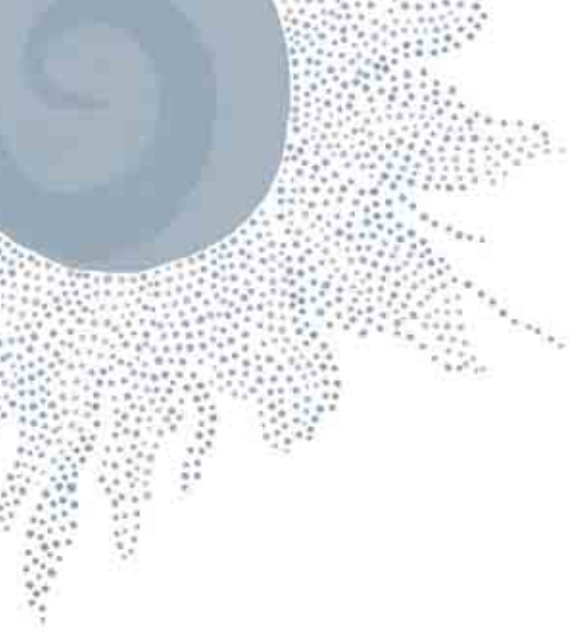


This icon indicates a **case study** which illustrates how an issue can impact on palliative care provision or on the patient and/or their family. All case studies are based either on anecdotal 'stories' told to the project team by palliative care personnel or Aboriginal and Torres Strait Islander people, 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.

Section 2

The Practice Principles and implementation strategies





2 The Practice Principles and implementation strategies.....

- 1 Include Aboriginal and Torres Strait Islander organisations and/or personnel in the planning, provision and monitoring of palliative care to ensure culturally relevant requirements are addressed and preferences of the patient and/or their family are considered.
- 2 Communicate with the patient and their family and community in a sensitive way that values cultural difference.
- 3 Provide training to all personnel to enable the provision of culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples.

These principles recognise that palliative care provision must be considered from both organisational and personal perspectives. Accordingly, strategies for implementing them are divided into organisational and personal strategies.



Implementing Practice Principle 1: Involving Aboriginal and Torres Strait Islander people

Organisational strategies

- Identify and resource an Aboriginal and Torres Strait Islander person (or person with Aboriginal and Torres Strait Islander cultural safety training/experience) to work with the organisation as a link between the patient, staff and support services.
- Provide cultural safety training to all staff as an organisational priority.
- Provide introductory training in palliative care concepts and approaches for Aboriginal and Torres Strait Islander staff in mainstream services and Aboriginal and Torres Strait Islander organisations².
- Partner with Aboriginal and Torres Strait Islander organisations and the local community in all levels of planning, service provision, communication processes, and in the monitoring of palliative care for Aboriginal and Torres Strait Islander patients and/or their families. This may include seeking advice from Elders/ community leaders and/or Aboriginal and Torres Strait Islander health/community organisations on what they see as issues in providing culturally sensitive palliative care. It may also include participation by Aboriginal and Torres Strait Islander staff in developing procedures.
- Seek advice from Aboriginal and Torres Strait Islander personnel, Elders or community leaders on grief and loss issues, and strategies for supporting the patient's family and community in their bereavement.
- Address the cultural responsibilities and emotional support needs of Aboriginal and Torres Strait Islander staff involved in palliative care planning and provision. This may include leave for attending funerals, recognition of the extent of community liaison required, holistic health philosophies and regular debriefing.

² It is acknowledged that the most appropriate Indigenous organisations for involvement in palliative care support are Indigenous Medical Services or Indigenous Primary Health Organisations. In the absence of these organisations, local Indigenous organisations could be approached

- Develop referral protocols with Aboriginal Medical Services, health services and community organisations. Protocols may include case conferencing and support which mainstream palliative care services can provide to Aboriginal and Torres Strait Islander organisations who are supporting the patient and their family.
- Establish communication processes with specialist centres and local health and community support services to support continuity of palliative care.
- Develop and promote policies and procedures to ensure cultural safety. This includes obtaining cultural advice, accessing support services, obtaining consent and adapting care provision models.
- Address legal and/or ethical issues in providing culturally appropriate palliative care. This may include developing locally appropriate policies and procedures in relation to gaining consent, disclosure and confidentiality. It may also require accessing information on state and territory legislative requirements.

Personal strategies

- Listen to the patient's needs and preferences in relation to cultural aspects of their care. This includes their choice of support person, involvement of Indigenous Australian personnel, and spiritual support needs.
- Identify the Aboriginal and Torres Strait Islander status of the patient and/or family and their preference for disclosure. Discuss the implications of disclosure/non-disclosure.
- Access national palliative care standards and organisational policies and procedures regarding provision of care for Aboriginal and Torres Strait Islander peoples.
- Identify and approach local Aboriginal and Torres Strait Islander organisations for advice. (For example, seek advice about consulting Elders or community leaders on cultural requirements for care. This includes consent requirements for treatment — these may differ from consent requirements under Commonwealth, state or territory law.)
- Incorporate culturally relevant requirements into individual practice in providing care.



***Providing culturally appropriate palliative care to
Aboriginal and Torres Strait Islander peoples***

- Work with Aboriginal and Torres Strait Islander support services on case conferencing to ensure continuity of care to meet cultural requirements and preferences of patients and their families.
- Consider the impact of one's own culture and values on the provision of care to Aboriginal and Torres Strait Islander patients, their families and communities.

For further information to support the implementation of this principle and the suggested strategies, see *Factors influencing involving Aboriginal and Torres Strait Islander peoples* in this document and the accompanying resource: *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples — Resource*.

Implementing Practice Principle 2: Communication

Organisational strategies

- Support the inclusion of traditional practices where requested by the patient and/or family. This may include working with traditional healers or Elders to provide traditional healing and singing, provision of traditional foods and supporting the practice of traditional ceremonies.
- Provide information in plain English (or, where needed, the appropriate language through an interpreter) and in different styles (for example, posters, artwork, diagrams, articles in Aboriginal and Torres Strait Islander publications, radio and television).
- Provide adequate information about the patient's/family's cultural requirements to staff and volunteers involved in the care.
- Provide training for staff in communication that is culturally sensitive to Aboriginal and Torres Strait Islander people.
- Include communication skills in all staff position descriptions and training in these skills in the organisation's professional development budget.

Personal strategies

- Seek information about the cultural background of the patient/family and community. This should include information about appropriate communication strategies and other relevant cultural considerations. Information may be sought from the patient, family, Aboriginal and Torres Strait Islander staff, community and/or Aboriginal and Torres Strait Islander organisations.
- Consider the patient's rights, especially in relation to information dissemination.
- Confirm with the patient and family that care and treatment information has been understood. Seek advice from Aboriginal and Torres Strait Islander personnel where required.
- Provide sufficient time for the patient and family to process treatment information and seek clarification from Aboriginal and Torres Strait Islander personnel/support person where required.



***Providing culturally appropriate palliative care to
Aboriginal and Torres Strait Islander peoples***

- Provide opportunities for discussion throughout the progress of the illness/disease. Where preferred by the patient or family, include an Aboriginal and Torres Strait Islander support person in the discussions.
- Take time to build relationships with the patient and family.

For further information to support the implementation of this principle and the suggested strategies, see *Factors influencing communication* in this document and the accompanying resource: *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples — Resource*.

Implementing Practice Principle 3: Training

Organisational strategies

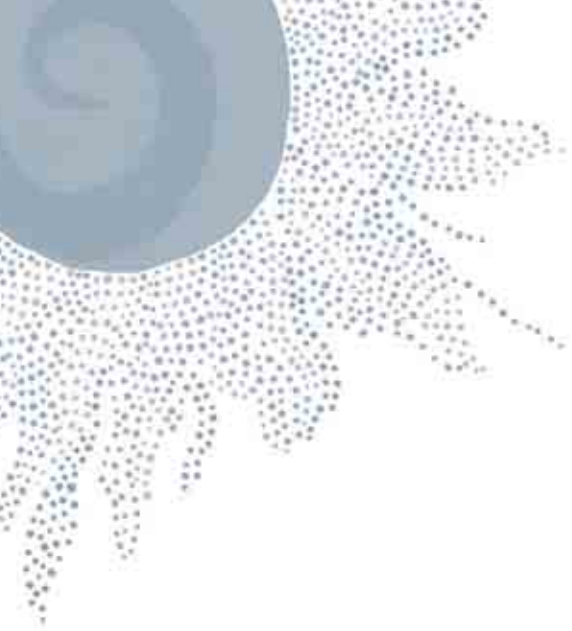
- Incorporate cultural safety training focused on Aboriginal and Torres Strait Islander peoples' needs into professional development for all staff. This includes induction/orientation for new staff and professional development policies and procedures.
- Establish relationships with Aboriginal and Torres Strait Islander organisations and personnel to facilitate the delivery of training which is locally relevant.
- Develop training strategies relevant to local needs.
- Support flexibility in the delivery of training to encourage participation by all target groups.
- Allocate resources to enable staff to attend cultural safety training.
(Refer to *Factors influencing training*)

Personal strategies

- Participate in training.
- Reflect on personal and organisational practice in the context of the training provided.
- Implement training in workplace activities and mentor others.
- Contribute to the development of culturally safe organisational policies, procedures and practice.

