a journey into

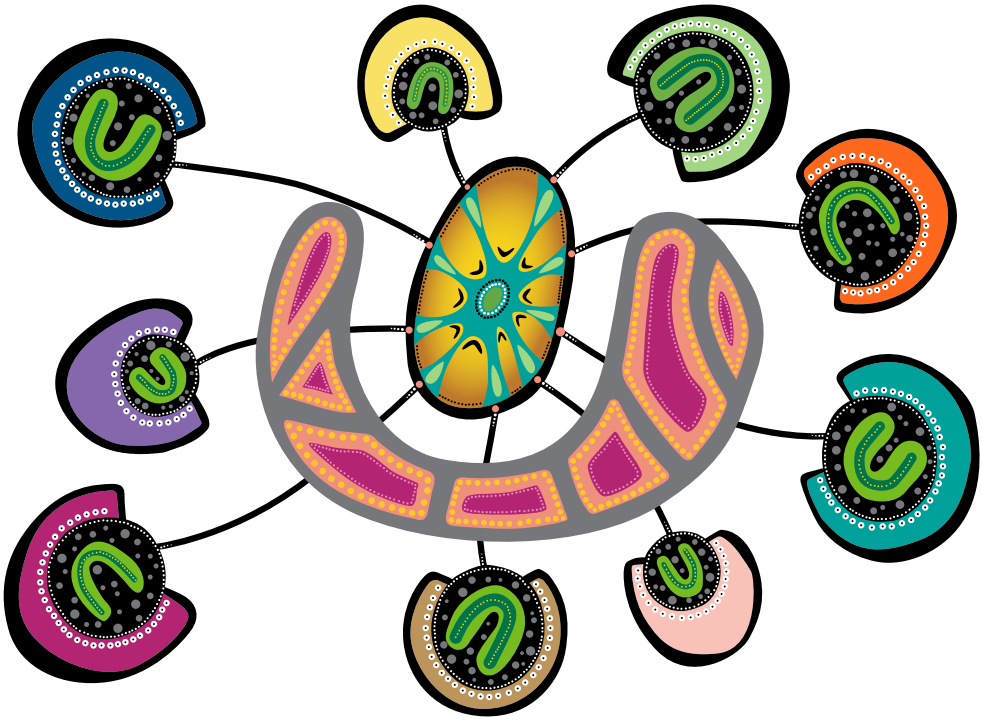
Sorry Business

Palliative care support information for
First Nations people
living in South Western Sydney

GANDANGARA Local Aboriginal Land Council

NSW GOVERNMENT Health
South Western Sydney
Local Health District

phn SOUTH WESTERN SYDNEY
An Australian Government Initiative



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

The Collaboration Group acknowledges the work of the original creators of this document and thanks them for their work and dedication.

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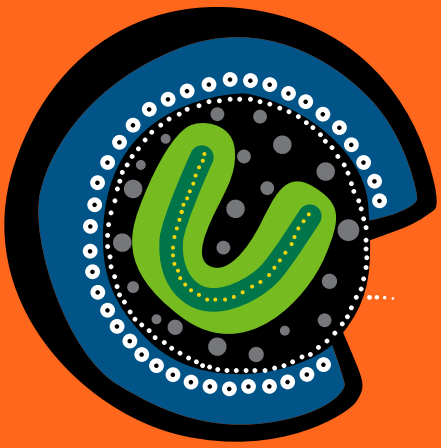
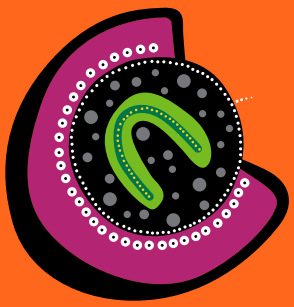
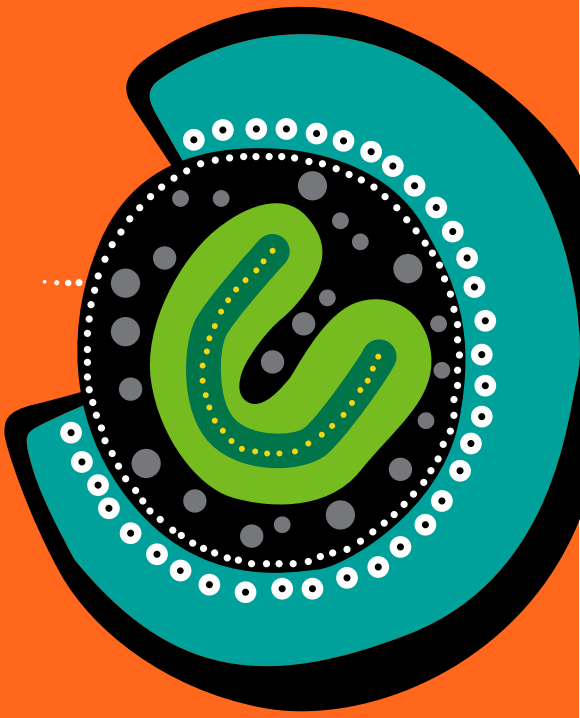
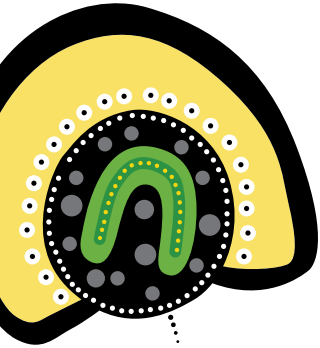






