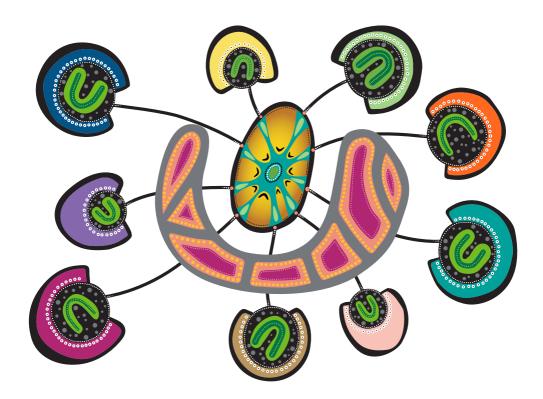


Palliative care support information for Aboriginal and Torres Strait Islander people living in South Western Sydney









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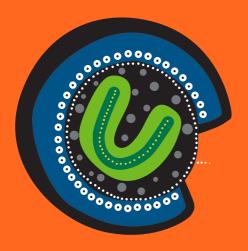
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Artwork By Danielle Mate. Read the story at www.swsphn.com.au/aboriginal-artwork-danielle-mate

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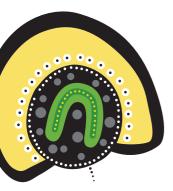






ACKNOWLEDGEMENT

South Western Sydney Primary Health Network, South Western Sydney Local Health District and Gandangara Aboriginal Land Council would like to acknowledge the traditional owners of the lands where we live and work and pay our respects to Elders past, present and emerging for they hold the traditions, culture, hopes and wisdom of Aboriginal Australia.



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. 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 supports Aboriginal people to journey into their wishes and preferences through 'Sorry Business' (life-limiting illnesses).

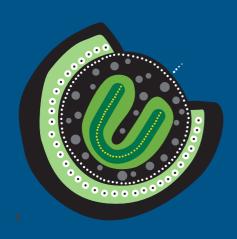
In consultation with South Western Sydney local Aboriginal Elders, we aim to connect health services with Aboriginal wisdom. Especially when assisting and caring for those with life threatening conditions, while also honouring their connection with land, community, family and tradition. We value the 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 would like to thank our local Elders, Aunties, Uncles, Brothers, Sisters, their families and communities who have shared their wisdom, support and insights on the Aboriginal journey through Sorry Business!

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



A SAD STORY ABOUT UNCLE



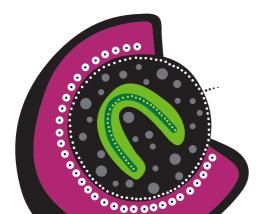
NOT MAKING HIS OWN DECISIONS

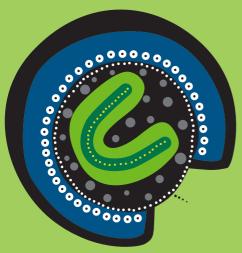
Uncle has always been an independent and important Elder in his community. He was an active man that enjoyed the company of his long-time friend Mary, family and community. Uncle got really sick last year and started yarning with Mary and family about his wishes of being taken back to country for his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

Three months ago, he was taken to hospital for not feeling well. Days later Uncle got really confused and could not speak anymore, his doctors said he is in palliative care and these were his last days. Mary 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 Mary's decision and demanded he should receive treatment and stay in the hospital.

They didn't come to an agreement and a court order was sought to decide this. Uncle passed away before a decision was made and Uncle 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.

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





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 the comfort of:

- Your home
- · A palliative care unit
- · Residential care
- In the hospital

Ask your health care 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

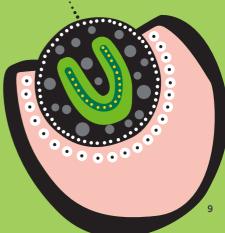
HOW DOES PALLIATIVE CARE WORK?

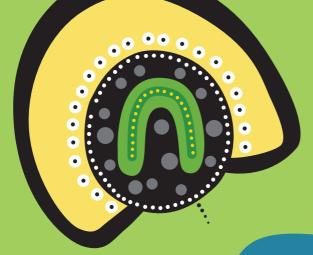
Palliative care works through conversations that will help you and your family make decisions about your place of choice for care, and your cultural needs.