For further information to support the implementation of this principle and the suggested strategies, see *Factors influencing training* in this document and the accompanying resource: *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples — Resource*.

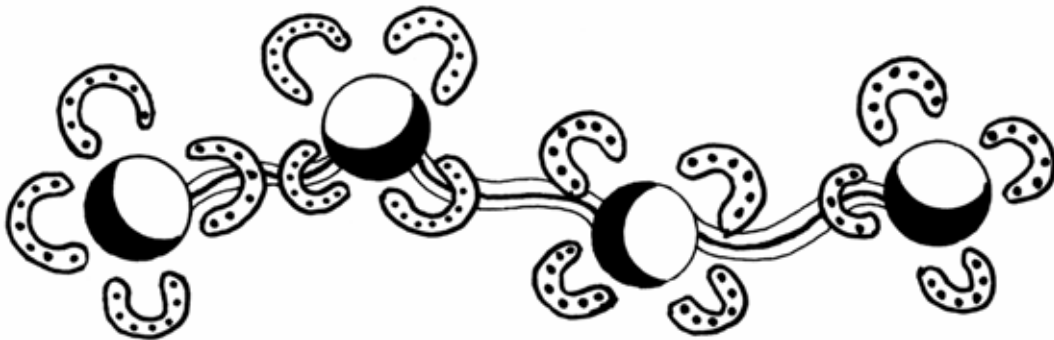


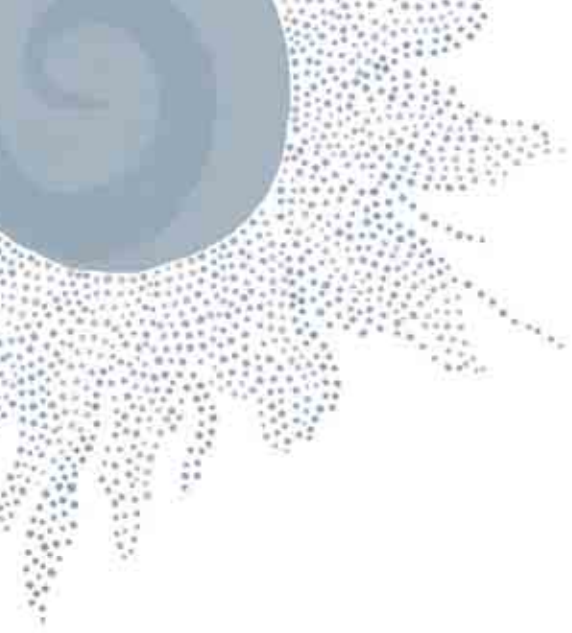


Section 3



Factors influencing implementation





3 Factors influencing implementation

The key to providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander people is to acknowledge the diversity of cultural needs within this group and to work in collaboration with the patient, their family, the Aboriginal and Torres Strait Islander community, and local Aboriginal and Torres Strait Islander organisations in all aspects of the care process.

This approach supports the concept of cultural safety and minimises stereotyping.

The following pages contain important background information to assist in implementing the principles. The information has been structured to provide:

- an overview of the issue
- insights into the potential impact of the issue on palliative care provision
- some ideas on addressing the issue.

Where possible, stories and case studies from consultation with Aboriginal and Torres Strait Islander peoples, health workers and palliative care providers have been included.



Factors influencing the involvement of Aboriginal and Torres Strait Islander people

Cultural factors

Cultural factors may include:

- recognising cultural diversity
- acknowledging and valuing Aboriginal and Torres Strait Islander peoples' identity
- choice of place of death
- family and kinship relationships
- who provides care
- culturally appropriate consent
- ceremonies and practices
- treatment environment
- models of care provision
- post-death requirements and support
- loss and grief support
- funerals.



Recognising cultural diversity

Aboriginal culture in Australia is not homogenous. It comprises a broad range of distinct cultural groups with distinct cultural practices, traditions and laws. Torres Strait Islander culture is distinct again, having links with Papuan and Pacific Island cultures. Additionally, Aboriginal and Torres Strait Islander people in rural, regional and urban areas may have a mixture of traditional and mainstream needs.

Impact on palliative care provision

The diversity of Aboriginal cultures and the distinct Torres Strait Islander culture means assumptions cannot be made about the requirements of a patient and/or their family. What may be culturally appropriate for some people may be offensive to others. ‘Cultural stereotyping’ can cause stress for patients and their families. It can also lead to assumptions about the patient’s needs, and the ability of the family to provide care.



Case study ...

An Aboriginal man living in a public housing area in a regional town in Victoria was diagnosed with liver cancer and his condition was deteriorating rapidly. The area in which he lived had a reputation for vandalism, crime and alcohol abuse. He wished to remain at home for what time he had left. Palliative care staff were concerned that he did not have a carer living with him. His brother offered to come and care for him in the terminal phase of his illness. Staff of the palliative care service were concerned that the brother would be an unreliable carer, based on their assumptions about the patient’s neighbourhood. When the man’s brother arrived, staff discovered he was a company executive who had arranged to work from his brother’s residence. His supportive care enabled the man to die at home as he wished.

(Palliative care nurse, regional Victoria)



Aboriginal and Torres Strait Islander communities in regional and urban areas often include people from a wide range of geographical areas. There may be requirements specific to the birth/ancestral area of the person not shared, or known, by others in the community.

Addressing this issue

- Ensure that admission information gathered includes the specific cultural needs and preferences of the patient and their family. It may be necessary to request assistance from local Aboriginal and Torres Strait Islander organisations and Aboriginal Liaison Officers/Health Workers to source information about cultural requirements which may impact on palliative care provision.
- If the local area is not the person's place of birth, Aboriginal and Torres Strait Islander communities/ organisations will have contacts with other communities throughout Australia to assist with gathering the relevant information. This allows enquiries to be made quickly and effectively.
- Establish information dissemination protocols which support security of information to assist the smooth sharing of information and effective continuity of care.



Acknowledging Aboriginal and Torres Strait Islander peoples' identity (disclosure/non-disclosure of Aboriginal and Torres Strait Islander status)

Data collection is a key tool in compiling evidence on the health and wellness of Aboriginal and Torres Strait Islander people. Asking Aboriginal and Torres Strait Islander status contributes to information gathering and improves the status and priority of Aboriginal and Torres Strait Islander peoples' health in determining service provision and funding. It also helps inform the future planning and development of palliative care provision for Aboriginal and Torres Strait Islander people.

Impact on palliative care provision

A significant percentage of Aboriginal and Torres Strait Islander people have a mixed heritage. The patient/family may not look Aboriginal and Torres Strait Islander but still identify as such, and may be offended if they are not asked about their status. Where it is considered by the patient/family to be 'shameful' to request special considerations (for example, in meeting cultural needs), they may not make their needs known.

On identifying Aboriginal and Torres Strait Islander people, it cannot be assumed that they and/or their families will have cultural support requirements. Some people may not wish their Aboriginal and Torres Strait Islander status to be known and may be offended if they are treated differently to other people (this may include people who have distinct Aboriginal and Torres Strait Islander features).



Case study ...

When my mother was dying, she was particular in insisting that she didn't receive care that was any different from other patients in the hospital. She didn't want to be treated like an Aboriginal person, even though it was very obvious that she was.

(Aboriginal Elder, regional centre,
about her mother who had lived in a capital city for most of her life)



In some instances the patient's family is Aboriginal and Torres Strait Islander and will have cultural requirements and preferences to be addressed.

Addressing this issue

- Establish standardised admission protocols to enquire as to the Aboriginal and Torres Strait Islander status of all patients.



Choice of place of death

Being able to 'finish up' in the place of their choice is very important to many Aboriginal and Torres Strait Islander people with strong connections to traditional lands playing an important cultural role.

Impact on palliative care provision

Cultural practices and requirements will vary from community to community, and even within communities (particularly in urban areas). If a patient wishes to return to their homeland to die, transfer arrangements will need to be planned and supported. This may involve liaising with Aboriginal and Torres Strait Islander organisations and/or government departments to access funding, organising transfer of equipment, disseminating information to other health services and ensuring the required medication is available in the patient's community of birth.

