

Central Coast Community Guide

FOR DEMENTIA SERVICES & SUPPORT

WHERE TO GO TO FOR HELP?
Information and support services
for people living with memory
loss and dementia, their carers
and family





Access to phone numbers listed in this booklet:

If you have a hearing or speech impairment call **1800 555 677** and ask for the phone number you want to call.

If you need an interpreter (free service) call **131 450** and ask for the phone number you want to call. It is important to know that people living with dementia often revert to their birth language.

Guide developed in 2022.

Accurate as of April 2023.

The Central Coast Dementia Alliance acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea, and community. We pay our respects to those lands that provide for us. We acknowledge and pay respect to the ancestors that walked and managed these lands for many generations before us. We acknowledge and recognise all Aboriginal people who have come from their own country and who now call Darkinjung country their home. We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

Contents

What is dementia?.....	4
When should I seek help?	5
What happens next?.....	5
What else do I need to know?.....	5
Where can I get information?	6
Changes in behaviour	7
Younger Onset Dementia (YOD)	8
Where can I get support?	8
Support for carers	10
Carer Support Groups	10
Social Groups.....	12
Other Community Support	12
How can I get help?.....	14
Help at home	15
What services can I access in my home?.....	16
Respite care	17
Respite in the home.....	17
Out of home respite	18
Emergency Respite Care.....	19
Planning ahead	20
Legal Matters.....	20
Palliative Care and End of Life Planning.....	24
Financial advice and support	26
Other Support Services	27
Acknowledgements.....	31

What is dementia?

Dementia is **not** a normal part of ageing. Dementia is a disease of the brain that can affect memory, thinking and behaviour, and how someone performs everyday tasks.

The symptoms of dementia can be caused by different diseases, including Alzheimer's disease, vascular dementia, dementia with Lewy Bodies, frontotemporal dementia, or alcohol-related dementia.

Dementia gradually affects a person's ability to carry out daily activities, such as driving, shopping, getting dressed, going places, and managing money. Over time, it can be difficult for a person living with dementia to live by themselves.



If you are concerned about yourself or someone you know who is experiencing symptoms of memory loss or confusion, it's important to have a conversation with your doctor.

When should I seek help?

Memory loss or changes to someone's thinking or behaviour can be caused by various conditions, including vitamin deficiency, hormone deficiency, infection or medications – the changes may not be caused by dementia.

If the changes are being caused by dementia, finding out early can help a person living with dementia, their carer and family:

- Understand what is happening and why
- Make timely decisions about planning for the future
- Access support and services to help them stay living independently at home

What happens next?

If you are experiencing symptoms, such as memory loss and confusion, your doctor may order tests. The tests may include blood tests and a brain scan. You may also be asked some questions to check your cognitive abilities and be asked to write or draw on a piece of paper.

You may be referred to Dementia and Behaviour Support Services (DABSS), where staff have specialised skills and experience in assessing memory loss and dementia. As part of their assessment, they may spend one or two hours with you, your carer and family, to ask all the questions needed, to feedback to your doctor.

You could also be referred to other specialist clinicians such as a neurologist, geriatrician, neuropsychologist or psychogeriatrician (old age psychiatrist), for further assessment and diagnosis.

It is recommended you have a regular doctor and local pharmacy.

What else do I need to know?

Your doctor can also refer you to **allied health services**, if you need them – such as:

- Aboriginal health worker
- Audiologist (hearing)
- Chiropractor
- Diabetes educator
- Dietitian
- Exercise physiologist
- Occupational therapist
- Osteopath
- Physiotherapist
- Podiatrist
- Psychologist
- Social worker
- Speech therapist



Where can I get information?