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
- · Will provide support for you and your family also in the hospital

YOU CHOOSE who is involved in your care GPs and specialists Palliative care services Aboriginal health workers 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:

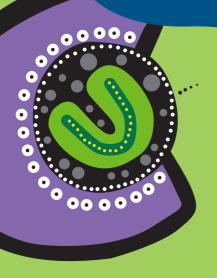
- Assistance for you and your family to come together to talk about sorry business.
- Practical advice and support for the family and carers about making you more comfortable.
 - Management of any pain and other symptoms, such as nausea, you may be feeling.
 - Resources such as equipment you may need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

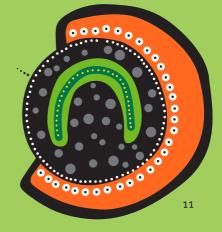
WHY YARNING YOUR WISHES?

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 for 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 health care)

Planning ahead will help you to honour what is important to you, what gives you life and meaning even when you are not able to make decisions for yourself.





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 consider will most likely make the decision 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?

Advance Care Planning	What medical treatment and care do I want in the future? Who should I talk to? My family and my GP. (see page 13)
Will	Who will get my stuff after I pass away? Who should I talk to? My family and my solicitor. (see page 14)
Power of Attorney	Who will make decisions about my money if I can't? Who should I talk to? My family and my solicitor. (see page 15)
Enduring Guardian	Who will make decisions about my health and where I live if I can't? Who should I talk to? My family and my solicitor. (see page 16)



What medical treatment and care do I want in the future?

ADVANCE CARE PLANNING

What is advance care planning?

Deciding what you want or don't want in your future medical treatment is called advance care planning. It involves yarning about things that matter to you, your choices and values to friends and family and making a document (called an Advance Care Directive) to record your 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, or a feeding tube when you cannot eat etc).

Advance Care Directives can be changed at anytime.

Did you know?

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

I want more information, who should I talk to?

Talk to your Aboriginal health worker, solicitor or GP.

Who will get my stuff after I pass away?



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.

Did you know?

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

Are Wills expensive? Where can I make mine?

Wills are not complicated or difficult, you can get a Will kit from your local post office and newsagency from \$20.

A solicitor may charge you a fee for preparing a Will on your behalf. However, you might be eligible for a free Will if you receive a full Centrelink Age Pension or the Department of Veterans Affairs (DVA) Pension.

Where can I get more information?

Talk to your Aboriginal health worker or contact the NSW Trustee & Guardian on **1300 364 103** or **www.tag.nsw.gov.au**.

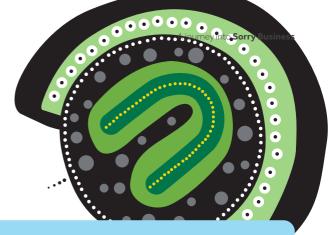












Who will make decisions about my money if I can't?

POWER OF ATTORNEY

What is Power of Attorney?

It is a document you sign naming 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!

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.

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, solicitor or contact the NSW Trustee & Guardian on **1300 364 103** or **www.tag.nsw.gov.au**

Who will make decisions about my health and where I live if I can't?

ENDURING GUARDIAN

Who is an Enduring Guardian?

Enduring Guardian 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 can decide:

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

You can sign a document naming someone to be your Enduring Guardian and you can change it at any time.

Your Enduring Guardian should be someone you trust, knows you well and understands your wishes.

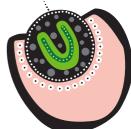
Did you know?