Where specific ceremonies must be performed at the place of death before that place can be used again (for example, a smoking ceremony) they need to be identified in the planning process. Policies need to be flexible to accommodate a range of specific cultural requirements. Special variations may be needed to some policies and procedures to allow specific ceremonies to occur.

In some communities the place of death may need to be avoided for a certain length of time before it can be used again. This can have major implications where a facility is multi-purpose (for example, in acute care/aged care facilities).

Addressing this issue

- Ask about the preferred place of death early in the process so that any wish to return to traditional lands to die can be planned for and to support continuity of care.





Case study ...

My father was a very important Torres Strait Islander man. It was important that he went home. I gave up my job to build a traditional fishing house in front of the fish traps. My father was a traditional man and he needed to come back and die in a traditional house. He rested on his place before leaving. It was preparation for the next journey.

(Torres Strait Islander Elder)

- Enlist the support of Aboriginal Health Workers and Aboriginal and Torres Strait Islander organisations to explain the progression of the illness to the community and arrange appropriate cultural support when the person returns to their land.
- Include the family in planning for choice of place of death to help them manage any potential dislocation caused if the patient chooses to pass away in the family home.



Case study ...

In the community I work with it is important to work with the family. Most of our people choose to pass away in their community. Often the family will build a special shelter so that the person can pass away in their traditional land, but the family doesn't have to vacate their house.

(Aged care coordinator, isolated Aboriginal community)





Family and kinship relationships

Family/kinship rules may mean that certain people who would in the mainstream system be regarded as distant relatives have strong cultural responsibilities to the patient or members of the patient's family.

How families respond to illness of a family member may also be significantly affected by their place in the family structure.

Impact on palliative care provision

The position of the patient within their family (or extended family) may affect their ability to meet appointments, access family resources and make decisions relating to their care, as well as their choices about care. Some family decisions may be different to mainstream notions of care of ill family members.

Kinship obligations can result in large numbers of relatives wishing to visit the patient during the palliative period. This may also extend to viewing the body and/or participating in post-death practices. Where this occurs, it can be very distressing for family members to be subject to policies that specify a maximum number of visitors.

Where the patient is an Elder or community leader, their condition has particular implications for the community and the passing on of the cultural knowledge they hold. Other members of the community (in addition to the family and extended family) may need to pay their respects during the palliative process. Specific ceremonies/practices related to the patient's position as Elder/community leader may also need to be carried out.

Addressing this issue

- Discuss cultural requirements and preferences early in the palliative process so that the impact of family and kinship relationships can be managed.
- Enlist the support of Aboriginal and Torres Strait Islander organisations as required to assist with transport for appointments, home and community care and personal care services.
- Consider room and bed placement where there is the possibility of large numbers of visitors at any given time. A room/position near an entrance to the external environment allows visitors to come and go as the need arises. It may be necessary to relax visitor number policies.
- For care in the home, work with Aboriginal and Torres Strait Islander organisations to support the family to cope with a large number of visitors (for example, finding accommodation, sourcing funding for travel and identifying and planning for family and kinship issues).





Caregivers

Family and kinship relationships can dictate who is most appropriate to provide care for the person. In some communities a person may have an 'avoidance relationship' with the patient or their family, and for cultural reasons cannot provide care. There may also be gender and/or age issues to take into account. In some communities care may fall under the restrictions of 'women's business' or 'men's business'.

It may not be appropriate for a man to be cared for by female personnel (or a woman by male personnel), or for a woman to be seen without clothing by male medical personnel.

Impact on palliative care provision

Avoidance relationships and kinship relationships can determine whether Aboriginal and Torres Strait Islander staff are able to provide care for a particular patient.

**'We are Aboriginal and Torres Strait Islander peoples before we are nurses.
We are first nation people and intend to maintain our cultural heritage.'**

(Abstract of Recommendations, Aboriginal and Torres Strait Islanders Nursing Forum, Sydney, 1997)

Addressing this issue

- Consult the patient and family early in the process to identify the most appropriate people to provide care and identify anyone culturally inappropriate. Seek clarification as required from Aboriginal and Torres Strait Islander staff, Elders, community leaders or Aboriginal and Torres Strait Islander people organisations.
- Check with Aboriginal and Torres Strait Islander staff about any avoidance relationships which affect them. Explore alternative support mechanisms where necessary (for example, Aboriginal and Torres Strait Islander staff advising mainstream staff or supporting appropriate family/community members to provide direct care).



Culturally appropriate consent

For some Aboriginal and Torres Strait Islander peoples the mainstream notion of ‘next of kin’ may not be appropriate. A member of the extended family, not the immediate family, may be the proper person to give permission about care options. There may be different people who must give consent at different stages in the palliative period, and following death. In some communities a group of people may collectively give consent on behalf of the family and the community.

The culturally appropriate person, or people, will vary depending on the specific cultural group of the patient.

Impact on palliative care provision

In some communities failure to gain consent from the appropriate person can have serious cultural repercussions. This may have ‘blame’ and ‘payback’ implications for the family. This can also involve the community holding the provider and/or service to account over the treatment provided and the death of the patient. This can impact on Aboriginal and Torres Strait Islander staff and also affect the credibility of the palliative care service and future accessing of palliative care support by community members.

Addressing this issue

- Identify early in the planning stages who is the culturally appropriate person, or people, to give consent for treatment and develop strategies for obtaining this consent. Services may need to consider liaising with health services in the patient’s home country.
- Where consent needs to be given by a specific person or group of people, obtain ‘cultural consent’ for proposed treatment and enquire as to the appropriate person/people to arrange transfer of the body for burial.
- Where English is not the main language of the person and/or their family, use an interpreter to seek consent and/or explain treatment/care issues so that informed choices are made.





Ceremonies and practices

Depending on the person's cultural background and the strength of their ties to cultural tradition, there may be specific ceremonies and practices around death and dying (for example, blame and/or payback practices, 'sorry business', singing rituals and dances) which need to be addressed during palliative care provision.

Some families may not have specific ceremonies but may have cultural practices which they would like supported.

Impact on palliative care provision

These requirements can have a significant impact on palliative care provision, palliative care personnel, and the reputation of the service. Some practices (and consequences) may cause a conflict between cultural considerations and professional duty of care for Aboriginal and Torres Strait Islander staff — particularly when the patient dies unexpectedly.



Case study ...

A person was referred late to a palliative care service in a rural community. The person was an Aboriginal Elder who was dying of end-stage diabetes. When visited by the palliative care nurse, the person appeared to be experiencing pain. Recognising that the person was close to death, the nurse commenced a sub-cutaneous infusion of narcotic to relieve the pain. She assumed the family recognised that the person would most likely die in the next few hours. The person subsequently died within an hour. The family blamed the nurse for the person's death although this was not the case. As a result, she and her family needed police protection until a solution was negotiated by community leaders and the palliative care service. After this incident there was very little use of the palliative care service by the local Indigenous Australian community.

(Registered nurse, rural palliative care service)

Factors influencing implementation

Families may not be willing to have the person ‘finish up’ at home (despite the person’s express wish to do so) because of potential consequences.

Aboriginal and Torres Strait Islander staff in some areas may have cultural responsibilities as part of ‘sorry business’ which may affect their attendance at work.

Addressing this issue

- Seek information from the patient and/or their family early in the planning process, as cultural ceremonies and practices are specific to each community. Seek clarification as required from the local community through Elders, community leaders, Aboriginal and Torres Strait Islander Health Workers and Aboriginal and Torres Strait Islander organisations.
- Where the person has strong traditional ties to their community of birth, seek information through Aboriginal and Torres Strait Islander staff or the local community from the person’s community of birth.





Treatment environments

Some Aboriginal and Torres Strait Islander peoples may not feel comfortable in a mainstream style hospital/hospice/aged care environment. A person who has been used to spending significant time outside (for example, an older person from a remote area), may find mainstream style facilities with rooms, beds and routines confining. Other people may be comfortable in the physical environment but find the facility routines, or sharing a room with people of other cultural backgrounds, uncomfortable.

For some Aboriginal and Torres Strait Islander communities it is an important family responsibility for extended family members to visit the person. A person can, and often does, have many visitors at a time — especially if they are a community leader or Elder. This may cause problems where the patient is sharing a room with others.

Impact on the provision of palliative care

Early self-discharge, unauthorised absences, withdrawal and/or aggressive behaviour can indicate that an Aboriginal and Torres Strait Islander patient is uncomfortable in the treatment environment. Early self-discharge disrupts treatment routines, compounding the illness of the person. Valuable staff resources, and time, can be wasted trying to track people who have ‘gone home’ or ‘gone with friends/relatives’.

Withdrawal may result in non-compliance with medication schedules, withdrawal from food and/or lack of communication about pain and discomfort, and any needs that the patient and their family may have.

Aggressive behaviour may be directed at staff members, particularly when the patient is also in pain. The patient may deliberately not comply with medication schedules.