Acknowledgement

South Western Sydney Primary Health Network, South Western Sydney Local Health District and Gandangara Local 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?

First Nations 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.

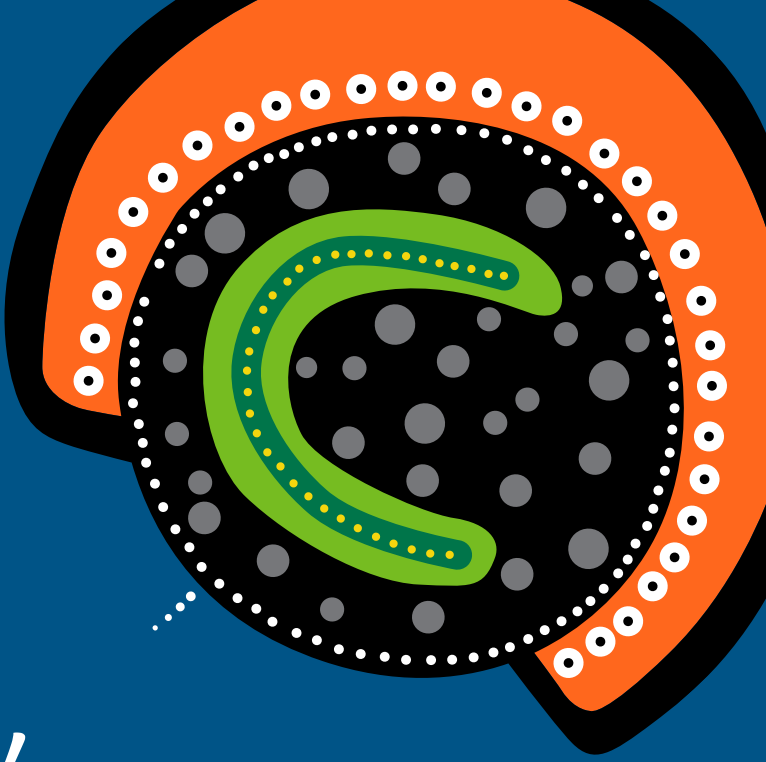
Palliative care yarning

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

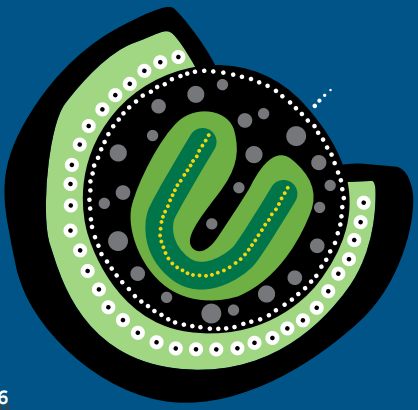
In consultation with South Western Sydney local Aboriginal Elders, we aim to connect health services with Aboriginal wisdom. Especially when assisting and caring for those with life threatening conditions, while also honouring their connection with land, community, family and tradition. We value the importance of advance care planning yarning and this resource has been developed to provide culturally appropriate, respectful and mindful information to encourage First Nations 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



