



An Australian Government Initiative

# journey SORRY BUSINESS

A palliative care supportive booklet for Aboriginal people living in Wiradjuri, Yorta Yorta, Waveroo and Duduroa Countries

# ACKNOWLEDGEMENT

Murray PHN acknowledges its catchment crosses over many unceded First Nations Countries following the Dhelkunya Yaluk.

We pay our respects and give thanks to the Ancestors, Elders and Young People for their nurturing, protection and caregiving of these sacred lands and waterways, acknowledging their continuation of cultural, spiritual and educational practices.

We are grateful for the sharing of Country and the renewal that Country gives us. We acknowledge and express our sorrow that this sharing has come at a personal, spiritual and cultural cost to the wellbeing of First Nations Peoples.

We commit to addressing the injustices of colonisation across our catchment, and to listening to the wisdom of First Nations communities who hold the knowledge to enable healing.

We extend that respect to all Aboriginal and Torres Strait Islander Peoples.



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#### **DISCLAIMER**

No person should rely on the contents of this manual without first obtaining advice from a qualified person.

Murray PHN acknowledges that content in this toolkit has been extracted from materials created by South Western Sydney PHN.

This activity is supported by funding from Murray PHN through the Australian Government's PHN Program.

Artwork by Madison Connors



Country encompasses land, waterways, seas and skies, as well as the energy and space in between. It also encompasses relationships. Relationships with plants, relationships with animals and relationships with Ancestors (to name a few).

First Nations relationships within Country are grounded in reciprocity. Reciprocity is about mutual respect and exchange.

So while Country is place, it is also relationship."

Gemma Pol (Wiradjuri, Ngemba and Paakantji) - Common Ground

(commonground.org.au/article/what-is-country)



# WHAT IS MEANT BY SORRY BUSINESS?

Aboriginal people refer to a period of cultural practices and protocols associated with death as Sorry Business. The most widespread ceremonies of Sorry Business are conducted around the bereavement and funerals for a deceased person. It is an important time of mourning that involves responsibilities and obligations to attend funerals and participate in other cultural events, activities or ceremonies with the community.

# PALLIATIVE CARE YARNING

This booklet has been prepared to support Aboriginal people to journey into the health system through 'Sorry Business' (life-limiting illnesses).

In consultation with Aboriginal Elders, we aim to connect health services with Aboriginal wisdom when assisting and caring for those with life-limiting conditions while honouring their connection with land, community, family and tradition. We value the importance of advance care planning yarning and this resource has been developed to provide culturally appropriate, respectful and mindful information to encourage Aboriginal people in opening up conversations about their rights, wishes and how to plan ahead when circumstances change through their lives.

We hope you, your family and community find this booklet useful and we encourage you to share it with your mob.

# WHAT IS PALLIATIVE CARE?

Palliative care strives to ensure quality of life for those who have an illness that can't be cured. It offers professional care, pain-free living and support for the individual, family and/or carer.

# WHERE CAN I ACCESS PALLIATIVE CARE?

- Palliative care can be offered in your home
- A palliative care unit
- Residential aged care
- In the hospital

Ask your Healthcare professional or GP to provide you with information on this process

"We are all visitors to this time, this place. We are just passing through. Our purpose here is to observe, to learn, to grow, to love...and then we return home" Aboriginal proverb

# A SAD STORY ABOUT UNCLE

Planning ahead and yarning your wishes can help the people you care about in deciding what do you want in terms of treatment and who will be responsible for taking care of your business.

# NOT MAKING HIS OWN DECISIONS

Uncle has always been an independent and important Elder for his community. He was an active man that enjoyed the company of his woman Mary, family and community. Uncle got really sick last year and started yarning with Mary, family and community about his wishes of being taken back to Country for his last days. He also had a house he wanted to leave to his children. Uncle has moved to the big city decades ago but used to visit Country every year.

Three months ago, Uncle was taken to hospital for not feeling well. Days later, he got really confused and could not speak anymore. His doctors said he was in palliative care and these were his last days. His woman wanted to fulfil Uncle's wishes to be taken back to Country and buried on his own land and asked the doctors to take him there. Uncle's children were not happy with her decision and demanded he should receive treatment and stay in the hospital.

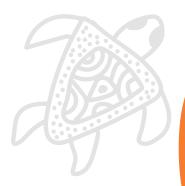
They didn't get into an agreement and a court order was sought to decide this. Uncle passed away before a decision was made and his body was buried in the city, his house was sold and money given to Mary only. Nowadays, Uncle's family, children and Mary do not get along and blame each other for what happened.