Addressing this issue

- Consult with the patient and family as cultural needs will differ, depending on the cultural background of the person and the strength of their ties with traditional ways of life. Clarify as required with local Elders, community leaders, Aboriginal and Torres Strait Islander staff and/or Aboriginal and Torres Strait Islander organisations.
- Consider what modifications can be made to make the physical environment more culturally appropriate (for example, using a room close to an external exit, purchasing Indigenous artwork, allowing personal items).
- Consider whether such cultural requirements as traditional healers and/or medicines, traditional food, and the support of Aboriginal and Torres Strait Islander personal care services would provide comfort to the patient and make the care environment feel more culturally safe.





Models of care provision

In some instances the patient may wish to be cared for at home or in their own community. For some Aboriginal and Torres Strait Islander people, cultural requirements may be more important than treatment or meeting physical needs. The medical model of care provision may not be the most appropriate in providing support.

Past experiences with mainstream services (particularly for older Aboriginal and Torres Strait Islander people) may have left a legacy of distrust. This can result in some people not wishing to be cared for in an acute care hospital environment, even though their treatment requirements may involve acute care hospital equipment. Misunderstanding of the use of morphine and other aspects of care can also be an issue.

Some Aboriginal and Torres Strait Islander people may prefer to be cared for by Aboriginal and Torres Strait Islander personnel only. They may feel uncomfortable having a palliative care service staff member in their home or a clearly marked palliative care service vehicle at their home.

Some people may request traditional healers, traditional food and/or other traditional practices as part of their care.

Impact on palliative care provision

The wishes of the patient and/or their family about care provision, environmental and social conditions may necessitate flexible models of care.

Palliative care services may need to consider working with Aboriginal and Torres Strait Islander organisations in auspicing care provision or supporting and training family members to provide care.

A range of environmental and social conditions, particularly in remote areas where some services are not readily available (or reliable), may necessitate creative solutions to sourcing equipment and medication.



Case study ...

A very traditional lady was dying in a metropolitan city. She wished to remain at home with her family caring for her. The family provided all the care. The palliative care service was really just there in the background supporting the family with equipment and advice as required.

This enabled the family to provide traditional care, knowing they were supported by the mainstream health service and that their mother's desire for traditional care was being met.

The palliative care service was unsure whether there was more they could have done to support the family. They were unsure of where to get advice without asking the family too many questions — they didn't want to impinge on the privacy of the family. However, the family seemed happy with the support provided.

(Metropolitan palliative care service)

Addressing this issue

- Where the patient prefers to be cared for at home, support the family to provide the palliative care. This may involve training in bathing, feeding, toileting and administering medication, as well as organising respite care.
- Palliative care services/personnel may play a role in educating community members in how they can support the patient and their family, thus helping to meet the person's choice of place to 'finish up', and helping family/community members feel they have appropriately supported the person in the 'finishing up' process.
- The family may need to be supported in providing care until the final time when the person may need to be moved to hospice care, or to a special 'shelter', so that they do not die in the family home.



- Where the person and/or family prefer care to be provided by Aboriginal and Torres Strait Islander personnel, support Aboriginal and Torres Strait Islander people organisations to provide direct care by providing training in care procedures, observing the progress of the disease and supporting family members.
- Consider the role that Aboriginal Health Workers (or a trusted Aboriginal and Torres Strait Islander community member) can play in helping the patient and/or their family feel more comfortable with palliative care personnel by accompanying them on home visits.
- Where there are legal and/or ethical issues in supporting the palliative care choices of the patient and/or their family, consult Elders and/or community leaders about ways of minimising the impact of the issues.



Post-death requirements and support

For some Aboriginal and Torres Strait Islander communities it is particularly important to meet specific post-death requirements to fulfil cultural obligations.

In other communities it is important that the body is returned to the community within a certain time so that specific rituals may be commenced according to cultural law.



Case study ...

In our area it is really important for a lock of hair and piece of clothing to be returned to the community to prove that the person has passed away.

(Palliative care nurse, remote area)

In my culture, it would be *really* offensive for a lock of hair or piece of clothing to come to the family. We don't have this practice.

(Torres Strait Islander Elder)

Post-death practices/requirements will differ in different communities. For this reason, it is important to enquire about them early in care planning.

For some Aboriginal and Torres Strait Islander peoples, post-death practices and requirements may not differ markedly from those of mainstream people. However, it is important not to assume this. For example, some urban Aboriginal and Torres Strait Islander people have strong links to cultural traditions and may have particular post-death requirements they wish fulfilled. The family of the patient may need support to fully understand what mainstream official post-death requirements need to be complied with (for example, which authorities/government departments need to be notified, what information must be provided et cetera).

Impact on palliative care provision

Where these post-death requirements are not met, there can be significant cultural consequences for the family or considerable distress caused to the family/extended family and community.



Being denied access to viewing the body may mean family members (or culturally important community members, for example, Elders) cannot fulfil their responsibilities. This results in stress for the family and community. In some instances there may be consequences for the family and a loss of credibility of the palliative care service with the community.



Case study ...

A young man from a remote community died of leukaemia in a regional hospital. The Elder from the community arrived to view the body, to ascertain death and carry out certain post-death practices which were cultural requirements of that community. The Elder was denied access to the body by hospital staff because he was not close blood kin to the deceased person. This caused offence to the Elder who was an important leader in the community, and considerable distress to the family.

(Aboriginal Health Worker, regional/remote area)

Other cultural requirements such as vacating or smoking premises after a death and wailing/self-harm can impact on the operations of a palliative care facility. A death on the premises can result in self-discharge of all Aboriginal and Torres Strait Islander patients until the cultural requirements have been carried out.

Addressing this issue

- Make sensitive enquiries early in the process about any specific post-death requirements. Policies and procedures may need to be modified to accommodate some practices.
- Palliative care services may act as brokers of information for the patient and/or their family. Information needed may include details of services that can be accessed and the requirements of government departments during illness and after deaths. Aboriginal and Torres Strait Islander organisations may be able to assist the patient and/or their family to access services during the illness (for example, carer payments) and afterwards (for example, funeral support funds).



Loss and grief support

Research has shown that there is a large burden of unresolved grief in Aboriginal and Torres Strait Islander people communities and this can influence reactions by the patient, their family and community to the news of impending death and the death itself.

Forced relocation and the stolen generations, decimation of culture, past clashes and the subsequent disempowerment of Aboriginal and Torres Strait Islander people are still very close to some Aboriginal and Torres Strait Islander communities — both urban and traditional. Older Aboriginal and Torres Strait Islander people particularly may have been part of the stolen generation; families may have had stories handed down from their relatives. An outcome of these factors has been the loss of culture.

Statistics show high rates of death in Aboriginal and Torres Strait Islander communities and significantly lower average age of death. The mortality rate in some communities can result in multiple experiences of grief, leading to cumulative grief. The community may not have time to come to terms with deaths before more occur.

Grief reactions may vary considerably depending on the extent of remaining traditional culture and the amount of unresolved grief in the community. Traditional grief reactions can vary from extended periods of wailing to physical self-harm to withdrawal and extended periods of absence.



Case study ...

A lady from a remote area died in a (capital city) hospital. The family members had come to (the city) to be with her. The Aboriginal staff from the Aboriginal Medical Service told the ward staff when she was near death that they should remove solid, moveable objects from the room before she died. They ignored the advice. When she died, the waiting relatives began wailing and started hitting themselves with all sorts of dangerous objects that were in the room. The staff had not listened, had not removed the objects and had not found a better room for the lady where the family could be with her safely.

(Aboriginal Health Worker,
Sullivan 2003, Reproduced with permission of the
Australian Government Department of Health and Ageing)



Impact on palliative care provision

Specific cultural practices, such as wailing, may impact on other people in a hospice or hospital environment. Grief reactions may be also more extreme due to previous unresolved grief.

There are few Aboriginal and Torres Strait Islander loss and grief counselling services available. Aboriginal and Torres Strait Islander people and/or their families may not feel comfortable accessing mainstream services. It cannot be assumed that Aboriginal and Torres Strait Islander families will access a grief and loss service even if it is available.

Addressing this issue

- Consult Elders/community leaders/Aboriginal organisations or Aboriginal Liaison Officers/Health Workers for advice on, and planning for, possible grief reactions.



Funerals

Funerals are significant events for Aboriginal and Torres Strait Islander peoples. They are a critical part of the mourning and healing process for the family, extended family and community, and cannot be hurried. Attending a funeral (and in some instances participating in post-funeral arrangements) is regarded as an important responsibility.

In some instances extended family will need to travel across several states to attend a funeral, and may have to stay with the family for an extended period. This can result in financial strain on the family they are staying with.

Impact on palliative care provision

Aboriginal and Torres Strait Islander families may request support in managing funeral requirements from palliative care services.

