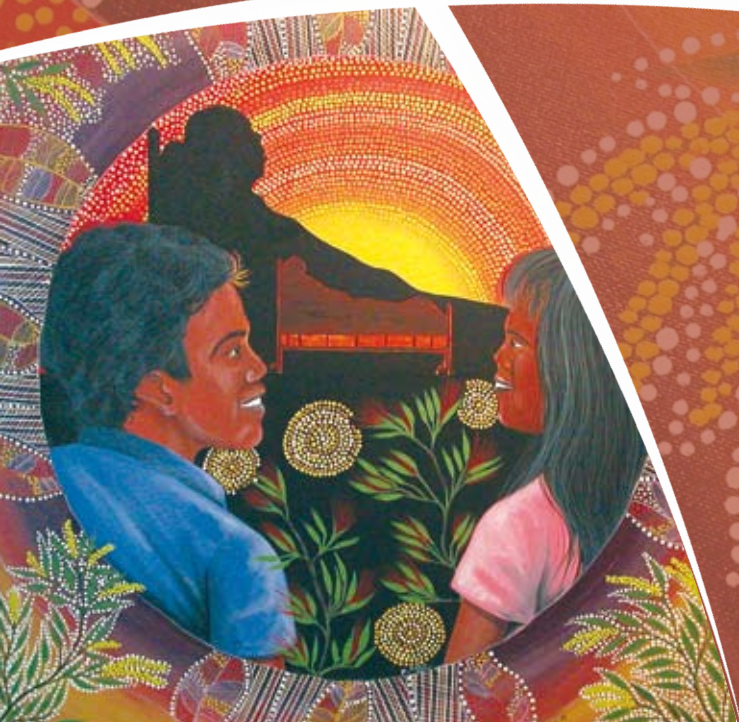




# Best Practice Palliative Care

for Aboriginal and Torres Strait  
Islander People in the ACT

WORKBOOK



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## ACKNOWLEDGEMENTS

Thank you to the many Aboriginal and Torres Strait Islander health workers who have provided valuable input to the development of the workbook and associated posters and brochures.

We would also like to thank Mr Dale Huddleston (Wiradjuri/Ngandi) and Mr Dean Keed for the artwork used through this workbook.

**Concept:** The art shows palliative care in a warm, kind, sharing environment where Aboriginal people should be encouraged to visit and feel comfortable.

Mr Huddleston has requested that the artwork continue to be used only in relation to this project.

**Copies of the National Resource Kit can be obtained from:**

Rural Health and Palliative Care Branch  
Australian Government Department of Health and Ageing  
Phone: 1800 020 787  
Website: [www.palliativecare.gov.au](http://www.palliativecare.gov.au)

## INTRODUCTION

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This Workbook has been developed to provide an ACT specific complementary resource to the national “Providing culturally appropriate palliative care to Indigenous Australians – Resource Kit”. The Resource Kit aims to support palliative care professionals in the provision of culturally appropriate and safe palliative care to Indigenous Australians.

The workbook is an integral part of the nationally funded “Community Awareness Raising of Indigenous Palliative Care Practice Principles – ACT”. This Project also aims to raise awareness of palliative care in the ACT Aboriginal and Torres Strait Islander community through the provision of promotional posters and brochures.

The provision of a quality, appropriate palliative care response to the needs of Indigenous Australians is a focus under the National Palliative Care Strategy.

The Workbook facilitates implementation of the National Resource Kit Practice Principles to:

1. Involve Aboriginal and Torres Strait Islander Australians in the provision of palliative care and the implementation of culturally appropriate treatment;
2. Facilitate a concerted effort on communication and liaison with the patient and their family/carers; and
3. Ensure training is provided to key personnel to enable them to provide culturally appropriate care to Aboriginal and Torres Strait Islander patients.

This workbook can be used as an information point to assist palliative care personnel to provide culturally safe palliative care. It includes a range of resources, information and general issues which can assist when providing care for, and assistance to, Aboriginal and Torres Strait Islander patients and their families and carers.



## IMPROVING ACCESS TO SERVICES

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This section of the workbook provides some information on the factors which influence Aboriginal and Torres Strait Islander people approaching palliative care providers in time to receive appropriate treatment and care for their illness.

This section also provides some points of interest and direction regarding strategies that could be adopted to enhance access to your service.