# HOW DOES PALLIATIVE CARE SUPPORT DECISION MAKING?

Palliative care works through conversations that will help you and your family make decisions about your place of choice for care and your cultural needs.

Palliative care health staff (doctors, nurses, etc):

- Want to make your Journey as comfortable as possible
- Are specially trained to work in this area
- Will support you where you want to be cared for
- Will provide support to family and/or carers when needed.



**YOU CHOOSE** who is involved in your care. You could choose:

- Your GP and specialists
- Aboriginal health workers
- Palliative care services
- Home carers

# WHAT CAN PALLIATIVE CARE HELP ME WITH?

Palliative care services can provide specialist advice, support and effective care of symptoms to assist the family and persons living with an illness that can't be cured.

# Depending on what you and your family want, the palliative care team will provide:

- Assistance for you and your family to come together to talk about Sorry Business
- Practical advice and support for the family and carers about making you more comfortable
- Management of pain and other symptoms, such as nausea, that you may be feeling
- Resources such as equipment you may need at home
- Links to other services such as home help and financial support
- Support and culturally-appropriate care of what is most important for you
- Referral to bereavement services if needed to help and support family and community after a loved one passes away.

# WHY YARNING YOUR WISHES?

As we get older, we start to question how we will take care of business and wonder what are the most important things for us.

- We might want to be cared by an important person in our lives
- We might want to wear traditional clothes or listen to music that we like
- We might want to be taken back to Country after we pass away
- We might want to know who will be responsible to take care of our business (money, belongings and healthcare)
- We might want to make sure that healthcare workers understand that we might need space for our family and kin to visit us.



# HOW CAN I PLAN AHEAD?

You can start planning ahead by yarning and making four documents.

#### Who do I yarn to?

Yarn to your family and those who you think will be making decisions about your health when you can't make decisions for yourself.

Yarn to your Aboriginal Health Worker. They can help with understanding what is available in your region and can yarn up for your wishes.

#### What documents do I need to PLAN AHEAD?

What document?	What's it for?	Who should I yarn with?
Advance care planning	What medical treatment and care do I want in the future?	My family and my GP (See page 14)
Will	Who will get my stuff after I pass away?	My family and my solicitor (See page 15)
Medical Treatment Decision Maker (Vic)/ Enduring Guardian (NSW)	Who will make decisions about my health and where I live if I can't?	My family and my solicitor (See page 16)
Power of Attorney	Who will make decisions about my money if I can't?	My family and my solicitor (See page 18)

# WHAT MEDICAL TREATMENT AND CARE DO I WANT IN THE FUTURE?

#### **ADVANCE CARE PLANNING**

#### What is Advance care planning?

Deciding what you do and don't want in your future medical treatments is called advance care planning. It involves yarning about things that matter to you, your choices and values, to friends and family. Then making a document (called Advance Care Directive) to record your specific choices.

You can decide in advance:

- Where you would like to be cared in your last days (for example, at home or hospital)
- Where you would like to be buried and if you would want to be taken back to Country
- Treatments you would like to receive or refuse (for example, surgeries, pumping on your chest and electric shocks if your heart stops beating, medication injected into your veins, putting breathing tubes in your throat when you can't breathe by yourself, etc).

Advance Care Directives can be reviewed at anytime.

## Did you know?

Advance Care
Directives are legal
documents that will
only be used when you
can no longer say what
you wishes are.

# I want more information - who should I talk to?

Talk to your Aboriginal Health Worker, solicitor or GP.

Ask your Aboriginal Medical Service for the Advance Care Yarning – Giving our Mob a Voice kit.

# WHO WILL GET MY STUFF AFTER I PASS AWAY?

#### WILL

#### What is a will?

A will is a legal document that says who your stuff will go to when you pass away. It instructs who your money, property, land and belongings (photos, furniture, jewellery, artwork, etc) will go to.

## Are wills expensive? Where can I make mine?

A solicitor may charge you a fee for preparing you one, but is an option for writing a will. Victorian State Trustees and NSW Trustee and Guardian both have low-cost options for writing a will (contact details below). Legal will kits can be purchased, but can result in disputes if not written correctly.

## Where can I get more information?

Talk to your Aboriginal Health Worker or contact Victorian State Trustees on 1300 138 672 or <u>statetrustees.com.au/wills/</u> NSW Trustee & Guardian on 1300 364 103 or <u>tag.nsw.gov.au</u>

## DID YOU KNOW?

Your will can also say where you want to be buried, including getting back to Country and funeral arrangements.