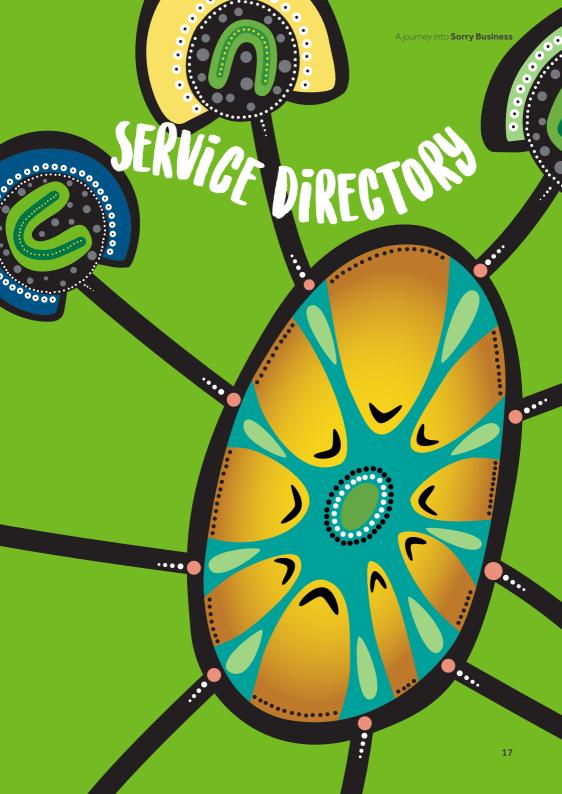
Enduring Guardian **can't** make decisions for you about your money, property, vote or making a Will under your name.

I want more information, who should I talk to?

Talk to your Aboriginal health worker, solicitor or contact NSW Trustee & Guardian on ${\bf 1300\,364\,103}$ or ${\bf www.tag.nsw.gov.au}$







SERVICE DIRECTORY

Airds

Service provider: Tharawal Aboriginal Medical Services

Location: 187 Riverside Drive, Airds

Phone number: (02) 4628 4837

Service offered: Referral source to palliative care services.

Bankstown

Service provider: Community Health Services

Location: Level 1, Suite 101/17 Kitchener Parade, Bankstown

Phone number: (02) 9780 2777

Service offered: Community palliative care support to patients in

the home.

Community Health Services

Service provider: <u>Triple I Community referral</u>

Phone number: 1800 455 511

Service offered: Community palliative care support to patients in

the home.

Liverpool

Service provider: Gandangara Health Services
Location: 64 Macquarie Street, Liverpool

Phone number: (02) 9601 0700

Service offered: Referral source to palliative care services.

Liverpool Hospital

Service provider: Senior Aboriginal Health Worker – District Palliative

Care Services

Location: Liverpool Hospital, Goulburn Street, Liverpool

Phone number: (02) 8738 8991

Service offered: Community and hospital palliative care support

to patients in the home, and referral source to

palliative care services.

Miller

Service provider: Budyari (Miller) Community Health Centre

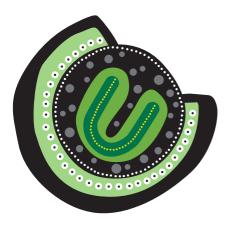
Aboriginal Chronic Care Program

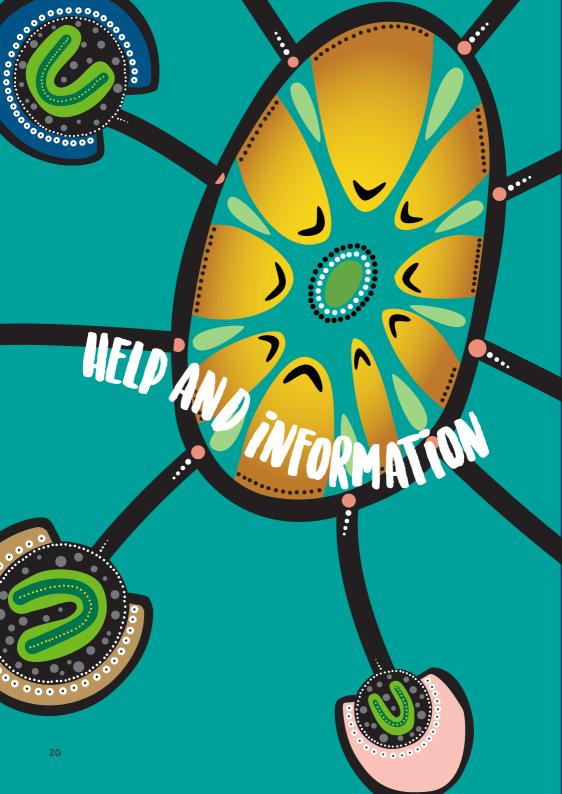
Location: 18 Woodward Crescent, Miller

Phone number: (02) 8781 8020

Service offered: Referral source to palliative care services.