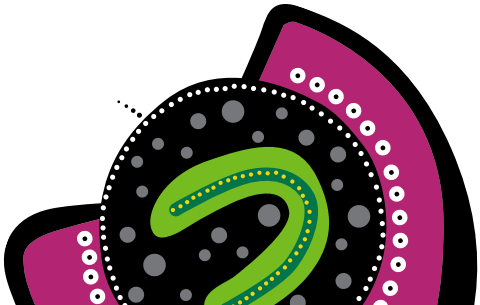
Not making his own decisions

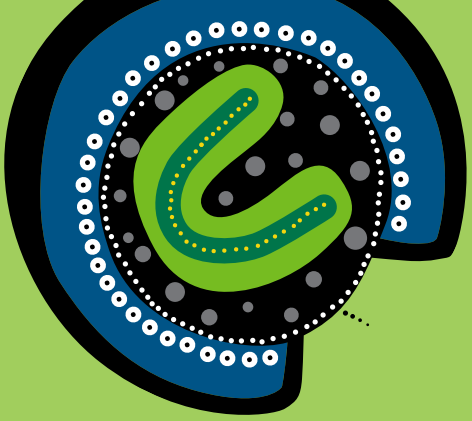
Uncle has always been an independent and important Elder in his community. He was an active man that enjoyed the company of his long-time friend Mary, family and community. Uncle got really sick last year and started yarning with Mary and family about his wishes of being taken back to country for his 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?

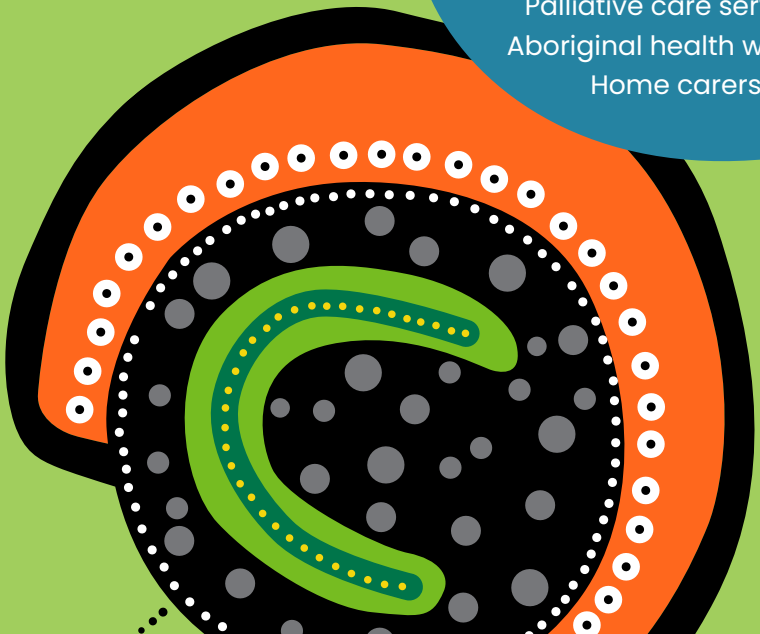
Palliative care works through conversations that will help you and your family make decisions about your place of choice for care, and your cultural needs.

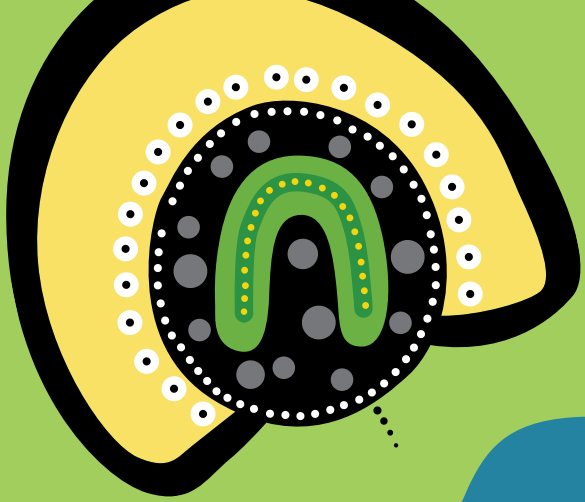
Palliative care health staff (doctors, nurses, allied health etc)

- 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:

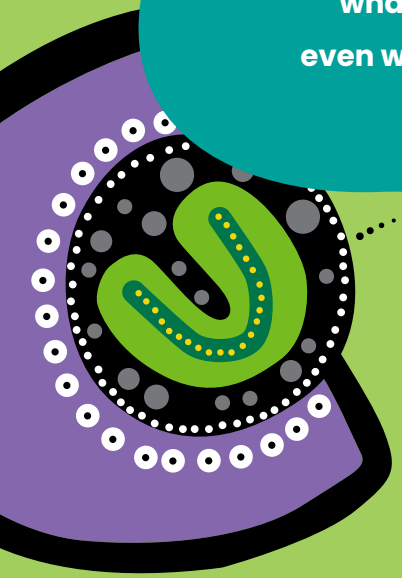
- Assistance for you and your family to come together to talk about sorry business.
- Practical advice and support for your family and carers about making you more comfortable.
- Management of any pain and other symptoms, such as nausea, you may be feeling.
- Resources such as equipment you may need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