# WHO WILL MAKE DECISIONS ABOUT MY HEALTH AND WHERE I LIVE IF I CAN'T?

# MEDICAL TREATMENT DECISION MAKER (VIC) or ENDURING GUARDIAN (NSW)

# Who is a Medical Treatment Decision Maker (Victoria) or an Enduring Guardian (NSW)?

This is the person appointed by you to make decisions about your health, only when you can't make decisions for yourself. For example, if you develop dementia. They have a different name depending on which state you live in.

#### They can decide:

- Treatment your doctor or dentist prescribe
- Where you live
- What kind of services you get, like Meals on Wheels and home care.

You can sign a document nominating someone to be your Medical Treatment Decision Maker or Enduring Guardian and you can change it at any time.

It should be someone you trust, who knows you well and understands your wishes.

In Aboriginal societies, the next of kin is not always the preferred spokesperson for the patient. Nominating someone of your choice to be your Medical Treatment Decision Maker or Enduring Guardian helps health care workers understand who you want them to talk to about your health and decisions.

# I want more information - who should I talk to?

Talk to your Aboriginal Health Worker.

Ask your Aboriginal Medical Service for the Advance Care Yarning – Giving our Mob a Voice kit.

Also contact State Trustee in VIC on 1300 138 672 or visit: statetrustees.com.au





and NSW on 1300 109 290 or visit tag.nsw.gov.au



# DID YOU KNOW?

Medical Treatment Decision Makers and Enduring guardians can't make decisions for you about your money, property, vote or make a will under your name.

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# WHO WILL MAKE DECISIONS ABOUT MY MONEY IF I CAN'T?

### **POWER OF ATTORNEY**

## What is Power of Attorney?

It is a document you sign, nominating someone to look after your money when you can't do it yourself. Attorney is the person you appoint to take care of your money – it needs to be someone you trust.

#### Where can I make mine?

You can make your Power of Attorney document with your local solicitor or community legal centre.

#### I want more information - who should I talk to?

Talk to your Aboriginal Health Worker or contact Victorian State Trustees on 1300 138 672 or <a href="statetrustees.com.au/wills">statetrustees.com.au/wills</a> NSW Trustee & Guardian on 1300 364 103 or <a href="tag.nsw.gov.au">tag.nsw.gov.au</a>.

## DID YOU KNOW?

You can decide how much power you can give to your attorney. For example, you might only give them the power to pay your bills.

## HELP AND INFORMATION

### **Contact your Aboriginal Medical Service:**

# Albury Wodonga Aboriginal Health Service (AWAHS)

https://awahs.com.au

Freecall: 1800 421 640 Phone: (02) 60401200

ALBURY 664 Daniel Street (02) 6040 1200

WANGARATTA 86-90 Rowan Street WODONGA 12 Stanley Street



#### Bendigo and District Aboriginal Co-operative (BDAC)

bdac.com.au

119 Prouses Road North Bendigo (03) 5442 4947



# Njernda Aboriginal Corporation

njernda.com.au

84 Hare Street Echuca (03) 5480 6252 (Option 1)



# Mallee District Aboriginal Services (MDAS)

mdas.org.au

MILDURA 120 Madden Avenue (03) 5018 4100

SWAN HILL 70 Nyah Road (03) 5032 8600

KERANG 9 Nolan Street (03) 5412 6004



# Mungabareena Aboriginal Corporation

https://mungabareena.org.au

53 Ryley Street, Wangaratta (02) 6024 7599



# Murray Valley Aboriginal Cooperative (MVAC)

mvac.org.au

87 Latje Road, Robinvale (03) 5026 3353



# Rumbalara Aboriginal Co-operative

https://rumbalara.org.au

39 Archer Street, Mooroopna (03) 5820 0035





# YARNING YOUR WISHES

# What if you got too crook to speak for yourself?

Your family may need to make decisions for you. It is important to have a Yarn about your future, and write down what kind of healthcare and treatment you want.

These tool documents will help you to voice your needs:

## **Advance Care Planning** for

Dja Dja Wurrung Country (Central Vic):
bit.ly/3ECSfd4

#### **Advance Care Planning**

for Ngargad, Ladji Ladji, Jarijari, WadiWadi, Wemba, Wergaia, Baraba, Dja Dja Wurrung, Baraba Countries (Mallee Region): bit.ly/3EFJglc

#### Help with legal documents:

#### **Trustee Services**

It can help you with your planning ahead documents

NSW Trustee & Guardian 1300 554 791 tag.nsw.gov.au



VIC State Trustees 1300 138 672 statetrustees.com.au



#### Aboriginal Handbook for legal documents -

Taking Care of Business

Booklet with extra information about the legal documents needed to plan ahead.