Addressing this issue

- Where possible, assist in identifying sources for financial assistance to meet funeral costs, travel to return the body for a homeland burial, or for important relatives to attend the funeral. Aboriginal and Torres Strait Islander organisations may play a key role in these areas.



Including Aboriginal and Torres Strait Islander organisations and/or personnel

Inclusion of Aboriginal and Torres Strait Islander people and/or organisations can cover:

- Aboriginal and Torres Strait Islander peoples advocacy
- inclusion at each stage of care (planning, provision and monitoring)
- consideration of shared care models of care provision
- supporting the Aboriginal and Torres Strait Islander family
- development of support strategies for Aboriginal and Torres Strait Islander staff
- Aboriginal and Torres Strait Islander participation at policy development level.

Elders, Aboriginal and Torres Strait Islander community leaders, Aboriginal organisations and Aboriginal Liaison Officers/Health Workers can provide valuable support in sourcing cultural information. Elders/community leaders may not be able to share information about specific practices, requirements or ceremonies, but may be able to advise about the implications of cultural requirements for palliative care provision.

There are often specific protocols/courtesies to be followed when asking for cultural information. Aboriginal Liaison Officers/Health Workers or Aboriginal and Torres Strait Islander organisations may be able to advise about these protocols.



Advocacy by an Aboriginal and Torres Strait Islander person

Some patients and/or families may wish an Aboriginal and Torres Strait Islander support person to assist them during the palliative term. This person can help ensure needs are identified and cultural safety is supported. The support person could be an Aboriginal Health Worker (or Liaison Officer), an Elder or community leader, a trusted friend or a community member.

Advocacy by Aboriginal and Torres Strait Islander advocacy can be extremely important to some patients, while other Aboriginal and Torres Strait Islander people may not require it. Some people may feel quite confident in communicating directly with mainstream staff, while some patients will not wish their Aboriginal and Torres Strait Islander status to be known or acknowledged, choosing to receive mainstream support services.

In some instances it may not be possible for an Aboriginal Health Worker (or Liaison Officer) to offer advocacy because of avoidance relationships. Where this happens, the Aboriginal Health Worker (or Liaison Officer) may be able to advise on alternatives.

Impact on palliative care provision

Advocacy by an Aboriginal and Torres Strait Islander person (or trusted friend of the patient/family) helps ensure cultural needs are identified and communicated to palliative care providers. Cultural safety is supported and the advocate can seek clarification on behalf of the patient/family.

If the patient and/or their family does not feel comfortable with mainstream palliative care providers and there is no Aboriginal and Torres Strait Islander advocate (or trusted friend to act as advocate), cultural needs may not be effectively communicated to the providers and cultural safety may be compromised by assumptions on the part of providers about the needs of the patient and their family.

Where care is being provided in the home, the patient and/or family may wish for a support person to be present during treatment discussions or home visits. This may mean palliative care providers working closely with Aboriginal Health Workers or support personnel. It may be more appropriate for the Aboriginal and Torres Strait Islander person to lead discussion about symptoms, needs and choices, with the palliative care provider taking a supporting role.



Addressing this issue

- Ask the patient and/or their family if they would like an Aboriginal and Torres Strait Islander person to provide advocacy at any stage during palliative care (from explanation of prognosis to post-death arrangements) to ensure needs are identified and appropriately met.
- If so, have the Aboriginal and Torres Strait Islander advocate present during explanations of palliative care provision, pain or symptom management to help ensure the explanations are understood. If the patient, or their family, has questions they are unwilling to ask medical staff, they may ask their advocate after the medical staff depart.



Inclusion at each stage of care

Aboriginal and Torres Strait Islander organisations — particularly health and medical services — may be a preferred avenue of care for some people or their families. They can also be an invaluable source of advice and provide advocacy for the patient with other agencies.

Aboriginal and Torres Strait Islander organisations may provide indirect support through supporting the family or may provide direct support where mainstream support is not accessed (for example, direct care may be provided by home and community care staff).

Impact on palliative care provision

Aboriginal and Torres Strait Islander people are generally not accessing palliative care services despite having a mortality rate higher than average. Anecdotal evidence suggests that cultural inappropriateness is a contributing factor to the low access rates (Sullivan 2003). Including Aboriginal and Torres Strait Islander representatives in all stages of the care process (from planning to discharge/post death arrangements) allows Aboriginal and Torres Strait Islander perspectives to be considered throughout the development of the care plan.

It can also be important in creating ‘bridges’ between palliative care services and local Aboriginal and Torres Strait Islander communities.

Addressing this issue

Forming partnerships with local Aboriginal and Torres Strait Islander providers of primary health and community care services can help provide culturally appropriate palliative care support, raise the profile (and acceptability) of the palliative care service in the Aboriginal and Torres Strait Islander community, and complement the service provision of both parties.

- Seeking information about Aboriginal and Torres Strait Islander organisations

Information about Aboriginal and Torres Strait Islander organisations, their role and environment, and the extent of their service provision, can be obtained from government departments, bodies such as National Aboriginal Community Controlled Health Organisations (NACCHO), state and regional councils of ATSIC (Aboriginal and Torres Strait Islander Commission) and the Aboriginal and Torres Strait Islander organisations themselves.



- Making contact and establishing links

Contact may be initiated formally (for example, with the CEO) or informally through individual personnel who have contacts within Aboriginal and Torres Strait Islander organisations. Both formal links through Memorandums of Understanding or formal partnerships, and informal links between staff are important.

Informal networks with health workers can be a valuable mechanism for sharing of ideas, knowledge and skills, as well as providing professional support and links to the local Aboriginal and Torres Strait Islander community.

Protocols may be developed for:

- establishing relationships with Aboriginal and Torres Strait Islander doctors and nurses³
- establishing relationships with Aboriginal and Torres Strait Islander medical services and health organisations
- non-medical referral by Aboriginal Health Workers and/or Aboriginal organisations
- sharing information with Aboriginal and Torres Strait Islander organisations.

Some Aboriginal and Torres Strait Islander organisations provide a wide range of services and may therefore not respond initially or quickly to requests for advice/assistance.

Documenting the formal relationship can provide an efficient framework and shared understanding for personnel from both organisations to work together in supporting patients and their families. Holistic models of care, based on a team approach which recognises the importance of the cultural contribution of Aboriginal and Torres Strait Islander organisations, may be more appropriate for some patients than models of care where the main focus is medical support. A team approach can help ensure palliative support is provided even if direct care is not provided by the palliative care service.

³ Where possible, check details of Aboriginal Medical Services located in the area, or seek to establish a relationship with a larger service that has Indigenous Australian medical/nursing personnel who may be able to provide advice

- **Diagnosis communication**

Aboriginal and Torres Strait Islander advice should be sought about culturally appropriate ways of communicating the diagnosis to the patient/family. The patient, and/or their family, may feel more comfortable with an Aboriginal Liaison Officer/Health Worker or a trusted friend present to act as an advocate, to ask questions, or request clarification.

The offer to have an Aboriginal and Torres Strait Islander advocate present during the discussion needs to be made prior to the discussion commencing.

- **Admission**

All care recipients should be asked about Aboriginal and Torres Strait Islander status and whether they wish to have this publicly acknowledged. This supports cultural safety and allows cultural needs to be addressed in care plans. Involving Aboriginal Health Workers/Liaison Officers in admission procedures for Indigenous Australians, or those with Aboriginal and Torres Strait Islander family, can help in identifying cultural requirements.

Aboriginal and Torres Strait Islander personnel should be included in reviewing admission processes to ensure they are culturally appropriate.

Aboriginal and Torres Strait Islander people -specific literature about palliative care can be a valuable support to verbal information. Involving Aboriginal and Torres Strait Islander staff, community representatives and Aboriginal and Torres Strait Islander organisations in developing the literature will help ensure it meets the needs of patients and their families.

- **Developing care plans**

For some Aboriginal and Torres Strait Islander patients, ensuring their cultural needs are met is a higher priority than ensuring physical or pain relief needs are met. A care plan can address:

- how the family and community are to be involved in care
- cultural preferences/requirements during care
- post-death preferences and requirements
- the culturally appropriate person or people to notify for treatment/ medication consent and when the person deteriorates/‘finishes up’
- how the family would like to be supported following the ‘finishing up’.



This helps to determine appropriate resourcing of care for the person, and enables individual personnel to adjust their practice to incorporate the cultural requirements of the patient and/or their family.

Some cultural practices have significant impact on the lives of the family and carers of the patient, so ***it is important that the family is included in developing the care plan.***

In some instances, Aboriginal and Torres Strait Islander people may have preferences for traditional healing services, food or other support services. Traditional healers can provide significant emotional and spiritual support for the patient and their family. Elders, Aboriginal and Torres Strait Islander people community leaders and organisations will know if there are traditional healers or people who know traditional healing practices in the area. Traditional medicines may be used in conjunction with other treatments, and incorporated into the care plan.