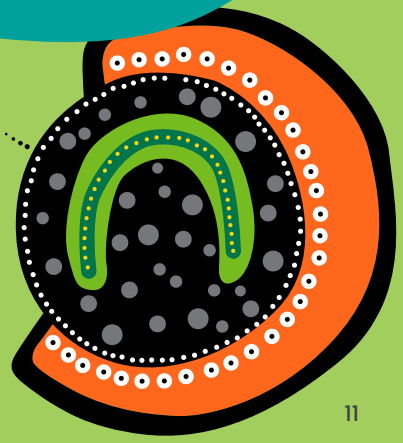
Why yarning your wishes?

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 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 for in your last days (for example at home or hospital)
- Where you would like to be buried and if you 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).

Advance Care Directives can be changed at anytime.

I want more information, who should I talk to?

Talk to your Aboriginal health worker, solicitor or GP.

Did you know?

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

Who will get my stuff after I pass away?

Will

What is a Will?

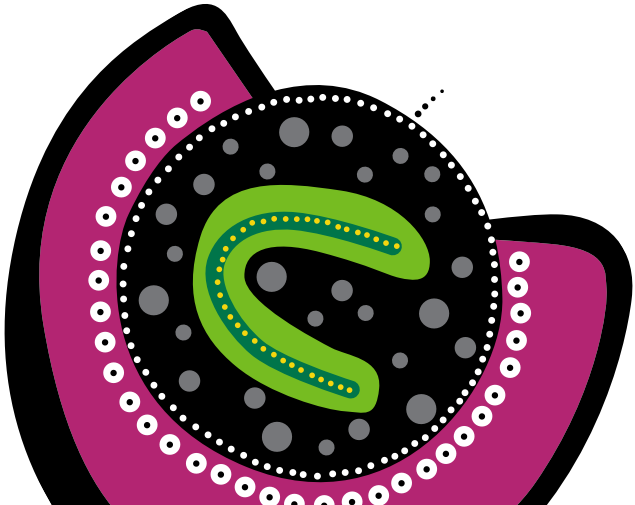
A Will is a legal document that says who your stuff will go to when you pass away. It instructs who your money, property, land and belongings (photos, furniture, jewellery, artwork, etc) will go to.

Are Wills expensive? Where can I make mine?

Wills are not complicated or difficult. A Will will be read often after the funeral has taken place. 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. Power of 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 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. 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.

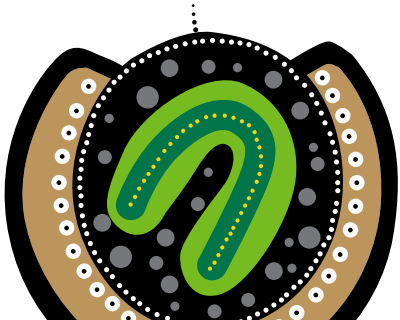
Your Enduring Guardian should be someone you trust, knows you well and understands your wishes.

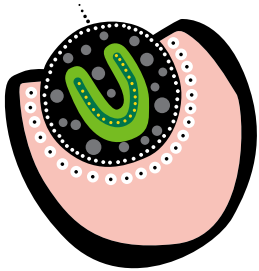
Did you know?