For a copy: 1300 554 791

tag.nsw.gov.au/aboriginal-planning-ahead.html



### **Aboriginal Legal Service**

Can help find a local solicitor to make your will.

NSW/ACT: (02) 8303 6600

alsnswact.org.au



Victoria: (03) 9418 5999

vals.org.au





#### **Funerals and financial assistance:**

#### Services Australia (Centrelink)

They can help with disability, sickness and carer allowances.

13 27 17 (Mon-Fri 8am-5pm) servicesaustralia.gov.au



#### **NSW Aboriginal Lands Council**

Help you to discuss your eligibility for Funeral Assistance Grants.

1800 647 487 https://alc.org.au/funeral-fund/



#### **Can Assist**

Financial and Accommodation Assistance for Cancer patients

1300 226 277 canassist.com.au



#### **Medicare Services for Indigenous Australians**

To see if eligible for Medicare help with cost of health care medicine

Aboriginal and Torres Strait Islander Access Line – 1800 556 955

<u>servicesaustralia.gov.au/medicare-services-for-indigenous-australians?context=60092s</u>



#### Extra support (health, bereavement, counselling):

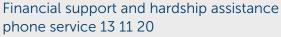
#### Lifeline

13 11 14 - Open 24 hours to talk <u>lifeline.org.au</u>



#### **Cancer Council**

Cancer information and support.



- <u>cancercouncil.com.au/cancer-information</u>
- <u>cancercouncil.com.au/get-support/</u>





#### **Bereavement Assistance Centrelink**

Services available to help you with payments, counselling and other services to help you adjust after someone close has died.

13 23 00 (Mon-Fri 8am to 5pm)

## Support for people with dementia:

#### **Dementia Australia**

They provide support with legal documents, information and support for people, families and carers.

National Dementia Helpline: 1800 100 500 (free call)



Webchat: dementia.org.au/helpline/webchat

Email: helpline@dementia.org.au

Learn more about dementia: bit.ly/3OWk30E



#### **Dementia Support Finder**

Find dementia support services in your region <a href="https://services.murrayphn.org.au/dementia.html">https://services.murrayphn.org.au/dementia.html</a>



# GETTING MORE HELP FOR CONDUCTING SORRY BUSINESS

#### 13YARN (13 92 76)

13YARN is a crisis support line for First Nations people who are feeling overwhelmed or having difficulty coping. 13YARN offers confidential one-on-one yarning with a Lifeline-trained First Nations Crisis Supporter. They can provide crisis support 24 hours a day, 7 days a week.

# Mob Strong Debt Help (1800 808 488)

Mob Strong Debt Help is a free legal advice service. They give advice on money matters for Aboriginal and Torres Strait Islander peoples from anywhere in Australia. Mob Strong are experts in laws about consumer loans (like credit cards, pay day loans, car loans and home loans), banking, debt recovery and insurance (like funeral, car, home, travel, life and pet insurance).

# Indigenous Consumer Assistance Network (ICAN) (1800 369 878)

ICAN offers free help with money troubles through its financial counselling and financial capability services to Aboriginal and Torres Strait Islander peoples. ICAN can assist by negotiating with creditors and debt collectors about your debts; and assisting you with banking issues, superannuation and insurance.

# Moneysmart Indigenous Help Line (1300 365 957)

Call the Indigenous Help Line or visit moneysmart.gov.au/indigenous/paying-for-funerals for a list of organisations that may be able to provide financial support to conduct Sorry Business.

# Services Australia (1800 136 380)

You can contact the Indigenous call centre to see if you may be eligible for Centrelink payments to help pay for Sorry Business.

# Department of Veterans Affairs (1800 838 372)

Veterans or former members of the Australian Defence Force may be able to get help with funeral costs.

# Australian Taxation Office (13 10 30)

You can contact the ATO's Indigenous Helpline to see if you are eligible for early release of superannuation to help pay for Sorry Business.

# WHO IS IN MY PALLIATIVE CARE TEAM?

My Local Aboriginal Medical Service		
Name		
Phone number		
My GP		
Name		
Clinic		
Phone number		
My Aboriginal Health Worker		
Name		
Clinic		
Phone number		
My Nurse		
Name		
Clinic		
Phone number		

# My Palliative Care Specialist Palliative Care Doctor Name Clinic Phone number Palliative Care Nurse Name Clinic Phone number



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## For health advice during emergencies:

#### **Victorian Virtual Emergency Department (VVED)**

A public health service to treat non-life-threatening emergencies.



https://bit.ly/3Ze6vUI

#### For non-emergencies:

Palliative Care Advice Service - ph. 1800 360 000

Free advice available to families and patients about all aspects of palliative care.



https://www.pcas.org.au