Want to know more? Please contact your local Aboriginal medical service, community health centre or speak to your GP.





GETTING MORE HELP AND INFORMATION

Help with legal documents:

NSW Trustee & Guardian

Can help you with your planning ahead documents

Phone:......1300 554 791

Website:www.tag.nsw.gov.au/wills/make-will/wills-aboriginal-people

Recommended reading: "Taking Care of Business"

Read this booklet for Aboriginal people in NSW for extra information about the legal documents needed to plan ahead.

Contact the NSW Trustee and Guardian for a copy:

Phone: 1300 554 791

Website: www.taq.nsw.gov.au/media/680



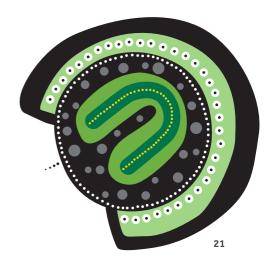
Aboriginal Legal Service (NSW/ACT)

Can help you in finding a local solicitor to make your Will.

Phone:....(02) 8303 6600

Website:www.alsnswact.org.au





Funerals and financial assistance

Department of Human Services (Centrelink)

Can help with disability, sickness and carer allowances.

NSW Aboriginal Lands Council

Can help you to discuss your eligibility for Funeral Assistance Grants.

Phone:......1800 647 487

Website:alc.org.au/funeral-fund

Can Assist

Financial and accommodation assistance for cancer patients.

Phone:.....1300 226 277

Website: www.canassist.com.au

Medicare services for Indigenous Australians

To see if you are eligible for Medicare help with cost of healthcare medicine.

Phone:.....1800 556 955

Website: www.humanservices.gov.au/individuals/subjects/

medicare-services-indigenous-australians

Extra support (health, bereavement, counselling)

Lifeline

Available 24 hours a day to listen to you.

Phone:.....13 11 14

Website:www.lifeline.org.au

Cancer Council

Provides cancer information and support and financial support and hardship assistance.

Phone:.....13 11 20

Website:www.cancercouncil.com.au/aboriginalcancer

Bereavement assistance at Centrelink

Payments, counselling and other services to help you adjust after someone close to you has died.

The SWSLHD palliative care service

You may be referred to South Western Sydney (SWSLHD) palliative care by a hospital doctor or nurse, your local doctor, a community nurse, social worker or residential aged care facility staff. You may decide to call this service directly.

Phone:......1800 455 511

Website: www.swslhd.health.nsw.gov.au/cancer/palliative.html

GPs may make a direct referral to palliative care medical staff for home visits, or residential aged care facilities can phone the Area Palliative Care office (02) 8738 9753.

Support for people with dementia

Dementia Australia

Provides support with legal documents, information and support for people, families and carers

National Dementia Helpline: 1800 100 500 (free call)

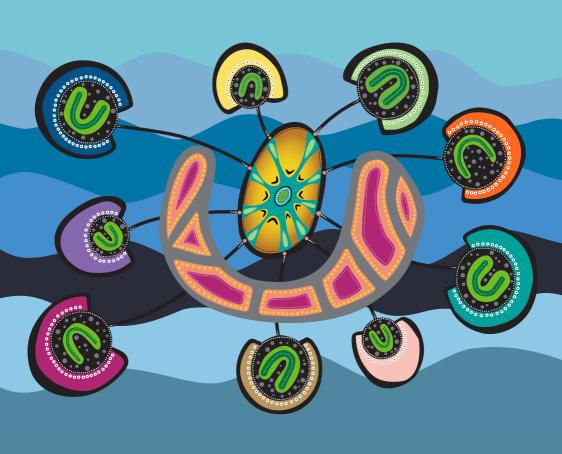
Webchat: <u>dementia.org.au/helpline/webchat</u>

Email:helpline@dementia.org.au

Learn more about what is dementia:

Website:www.dementia.org.au/resources/for-aboriginal-and-

torres-strait-islander-communities





An Australian Government Initiative

South Western Sydney PHN

PO Box 90, Macarthur Sq, NSW 2560

Phone 4632 3000

Email enquiries@swsphn.com.au

Web swsphn.com.au