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

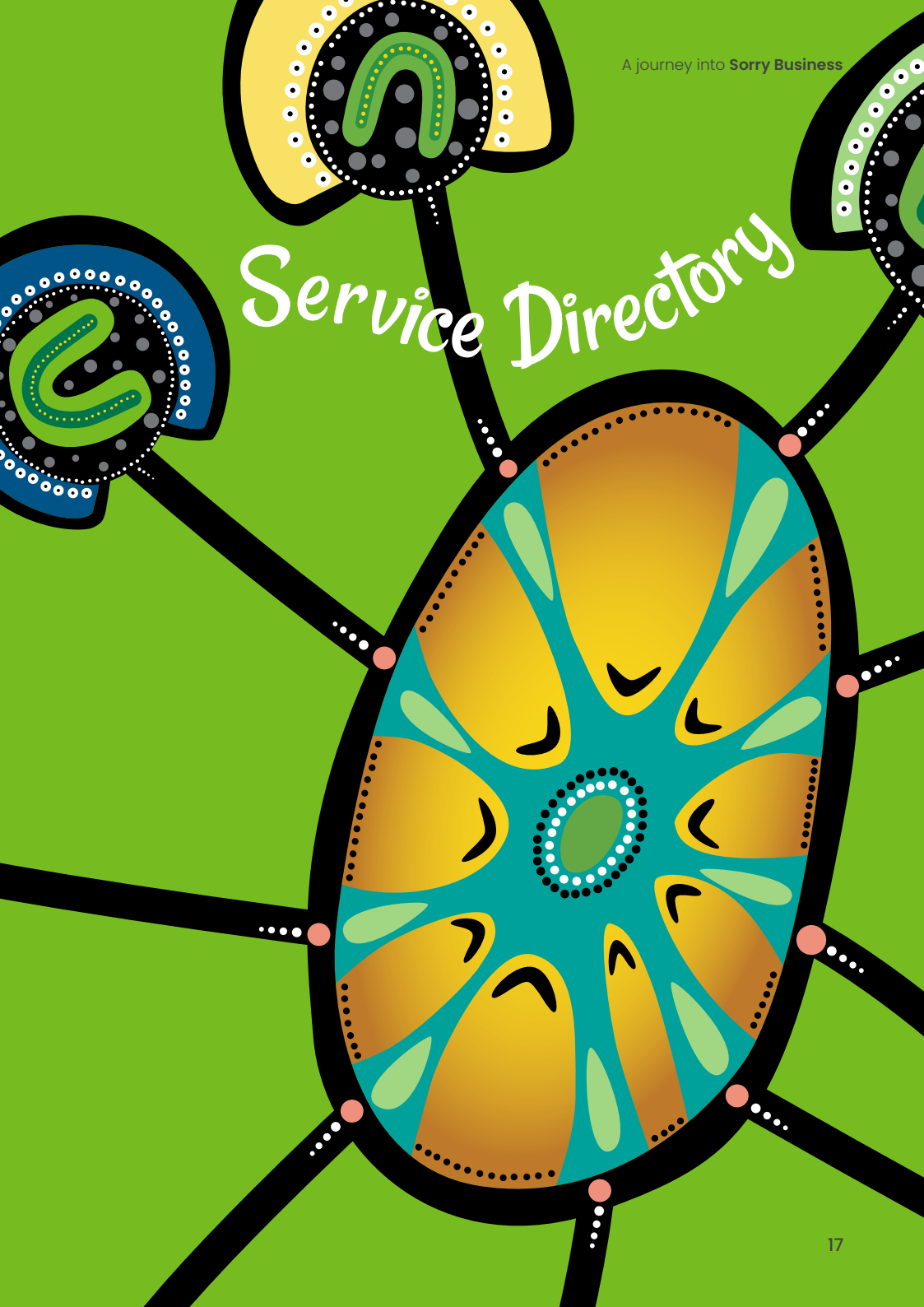
I want more information, who should I talk to?

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





Service Directory



Service Directory

Airds

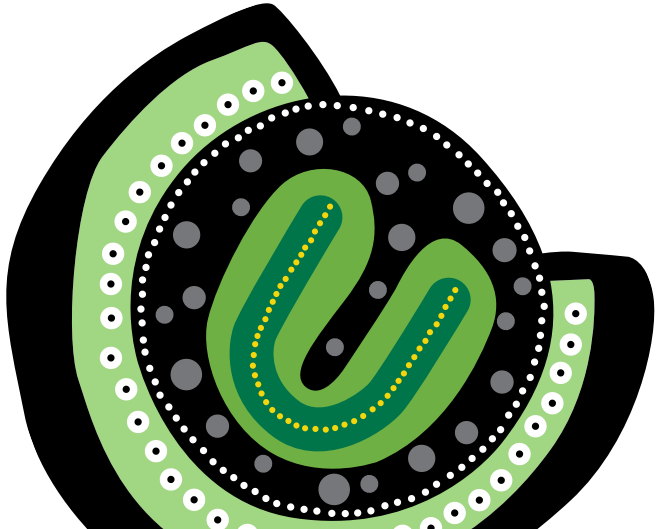
Service provider: Tharawal Aboriginal Medical Services
Location: 187 Riverside Drive, Airds
Phone number: (02) 4628 4837
Service offered: Referral source to palliative care services.