### **Issues Affecting Access by Aboriginal and Torres Strait Islander Australians to Mainstream Palliative Care Services**

It is well known that in palliative care the sense of impending loss experienced by individuals close to the end of their life can be magnified by earlier experiences. This is particularly so for Aboriginal and Torres Strait Islander people. Since the first European intrusion into their lives, Aboriginal and Torres Strait Islander people have lived with the consequences of losing their land, access to and acceptance of their culture, autonomy and, in many cases, their language, dignity and health. The impact of Government Policies has created a great amount of trauma, grief and loss. For example, the forced removal of children has meant that many Aboriginal and Torres Strait Islander people lost their knowledge of family and their role within it, as they were placed in institutions or adopted into non-Indigenous families. Consequently, deep emotional scars affect many Aboriginal and Torres Strait Islander people.

Various factors play a part in whether a patient or their family/carer decides to access mainstream palliative care services. For example, in many instances, many of the providers of palliative care services are non-Indigenous professionals, which may make Aboriginal and Torres Strait Islander people uncomfortable and it therefore difficult to develop a personal and trusting relationship with the service provider.



Undertaking travel and making drastic alterations to family life to enable the provision of care available in a hospice, nursing home or aged care facility can also be a significant problem for families. Families may also feel a loss of control of the care arrangements and necessary treatments if their loved one is in a nursing home or care facility. This can also lead to a perception of loss of family and culture within the Aboriginal and Torres Strait Islander community.

A close awareness of death and dying is facilitated by close involvement of the extended family in supporting a patient during terminal illness and following ceremonies or gatherings, which can extend over several weeks. This in effect can mean that Aboriginal and Torres Strait Islander people have no time to grieve as once one funeral is over preparations for another gathering is underway.

Whilst palliative care is a service that is provided there is no guarantee that the service will be sought or utilised by the Aboriginal and Torres Strait Islander community. The best and most effective way of communicating with the Aboriginal and Torres Strait Islander community in most cases, particularly in relation to palliative care, is through face-to-face meetings and word-of-mouth promotions. This is due to the delicate nature of the topic and the perceptions surrounding its meaning and circumstances.

# CHECKLIST

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To assist you in the process of managing your contact with Aboriginal and Torres Strait Islander patients, the following checklist has been created to give guidance to the necessary practices, which should be considered when communicating with Aboriginal and Torres Strait Islander patients and their family/carers. Remember that this checklist is a guide only.

## Communications

- Ensure that phone contact is made with all who you plan to be involved in the process before meeting with the patient. You may need to develop a plan of action prior to making any phone calls.
- Discuss whom the patient would like to have involved in the process, particularly Aboriginal and Torres Strait Islander Worker involvement. You should also speak with an Aboriginal or Torres Strait Islander Health Worker separately.
- If an Aboriginal and Torres Strait Islander Health Worker is accompanying you, ask them to determine whether the patient wishes to be their own advocate or if they wish for a family member or Aboriginal health worker to fulfil the advocacy role.
- Where possible, make face-to-face contact with the patient, their carer or family in a place that is familiar with them in the first instance, ensuring that they are as comfortable as possible with you before they are introduced to the facilities available.
- Establish communication processes for what works best with the patient, family, organisations and health support staff. Listen to their needs.
- Ensure that you have made, and are able to maintain, appropriate levels of contact with external community based health care assistance, such as Health Support Staff, Home and Community Care or the Aboriginal Medical Service.
- You need to ensure when developing your care plan, that there is a variety of choice in the services that can be provided to the patient.
- Don't rush the conversation. Make sure you use appropriate language. Do not necessarily expect a response straight away and take the time to have a yarn.

**Remember:** When making contact with a patient, be aware of their preferences regarding how they want to be contacted, whether it be directly or via a third party. You should establish this form of communication protocols well in advance to alleviate any tensions or cross communications. This could be done when taking a referral for the care of a patient.

**Remember:** Many Aboriginal people believe that mainstream service providers will not take the time that will be needed – this belief directly affects access to mainstream services.

NOTES: Use this space to make notes relevant to the care of Aboriginal and Torres Strait Islander palliative patients.