Aboriginal and Torres Strait Islander personnel can discuss cultural needs with the patient and/or their family and identify how these needs can be supported through the palliative care process. They can also identify where cultural factors (which the family may not wish to discuss openly) may impact on palliative care provision.

- Case management

Assigning responsibility for advocacy and liaison can help ensure cultural needs are consistently met, particularly where many people or organisations are providing care.

- Timely communication and discharge planning

Contact with local health care providers *prior* to the patient returning from treatment helps ensure continuity of care and a smooth transition for the patient back to their community. Local health services may need information about treatment details, preferences for care and implications of the progress of the condition, so that they can support the patient's needs.

Aboriginal and Torres Strait Islander health organisations can play a valuable role in transfer arrangements, ensuring that cultural needs are met and planned for. Where appropriate (for example, where specialist medical equipment is needed and not available in the local community), regional Aboriginal and Torres Strait Islander health services may be involved to assist in continuity of care.

Factors influencing implementation

- Networking across borders and regions

Aboriginal and Torres Strait Islander networks and regions may differ from palliative care/health care provision regions. Access to palliative care services for Aboriginal and Torres Strait Islander people can be increased through establishing and maintaining a network model of provision, allowing palliative care services to support people to remain close to their communities.

Networks could include:

- Aboriginal and Torres Strait Islander health organisations (particularly Aboriginal Medical Services)
- Aboriginal and Torres Strait Islander community organisations (for example, home and community care services)
- professional networks (for example, Aboriginal Health Workers)
- informal Aboriginal and Torres Strait Islander community groups.

Providing information to Aboriginal and Torres Strait Islander organisations can help raise awareness of palliative care and enable Aboriginal Health Workers to answer queries that Aboriginal and Torres Strait Islander people may feel uncomfortable asking mainstream health workers or palliative care providers.



Consideration of shared care models of care provision

This approach has been covered earlier in this document (see *Models of care provision* under *Factors influencing involving Aboriginal and Torres Strait Islander peoples*).





Supporting the Aboriginal and Torres Strait Islander family

Moving the patient away from family and community for treatment may cause considerable distress to the person, family and community. It may be extremely important for them to have frequent and/or extended visits from family members. The family will need accommodation if they are to be close by.

Family members who are providing care (at home or in a facility setting) will have specific support needs related to care provision in addition to emotional and spiritual support needs around grief and loss.

Impact on palliative care provision

Some Aboriginal and Torres Strait Islander people may display aggressive behaviours when visiting the patient. Family members experiencing difficulty in finding suitable accommodation or accessing required support services may direct their frustrations towards staff.

In some circumstances there may be misunderstanding of the treatment being undertaken by the patient. Misunderstanding can arise for a range of reasons, including:

- lack of understanding of medical terminology
- lack of understanding of English because it is not the main language of the family
- being unable to concentrate on explanations because of worry (about the patient, accommodation, finance et cetera)
- being unable to concentrate on explanations because of discomfort with the treatment facility environment.

For some Aboriginal and Torres Strait Islander families, particularly those from more traditional communities, ‘payback’ and ‘blame’ issues may arise if family members are held accountable for the patient’s death or the manner in which they died. (Further information on these issues is contained in the accompanying resource *‘Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples — Resource’*.)

Addressing this issue

- The palliative care service can play a valuable support role in assisting the family to source accommodation. Aboriginal and Torres Strait Islander organisations may also be able to assist in accessing funding support, or finding accommodation support within the local community.



Case study ...

I know of this one lady whose daughter had cancer. She had to move to Adelaide for treatment and her mother went with her. The Aboriginal housing service found her a nice house in Adelaide where she could stay — she couldn't afford the unit at the hospital because she was on a pension. When her daughter got really ill, she brought her home here to finish up. She was really glad she could be with her daughter in Adelaide because it would have cost too much to visit. Being on an old person's pension she couldn't afford that.

(Indigenous Australian Health Worker, rural town, SA)





Developing support strategies for Aboriginal and Torres Strait Islander staff

Aboriginal Liaison Officers/Health Workers can play a key role in providing support to Aboriginal and Torres Strait Islander people and acting as a 'bridge' or 'cultural interpreter' for mainstream staff. They may be seen by the Aboriginal and Torres Strait Islander community as 'the spokesperson' for the palliative care service/medical service and may be the preferred contact.

Impact on palliative care provision

Aboriginal Liaison Officers and/or Health Workers are critical in reaching into Aboriginal and Torres Strait Islander communities but are often overworked because they are the single Aboriginal and Torres Strait Islander face of the organisation. Anecdotal evidence (Sullivan 2003) suggests that this results in 'burnout' and frequent turnover of staff.

Addressing this issue

- Acknowledging and valuing the role of Aboriginal Liaison Officers/Health Workers



Case study ...

When he passed away I was supporting the brothers and sisters. Because there were so many relatives coming they ran out of food. I had to organise food, and to have the phone connected so they could let family members know. I provided family support, helped write the eulogy, sourced funding for the funeral, sourced accommodation for relatives and put other family members in touch with support services. I also met relatives coming in by bus and train and helped access other agencies to assist with phone expenses et cetera. Oh, that's right, I also liaised with Centrelink about bereavement payments.

It was really hard. I was dying inside, underneath. I had to talk through the treatment with the family because they were blaming the hospital for him getting sick.

(Aboriginal Health Worker, regional Victoria)

Community expectations mean that Aboriginal Liaison Officers or Health Workers may be informally taking on a range of roles because they are the people patients and/or their families feel most comfortable with. They may be providing informal counselling, explaining diagnoses, treatment choices and medication requirements, as well as notifying relatives, finding accommodation, arranging transport et cetera. It is important to acknowledge and value Aboriginal Liaison Officers/Health Workers for their knowledge of Aboriginal and Torres Strait Islander networks, resources and politics, the diversity of tasks they carry out and their importance in the planning and provision of palliative care to terminally ill people and support to families. This role needs to be acknowledged as integral to the palliative care team's provision of care to the terminally ill and their families.

- Formal recognition of liaison work



Case study ...

We live in the community. We get phone calls at night and on the weekend from people because they don't know who else to call. I talk to them. It's not a nine to five job. You can't be anonymous. There's an expectation that you'll be available. My husband gets really angry sometimes.

(Aboriginal Health Worker, Central Victoria)

The prevention of burnout among Aboriginal Liaison Officers/Health Workers would be helped by a recognition by palliative care services of the extensive community liaison role they play, and the importance of them being supported to meet community/cultural obligations such as attending funerals, as well as developing strategies to support these roles.

Opportunities for de-briefing/discussion with sympathetic colleagues can be an important source of support and assistance in managing a complex and demanding role.

Aboriginal and Torres Strait Islander staff may be taking on liaison work well beyond their formal job role. Community expectations and demands don't follow normal working hours or job descriptions. They may be contacted in response to all needs before mainstream staff will be accessed, so liaison takes up a large part of their time. To avoid staff burnout, this needs to be acknowledged and factored into formal assessments of their workload.



- Counselling and support

Aboriginal and Torres Strait Islander communities are usually small in size and most community members know one another well. Where the patient comes from the local community, Aboriginal and Torres Strait Islander staff members may be related or know the person well. This can result in significant emotional stress as the Aboriginal Health Worker/Liaison Officer may be the main support for the family and community whilst also dealing with their own grief. Access to appropriate counselling and support is important to avoid burnout and reduce stress.

- Cultural obligations

In some communities, Aboriginal and Torres Strait Islander staff may have cultural obligations and responsibilities (for example, 'sorry business'/'sorry camps') after a death. Leave may be required for these obligations and responsibilities to be carried out.



Aboriginal and Torres Strait Islander participation at policy development level

Aboriginal and Torres Strait Islander representation at board or executive decision-making level enhances consideration of cultural safety in policy development and planning directions for the organisation.

Impact on palliative care provision

Aboriginal and Torres Strait Islander participation at board or policy development level can be valuable in guiding palliative care services to establish culturally safe policies and procedures and develop a relationship with the local Aboriginal and Torres Strait Islander community and organisations. It can also increase knowledge of palliative care support services available to local Aboriginal and Torres Strait Islander people and their access to these services.

Addressing this issue

- Seek input to policy development from Aboriginal and Torres Strait Islander staff to identify any unintended barriers and to ensure policies are culturally appropriate. Community feedback on policies can be sought via Aboriginal and Torres Strait Islander organisations.
- Approach local Aboriginal and Torres Strait Islander communities to nominate a member to represent Aboriginal and Torres Strait Islander views on the board or at policy development level.