Community Health Services

Service provider: Triple I Community referral
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

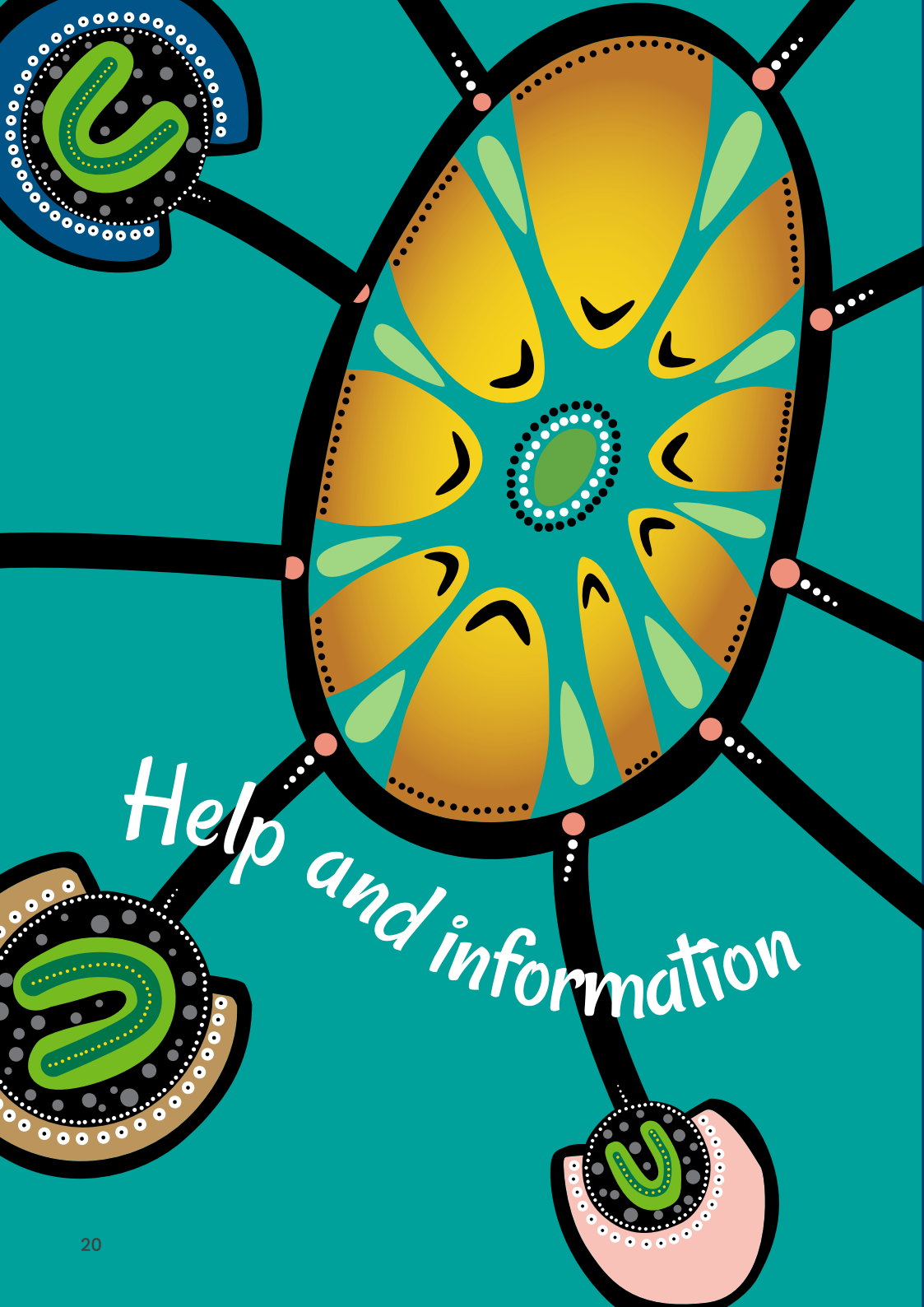
Service provider: Budyari (Miller) Community Health Centre Aboriginal Chronic Care Program

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.


Help and information

Getting more help and information

Help with legal documents:

NSW Trustee & Guardian

Can help 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.tag.nsw.gov.au/media/680

Aboriginal Legal Service (NSW/ACT)

Can help you find a local solicitor to make your Will.

Phone: .....(02) 8303 6600
Website:.....www.alsnswact.org.au

Macarthur Legal Centre (Macarthur Region and Outreach services)

Can help you with free legal advice, referrals and assistance to people living in the Macarthur region of NSW.

Phone: .....(02) 4628 2042
Website:.....www.maclegal.net.au

Justice Support Centre (Liverpool, Fairfield and Bankstown region)

Provides free services to the community. They support people in South Western Sydney with legal issues, as well as supporting women and children affected by domestic and family violence.