## Care Management

- Discuss the care management with the patient regarding who will be involved in the management of their case/health.
- Ensure you listen to the patient's needs and preferences in relation to their care. This should also include their choice of who they want to be the support person, and what involvement they want from Aboriginal or Torres Strait Islander support staff. Ensure that you ask if the patient would prefer that a designated Aboriginal and Torres Strait Islander support staff member accompany you on your first visit.
- You need to focus on patient AND their key family/community members and seek an understanding of their respective key roles and responsibilities.
- Ensure you make contact with individuals/organisations who the patient/their family/carer wants involved in their care and discuss what the process has been thus far, and how they would like their involvement to be managed.
- Aboriginal clients receiving care at home dislike receiving too many services at the one time ie: care needs to be well-timed and co-ordinated.
- Some clients will prefer a clinical approach adopted by professionals than that of a family/community carer particularly with regard to some personal care services.
- Take time to build relationships with the patient and their carer and family. This will take some time, and remember you will need to be supported too.

**Remember:** Take time to build trust and relationships, as some Aboriginal and Torres Strait Islander people may not want to talk about themselves and/or their needs straight away.

**Remember:** Aboriginal and Torres Strait Islander people come from diverse backgrounds and because of these differences and diversities, what works for one family may not be suitable for another.

**NOTES:** Use this space to make notes relevant to the care of Aboriginal and Torres Strait Islander palliative patients.



## Bereavement and Grief

- Ensure the family and carers, as well as the patient, is cared for in this stage of loss.
- Discuss options for the family and their carer regarding what support and services are available to them as an ongoing process.

**Remember:** Aboriginal and Torres Strait Islander families and carers consider bereavement, grief and loss as an integral part of both their and the community's healing process. This process needs to be allowed and embraced by all personnel involved in the care of patients.

NOTES: Use this space to make notes relevant to the care of Aboriginal and Torres Strait Islander palliative patients.

## Diversity of Aboriginal and Torres Strait Islander Culture

- There needs to be an understanding and appreciation that there is no difference between family kinship and blood relatives in Aboriginal and Torres Strait Islander culture. This could lead to a lot of people being involved in the family/care management of the patient.
- Family/kinship and extended family can congregate and provide support in the time of loss.
- As support personnel, you will need to ensure you give appropriate levels of information about the patient and family's cultural requirements to other personnel involved in their care.

**Remember:** That many Aboriginal and Torres Strait Islander people feel safer when around their own mob. Kinship and care by family is a natural process that is inherently provided in the community, and benefits all.

**NOTES:** *Use this space to make notes relevant to the care of Aboriginal and Torres Strait Islander palliative patients.*



## Be Flexible

- When dealing with each patient there needs to be flexibility in the way services are provided as well as what kind of borders and boundaries apply to those programs and services.
- Show that there are options available and that the options are conducive to a culturally safe environment and process.

**Remember:** An Aboriginal or Torres Strait Islander patient may or may not wish to be moved to an outside environment at the end-of-life with a clinician who is concerned about their physical well-being. Assistance with the flexibility in management of these services is crucial to the success of implementation of service delivery.

**Remember:** A patient or their family/carer may not always be able to keep appointments, as priority for some Aboriginal and Torres Strait Islander patients is determined by what is happening within the family/community. Check to see if transport assistance is required, as access to services may also be an issue for some clients.

*NOTES: Use this space to make notes relevant to the care of Aboriginal and Torres Strait Islander palliative patients.*

## Ongoing References

- Build relationships between palliative care service providers and Aboriginal and Torres Strait Islander organisations, particularly medical organisations and Aboriginal and Torres Strait Islander Programs, to reduce barriers to accessing those services.
- Ensure you have an updated and manageable list of service providers who are able to assist with the care and management of Aboriginal and Torres Strait Islander palliative care patients.
- Try to maintain contact with Aboriginal and Torres Strait Islander service providers, even outside of servicing the needs of a patient.

**Remember:** Aboriginal and Torres Strait Islander people will be more comfortable speaking with you if they know you or your organisation. Wherever possible, try to build partnerships with Aboriginal and Torres Strait Islander community groups outside of the hospice/hospital. Participating in the local Aboriginal and Torres Strait Islander community environment, will allow you the chance to break down barriers within the community in a culturally appropriate environment.