Factors influencing communication

Cultural sensitivity

Cultural sensitivity includes:

- using appropriate language
- appropriate non-verbal communication and attire
- considering gender issues
- considering the location or environment
- the presence of a support person
- using appropriate communication strategies
- providing sufficient information to the patient and their family to make informed decisions
- incorporating the needs of the extended family and the community
- avoiding cultural stereotypes.



Using appropriate language

Some Aboriginal and Torres Strait Islander people are uncomfortable with the terms 'death' and 'dying', preferring phrases such as 'not going to get better', 'unwell', 'very sick' or 'finishing up'. Referring to the terminally ill person as 'the sick person' is common. For some Aboriginal and Torres Strait Islander people these alternative terms reflect the desire to maintain hope, which can be important.

Impact on the provision of palliative care

Use of the terms 'death' and 'dying' may contribute to a culturally unsafe care environment for the patient and/or their family. The resulting 'cultural barriers' may impede communication about needs and choices.

Addressing this issue

- Seek advice from Aboriginal and Torres Strait Islander staff, personnel from Aboriginal and Torres Strait Islander organisations, or the local community if in doubt about asking the Aboriginal and Torres Strait Islander patient and their family about culturally inappropriate language.





Appropriate non-verbal communication and attire

Cultural safety for some Aboriginal and Torres Strait Islander people may be compromised by unconscious ‘messages’ sent through non-verbal communication, and attire that may be associated with past (or historical) negative experiences.

Factors such as persistent questioning, direct questions, prolonged eye contact, loud voices, being too close, rigid following of routines, ignoring visitors and talking whilst writing may cause cultural discomfort.

Uniforms may be associated with past (or historical) negative experiences of health services/bureaucracy.

Impact on palliative care provision

Palliative care providers may be compromising cultural safety in the care environment by behaviours/body language they are unaware of. This may then impact on the care patient/carer relationship and the patient’s confidence to make their needs and choices known.

Addressing this issue

- Consider how your own culture and values are reflected in behaviour, and seek information from Aboriginal and Torres Strait Islander staff or personnel about how this behaviour is perceived by Aboriginal and Torres Strait Islander people.
- Consider training in cultural safety to help raise awareness of the impact of a dominant culture (usually the culture of the provider). The impact can be compounded by the power relationship between patient and provider (for example, the person has little knowledge and needs care; the provider has extensive knowledge and provides care).

‘The philosophy that promotes peoples as equal, or to be treated in the same way, denies difference and cultural identity.’

(Abstract of Recommendations, Aboriginal and Torres Strait Islanders Nursing Forum 1997)



Considering gender issues, location and environment

These issues have been covered earlier in this document.
(See *Caregivers and Treatment environments* under *Factors influencing involving Aboriginal and Torres Strait Islander peoples*).



Presence of a support person

This issue has been covered earlier in this document.
(See *Advocacy by an Aboriginal and Torres Strait Islander person* under *Factors influencing involving Aboriginal and Torres Strait Islander peoples*).





Using appropriate communication strategies

Cultural differences can result in the communication strategies usually used by palliative care providers being inappropriate for Aboriginal and Torres Strait Islander people. Some communication strategies normally encouraged in palliative care provision (for example, direct questioning and direct mention of death and dying) may be culturally inappropriate for some Aboriginal and Torres Strait Islander people.

Communication strategies commonly used by mainstream people (dominant culture) may be culturally unsafe for some Aboriginal and Torres Strait Islander people.

Impact on palliative care provision

If the patient and/or family has not understood the information provided they may make ill-informed choices or provide uninformed consent. This presents ethical problems and, for some Aboriginal and Torres Strait Islander families, potential issues of blame and/or payback. The result can be a loss in credibility of palliative care providers in the community and a consequent lack of use of services.

Addressing this issue

It is important to seek information about appropriate and inappropriate communication strategies as these will differ depending on the cultural background of the patient and/or family and the strength of their ties to their culture. Information can be sought from the patient and their family (some people prefer to be asked directly), Aboriginal and Torres Strait Islander staff, Aboriginal and Torres Strait Islander people organisations, Elders, community leaders or the patient's chosen advocate.

Where English is not the main language of the patient and/or their family, assistance can be sought from interpreters. Interpreters may be sourced from the patient's own family, Aboriginal and Torres Strait Islander organisations in that community or through government departments. Where the patient's home community is some distance away, local Aboriginal and Torres Strait Islander organisations may be able to facilitate contact and organise an interpreter.

The initial diagnosis is a time of great vulnerability for any terminally ill person. When communicating the diagnosis to Aboriginal and Torres Strait Islander patients, personal discussion is often more effective than written communication, particularly when the information comes from another Aboriginal and Torres Strait Islander person.

Having an Aboriginal and Torres Strait Islander advocate present can assist in communication of prognosis, treatment options and care choices.

Appropriate communication strategies to use at the time of communication of diagnosis can include:

- an Aboriginal and Torres Strait Islander advocate or trusted friend of the patient/family acting as an intermediary
- speaking softly
- including questions about cultural needs, pain and any other issues, as part of a general conversation
- where sustained eye contact is uncomfortable for the person/family, acknowledging the person being spoken to, but not holding eye contact for a prolonged period of time.

Communication strategies for providing information during the palliative term can include:

- Identifying who is the most appropriate person to assist in keeping the extended family and the community informed, which is important to maintain a flow of communication about the patient. Distance and lack of transport can hinder family visits, so regular communication is critical to maintaining the links between the patient, their family and community.
- Written information in straightforward terms, supported by verbal explanations. This can be particularly important for medication schedules where the patient/family may understand the initial explanation but need to refer to clear, written instructions later on.

To disseminate palliative care information to Aboriginal and Torres Strait Islander people more generally consider:

- Written information specifically for Aboriginal and Torres Strait Islander patients available on admission to palliative care services, hospitals, hospices and aged care facilities. Any literature about palliative care should support verbal information given. In this way, family members are able to discuss treatment and care with extended family and their community.
- Contracting local artists to illustrate brochures, posters and information leaflets so that the local community can identify with the material.
- Information provided through posters, video, audiotapes, CDs, radio segments et cetera. These can be very useful in terms of raising awareness in communities of palliative care services and providing answers to frequently asked general questions about palliative care.





Providing sufficient information to the person and their family to make informed choices

It cannot be assumed that the patient, their family and/or significant others understand the terminal nature of the illness, the implications of the diagnosis and the care choices they have. The extent of understanding may be affected by:

- the patient having no family or community person with them
- being in an unfamiliar environment
- feeling uncomfortable with medical personnel and medical organisations
- not understanding medical terminology
- English being a second, third or even fourth language
- discomfort with mainstream communication strategies (for example, direct talk, eye contact, formal language structure)
- insufficient time being allowed to digest the information given and/or to seek clarification
- culturally appropriate people not being present
- information being given by a person who is culturally inappropriate.

Impact on palliative care provision

Some Aboriginal and Torres Strait Islander people may not indicate that they have not understood the information given. This can result in choices being made which do not address their needs and/or compromising cultural safety.

Addressing this issue

- Seek information about the patient's cultural background so that culturally appropriate communication strategies can be adopted. Consult Aboriginal and Torres Strait Islander staff, Elders, community leaders and advocates. Communication strategies, such as the examples given above, could be considered to ensure information is given in a culturally appropriate manner.
- Discuss the diagnosis, implications and care choices — preferably in plain English, taking particular care that the person/family understands the terminal nature of the illness. It may be necessary to have an Aboriginal and Torres Strait Islander advocate or trusted friend present and allow extra time for discussion.

Factors influencing implementation

- Thoroughly discuss and demonstrate treatment instructions. Written instructions may not be followed (but should be provided upon request).
- Provide opportunities for discussion throughout the progression of the disease to help the patient/family increase their understanding of the nature of the disease. This can also help in disseminating accurate information to the patient's community, thus building up trust in the palliative care provider and lessening the possibility of blame/payback consequences if the patient 'finishes up' unexpectedly.



Factors influencing training

Training

Training includes:

- training in ensuring cultural safety for Aboriginal and Torres Strait Islander people (including an orientation to the local Aboriginal and Torres Strait Islander people community and services offered) for palliative care personnel
- principles and concepts of palliative care for Aboriginal and Torres Strait Islander people personnel.

Participants

Participants in training include:

- general practitioners and medical specialists
- nursing and allied health professionals
- ancillary personnel
- volunteers
- personnel from associated agencies (for example, interpreters, flying doctor personnel)
- Aboriginal Liaison Officers and Health Workers
- Aboriginal medical and health service personnel
- Aboriginal and Torres Strait Islander community members and organisations
- family members and significant others involved in the care of the terminally ill person.