Phone: (02) 9601 7777

Website: www.justicesupportcentre.org.au

Funerals and financial assistance:

Department of Human Services (Centrelink)

Can help with disability, sickness and carer allowances.

Phone: 13 27 17 (Mon-Fri 8am-5pm)
Website: www.humanservices.gov.au

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

Service NSW

Provides a one-stop access to government services via online, phone or in-person at its service centres.

Phone: 13 77 88
Website: www.service.nsw.gov.au

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 and medicine.

Phone: 1800 556 955
Website: ..... www.humanservices.gov.au/individuals/subjects/medicare-services-indigenous-australians

Extra support (health, bereavement, counselling)

Lifeline

A crisis line that provides phone support. Available 24/7.

Phone: 13 11 14
Website: ..... www.lifeline.org.au

Cancer Council

Provides cancer information support, financial support and hardship assistance.

Phone: 13 11 20
Website: ..... www.cancercouncil.com.au/aboriginalcancer

Advance Care Planning Australia

Provides advice, support, training and education around Advance Care Planning.

Phone: 1300 208 582
Website: ..... www.advancecareplanning.org.au

Palliative Care Australia

Palliative Care Australia is the national peak body for palliative care. They provide resources, events and advocate for palliative care.

Phone: ..... (02) 6232 0700
Website: ..... www.palliativecare.org.au

Gwandalan

Provides education and training materials to support relationships between service providers, frontline staff and First Nations communities through cross-cultural education and sharing of knowledge.

Phone: 1300 362 111
Website:.....www.gwandalanpalliativecare.com.au

13Yarn

A First Nations crisis support line. Available 24/7.

Phone: 13 92 76
Website:.....www.13yarn.org.au

Brother to Brother

A crisis line that provides phone support for First Nations men. Available 24/7.

Phone: 1800 435 799
Website:.....www.dardimunwurro.com.au

Caring@home

Provides tailored resources for families, health professionals and clinical services to support the provision of palliative care at home for First Nations people.

Phone: 1300 600 007
Website:.....www.caringathomeproject.com.au/Family-Carer-Resources/Aboriginal-and-Torres-Strait-Islander-families-resources

Southern Highlands Bereavement Care Service

The Southern Highlands Bereavement Care Service offers counselling to individuals, families, teenagers and children who are experiencing bereavement through the death of a loved one.

Phone: .....(02) 4862 1701
Website:.....www.shbcs.org.au

Hammondcare/SWSLHD Palliative Care Bereavement Service

Provides a free counselling service to family members and friends of patients who are registered with the SWSLHD palliative care service.

Phone: .....(02) 9756 8878 (Bereavement Coordinator)
Website:.....www.swslhd.health.nsw.gov.au/cancer/palliative.html

Bereavement assistance at Centrelink

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

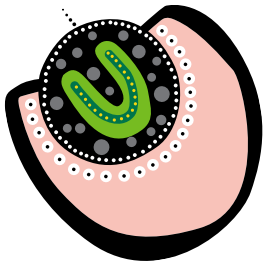
Phone: .....13 23 00 (Mon-Fri 8am - 5pm)
Website:.....www.servicesaustralia.gov.au/centrelink

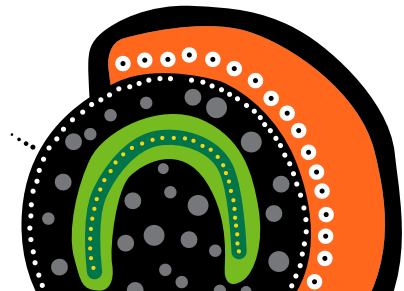
The SWSLHD palliative care service

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 living with dementia

Dementia Australia

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

National Dementia Helpline: 1800 100 500 (24-hour, free call)
Webchat: dementia.org.au/helpline/webchat
Email: helpline@dementia.org.au
Website: www.dementia.org.au