*NOTES: Use this space to make your own notes which are relevant to the care of Aboriginal and Torres Strait Islander palliative care patients.*



# COMMUNICATING WITH ABORIGINAL AND TORRES STRAIT ISLANDER CLIENTS REQUIRING PALLIATIVE CARE

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“Don’t walk for Aboriginal people – walk with us”

“A ‘friendship’ rather than ‘partnership’ approach is needed”


This section of the workbook provides information and examples on the communication methods and processes that could influence an Aboriginal or Torres Strait Islander person’s decision to access palliative care.

As a non-Indigenous provider of palliative care, there are several factors that may delay your progress in dealing with Aboriginal or Torres Strait Islander patients.

## **What Does Communication Mean To The Patient?**

Aboriginal and Torres Strait Islander clients are generally reluctant to use the palliative care services provided through a range of mainstream service providers because there is no Aboriginal or Torres Strait Islander face in the palliative care service. It is preferable that an Aboriginal person walks the patient through the service that is available to the patient. However, always ask the client what they prefer. In many instances, you may find that the Aboriginal Home Care Service provides the care that is needed to the patient instead of the palliative care service providers. This is because generally speaking, the Home Care Service has local Aboriginal people who can be accessed by the patient, allowing for a much greater level of comfort and relief for the patient.

In some instances it could prove very difficult for an Aboriginal or Torres Strait Islander patient to follow through with a referral to palliative care, unless they receive a necessary level of culturally appropriate support when the referral is made. It is strongly recommended that any palliative care providers



align themselves with Aboriginal and Torres Strait Islander community organisations that are in a position to assist with the patient's transition into palliative care. These organisations may be able to provide the cultural bridge needed to ease the patient into palliative care services.

Aboriginal people in general, have an historical dislike, distrust and sometimes fear of hospitals and non-Indigenous strangers coming to their homes. The involvement of Aboriginal and Torres Strait Islander Health Workers in clinical care increases confidence in the healthcare system as a whole.

**Paper based communications** – when writing communications for Aboriginal and Torres Strait Islander patients, family and carers, consideration needs to be given to the type of language used and how you, as a service provider, want the message to be received by the community. You will need to consider using language that is straight forward and easy to read.

**Physical/verbal communications** – when dealing with Aboriginal and Torres Strait Islander patients, ensure you are aware of the cultural factors necessary to manage the process of transition from current care to palliative care. Cultural safety and strength are imperative to the process of ongoing patient care.

When meeting with Aboriginal and Torres Strait Islander patients and their family, ensure you use clear, simple language. You will need to develop a personal relationship with the patient and their family.

**Telephone/email communications** – when making contact with Aboriginal and Torres Strait Islander patients, you should be aware of the appropriate use of electronic communications. Many Aboriginal and Torres Strait Islander patients may not have a telephone and certainly even fewer will have email or internet access. Therefore communications may need to be through a third party.



# LOCAL SERVICES/CONTACTS FOR ABORIGINAL AND TORRES STRAIT ISLANDER PALLIATIVE CARE CLIENTS

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<b>Service</b>	<b>Contact Details</b>	<b>Phone</b>	<b>Availability of Aboriginal worker</b>
Palliative Care Service (Hospice) - onsite and at home care	Clare Holland House	6273 0336	No
Aboriginal Liaison Officer	The Canberra Hospital	6244 2316	Yes
Respite and support for carers	ACT Carers Association	1800 059 059	Yes
Aboriginal Medical/Health Service <ul style="list-style-type: none"> <li>● GPs</li> <li>● travel assistance</li> </ul>	Winnunga Nimmityjah Aboriginal Medical Service	6284 6222	Yes
Home and Community Care Services (HACC) <ul style="list-style-type: none"> <li>● transport</li> <li>● meals on wheels</li> <li>● social support</li> <li>● respite</li> </ul>	Ngunnawal Community Care – Ngunnawal Aboriginal Corporation	6231 3422	Yes



## NOTES

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# NOTES

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## NOTES

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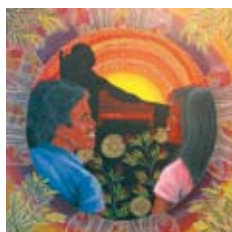
# NOTES

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## Art

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Aboriginal artists, Mr Dale Huddleston (Wiradjuri/Ngandi) and Mr Dean Keed, designed the art for this publication.

Concept: The art shows palliative care in a warm, kind, sharing environment where Aboriginal people should be encouraged to visit and feel comfortable.

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