Aboriginal and Torres Strait Islander cultural safety training

Cultural safety training focuses on the notion of the self as a cultural bearer. It includes the historical, social and political influences on palliative care and Aboriginal and Torres Strait Islander attitudes to palliative care services. It supports the development of relationships that build trust. Such training supports palliative care providers to recognise diversity and enables safe care to be defined by those receiving it.

In the context of these Practice Principles, cultural safety training includes an orientation to local Aboriginal and Torres Strait Islander communities as the context for providing palliative care.

Impact on palliative care provision

Provision of cultural safety training to staff in palliative care services will support each person to reflect on their own practice and the organisation to reflect on its overall provision of palliative care to terminally ill people and their families.

A knowledge of cultural safety principles allows palliative care providers to continually monitor provision, and adapt provision to the patient's/family's specific cultural background.

Addressing this issue

- It is recommended that all staff undertake cultural safety training. Culturally unsafe care, even from someone with a minimal influence in the care environment, can leave a lasting impact on the family of the patient and cause unnecessary stress.
- Where possible, training should also be provided to staff from associated services, particularly where they have direct contact with the patient and/or their family. This includes interpreters, flying doctor communications staff, staff in oncology clinics and dialysis clinics, mental health workers et cetera.
- It is recommended that training be delivered by a team consisting of a palliative care educator and Aboriginal and Torres Strait Islander trainer. Where required, this model could be supported by special presentations by local Elders/community leaders. Bringing together palliative care and local Aboriginal and Torres Strait Islander peoples' perspectives allows participants to examine cultural safety concepts within a local provision and local community context.





Principles and concepts of palliative care training

The Practice Principles recognise the important role undertaken by Aboriginal personnel (health workers, liaison officers, home and community carers, aged care staff, staff of Aboriginal and Torres Strait Islander organisations, volunteers with Aboriginal and Torres Strait Islander organisations and community members). The importance of working with Aboriginal and Torres Strait Islander personnel and organisations is also recognised.

Impact on palliative care provision

Personnel within the community and from Aboriginal and Torres Strait Islander organisations who understand the principles and practice of palliative care support can provide an important bridge between palliative care services and Aboriginal and Torres Strait Islander communities. They are able to disseminate information, act as an initial point of contact, provide palliative care service information to community members who would not approach the service directly, and provide cultural advice to palliative care services.

Aboriginal and Torres Strait Islander staff who have had no training in palliative care awareness (particularly hospital liaison officers) are often intimately involved in the provision of palliative support to the Aboriginal and Torres Strait Islander patient. Palliative care awareness training, or specific palliative care training, can improve the skills of Aboriginal and Torres Strait Islander staff and increase their understanding of the support available to Aboriginal and Torres Strait Islander people. Training in medical terminology can help Aboriginal and Torres Strait Islander staff support the person/family to understand medical terms involved in diagnosis, treatment and pain management. Written material needs to be available to support this training.

This knowledge also assists Aboriginal Health Workers and Liaison Officers in their community liaison and support roles, increasing understanding in communities, and in some instances lessening the possibility of negative consequences when the person ‘finishes up’.

Training in palliative care concepts and practices can also increase the knowledge of medical personnel and allied health workers and contribute to all stakeholders supporting holistic models of care provision.

Addressing this issue

Palliative care organisations have an educative role with mainstream health workers, professionals and organisations. This includes general practitioners, medical specialists, aged care and nursing home staff, government department staff involved in community health and Aboriginal and Torres Strait Islander organisations.

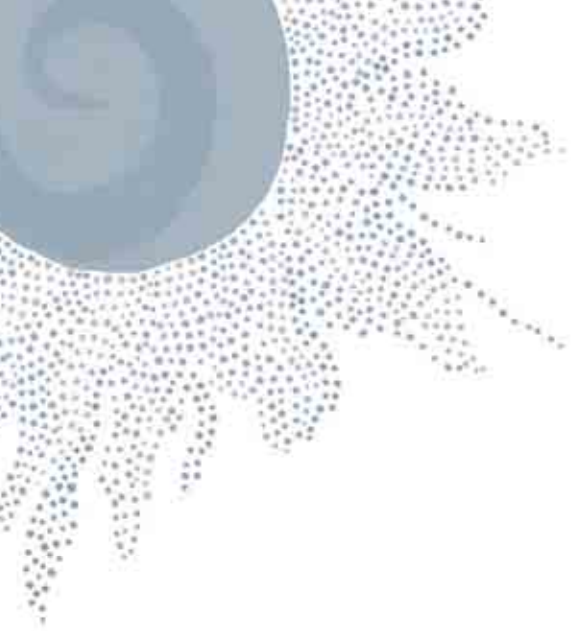
Health workers, professionals and organisations may have a low level of awareness of the range of supports palliative care services offer, the role of palliative care in treatment and how palliative care can increase choices for terminally ill people. This is particularly relevant to Aboriginal and Torres Strait Islander people where high rates of renal failure, diabetes and other non-cancer conditions are the main causes of death and late referral limits care choices.

Palliative care awareness training needs to be provided to Aboriginal Liaison Officers, Health Workers, home and community care workers and other personnel who provide direct support to Aboriginal and Torres Strait Islander people and their families.

Work placement opportunities for Aboriginal Health Workers

Work placement for Aboriginal Health Workers with palliative care service providers provides a valuable opportunity for raising local Aboriginal Health Workers' awareness of the palliative services available. They can support local Aboriginal and Torres Strait Islander people in making more informed care choices and in accessing care for their needs.





Bibliography

Baban J 2002, 'Spiritual applications in palliative care', *Conference Paper, Holistic and Creative Choices*, National Home and Community Care (HACC) Conference, Adelaide, February 20–22.

Bourke EA and Mobbs R 1998, *Developing an Aboriginal Palliative Care Strategy for South Australia*, Aboriginal Research Institute, University of South Australia, Adelaide.

Burton B 2002, 'Consumer focus', *Conference Paper, Holistic and Creative Choices*, National Home and Community Care (HACC) Conference, Adelaide, February 20–22.

Enoch W and Mailman D 1996, *The 7 stages of Grieving*, Playlab, Brisbane.

Fischer J 1997, 'Development of palliative care services in a remote and rural area', *Conference Paper, 4th National Rural Health Conference*, Perth, February 9–12.

Fried O 2000, 'Providing palliative care for Aboriginal patients', in *Australian Family Physician*, vol 29, no 11, pp1035–1038.

Improving Care for the End of Life: The Seven Promises for Patient Care
www.mywhatevery.com/cifwriter/library/source/src12400.html

Indigenous Australian Children: Educating for Health
222.mja.com.au/public/issues/174_10_210501/bauert.html

Jaklina M 2002, 'RDNS Working with cultural diversity', *Conference Paper, Holistic and Creative Choices*, National Home and Community Care (HACC) Conference, Adelaide, February 20–22.

Kellehear A 1999, *Health Promoting Palliative Care*, Oxford University Press, Melbourne.

Kellehear A 2000, *Eternity and Me*, Hill of Content, Melbourne.



Low P and Floyd J 1998, *Bessie's Story: Palliative Care in Remote Communities*, North Western Regional Palliative Care Committee, Broome.

NSW Health and Aboriginal Health Impact Statement and Guidelines: *Incorporating Aboriginal Health Needs and Interests in Health Policies and Programs*, 2003, Sydney.

Nursing Council of New Zealand, 2002, *Guidelines for Cultural Safety, the Treaty of Waitangi and Maori Health in Nursing and Midwifery Education and Practice*, Auckland.

Palliative Care Australia 1999, *Standards for Palliative Care Provision*, 3rd ed, Canberra.

Rothwell N 2003a, 'Sick at heart', *The Weekend Australian*, March 29–30 pp29.

Rothwell N 2003b, 'Staying alive', *The Weekend Australian*, April 5–6, p86.

Schneider D 2002, 'Carers linking hands across cultures', *Conference Paper, Holistic and Creative Choices*, National Home and Community Care (HACC) Conference, Adelaide, February 20–22.

Sullivan K and Associates 2003, *National Indigenous Palliative Care Needs Study Final Report*, Australian Government Department of Health and Ageing, Canberra.

Taylor BJ 2000, *Reflective Practice: A Guide for Nurses and Midwives*, Allen and Unwin, Sydney.

Wagstaff P 1997, *Appropriate Care: The Palliative Care Needs of Victorian Aboriginal People*, Draft Report for the Victorian Department of Human Services, Melbourne.

Walters C 2002, 'Achieving creative social support in your work with the Aboriginal and Torres Strait Islander Community', *Conference Paper, Holistic and Creative Choices*, National Home and Community Care (HACC) Conference, Adelaide, February 20–22.

Yarram B 2002, 'Consultation as a service delivery model', *Conference Paper, Holistic and Creative Choices*, National Home and Community Care (HACC) Conference, Adelaide, February 20–22.

NOTE: All web sites were current and accessible as at December 2003.