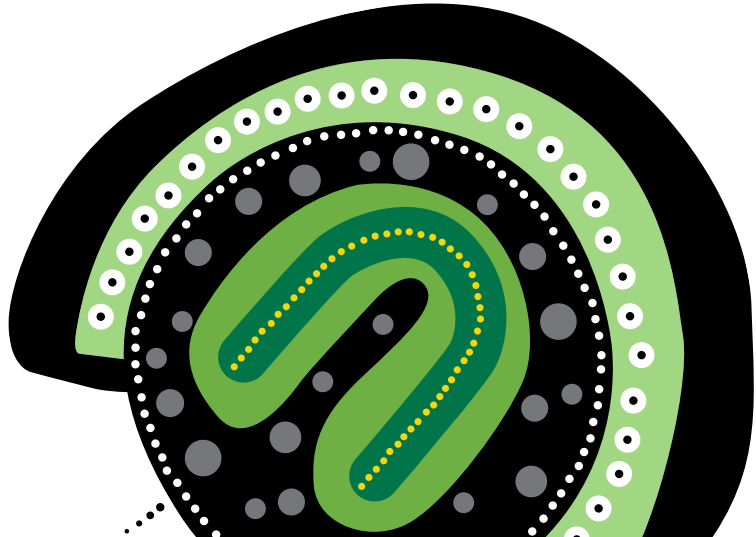
Learn more about dementia:

Website: www.dementia.org.au/dementia-and-aboriginal-and-torres-strait-islander-people

Dementia Support Australia

Dementia Support Australia has developed resources to support the wellbeing of First Nations people living with dementia.

Phone: 1800 699 799 (24-hour, free call)
Webchat: dementia.com.au/contact-us
Website: www.dementia.com.au
Communication cards: www.dementia.org.au/dementia-and-aboriginal-and-torres-strait-islander-people
First Nations language guide: www.dementia.com.au/resource-hub/first-nations-language-guide



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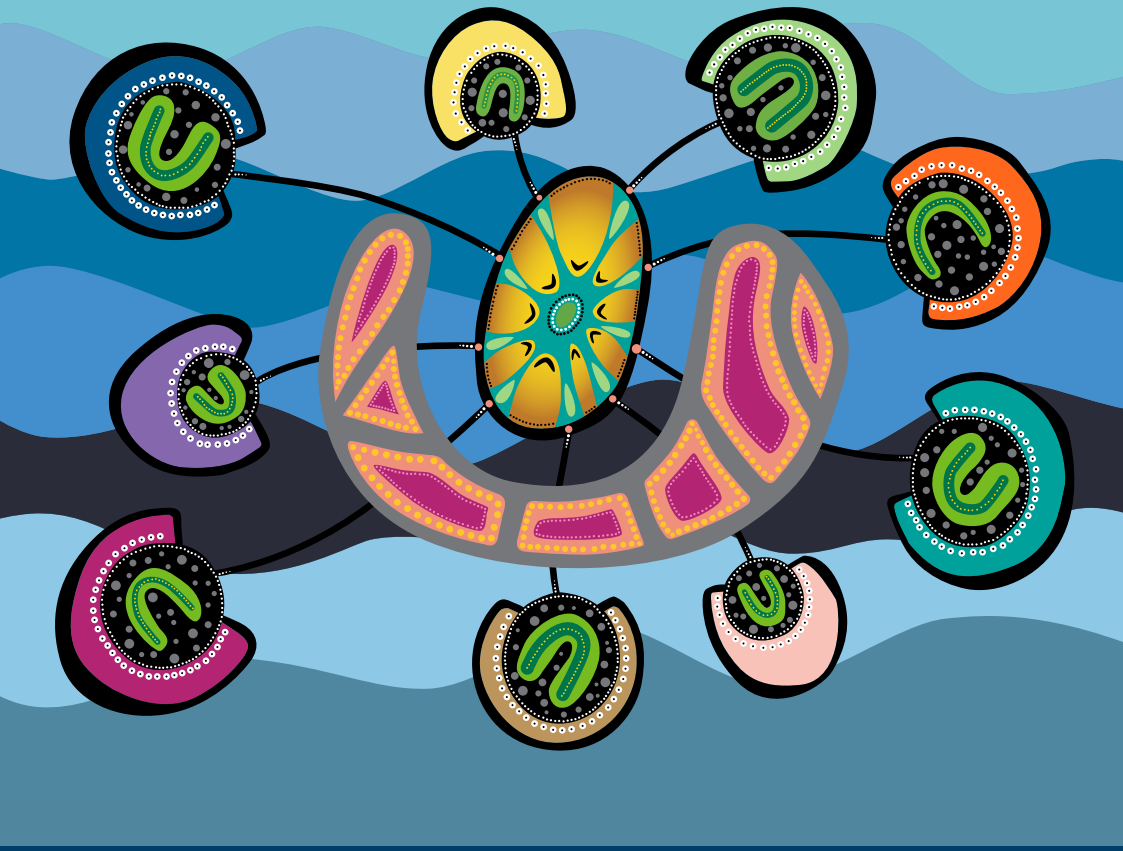

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