If you have been diagnosed with dementia, it's important to know where to access information, to help you and your carer:

- Understand the symptoms and progression of the disease
- Understand strategies that can be put in place to support your changing needs and behaviours
- Be informed about useful services and resources

Knowing where to find information and answers can also help carers to:

- Develop skills to care for the person living with dementia while looking after themselves
- Know where to meet and spend time with others who are having similar experiences

DEMENTIA AUSTRALIA

National Dementia Helpline: 1800 100 500, 24 hours

A free, confidential service that provides support and access to counsellors, who can help the person living with dementia, their carers and family manage the impact of dementia. The Helpline also provides information about dementia and support services in your area, and has a list of local education opportunities.

The website has brochures, help sheets, videos, a lending library, technology and resources, including resources designed specifically for the **Aboriginal and Torres Strait Islander** (*Your Story Matters*), **Culturally and Linguistically Diverse** (CALD), and **LGBTI** communities.

dementia.org.au

FORWARD WITH DEMENTIA

Information for People with Dementia, Carers and Health Professionals

This website gives you answers after a dementia diagnosis.

You'll find up-to-date information from clinicians and researchers, practical suggestions and stories from people with dementia and carers, and tools to help you manage living with dementia.

Many people with dementia live full and meaningful lives after diagnosis.

forwardwithdementia.org/au



Changes in behaviour

Sometimes dementia can cause changes in a person's behaviour which may be upsetting for them, as well as for their carer and family. Changes can also occur due to an underlying illness, pain or discomfort. It's important to always discuss any concerns or behavioural changes with your doctor.

CENTRAL COAST LOCAL HEALTH DISTRICT (CCLHD) DEMENTIA AND BEHAVIOUR SUPPORT SERVICES (DABSS)

The Dementia Advisory Service worker can assist with information, advice, education and support. Dementia assessments assist with management of the impact of dementia on the person and their family through person centred assessments and care planning.

A free memory screening assessment service is available via a doctor's referral.

Clinicians provide an acute response for behavioural changes associated with dementia for people living at home, in residential aged care facilities and in hospital.

Carer support groups operate on a monthly basis in four locations across the Central Coast.

Dementia and Behaviour Support Services (DABSS)

General enquiries: Phone the Community Access and Intake Line

Ph: 1300 725 565

Fax referrals to: 4320 9333

www.cclhd.health.nsw.gov.au

Central Coast HealthPathways
(for clinicians)

centralcoast.healthpathways.org.au/

CENTRAL COAST LOCAL HEALTH DISTRICT (CCLHD) BEHAVIOUR ASSESSMENT AND INTERVENTION SERVICE (BASIS)

Provides assistance to people with moderate to severe, and persistent behavioural and psychological symptoms of dementia (BPSD). Supporting people in their own home, residential aged care facilities and other community facilities.

BASIS is a non-acute response service.

Anyone can make a referral. Refer via the NSW Mental Health Line

Ph: 1800 011 511 available 24 hours, 7 days.

BASIS office:

Ph: 4320 2952 available Monday - Friday, 9am - 5pm

www.cclhd.health.nsw.gov.au/services/mental-health/older-people-and-mental-health/

Central Coast HealthPathways (for clinicians)

centralcoast.healthpathways.org.au

DEMENTIA SUPPORT AUSTRALIA

1800 699 799, 24 hours

Dementia Support Australia provides over the phone advice on how to manage and respond to changes in behaviour. Staff can also refer carers and family to other support services that can help.

dementia.com.au

Younger Onset Dementia (YOD)

There are services designed specifically for people **under 65 years** diagnosed with dementia. These services provide information, support, counselling and referral to other services that can help.

For further information call the **National Dementia Helpline** on **1800 100 500** or visit **dementia.org.au**.

NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

1800 800 110, Mon-Fri from 8am to 8pm

The NDIS provides access to support services for **people aged under 65 years**, including those diagnosed with Younger Onset Dementia. These services can help you manage at home, access health services, or get you out and about. Visit **ndis.gov.au** for further information or speak to your doctor.

Where can I get support?

Family and friends, church groups, men's and women's groups, social and sporting clubs are places where you may find support. However, there are also support groups that are just for people living with dementia and carers.

Dementia support groups are for people living with dementia. The groups provide a supported, social environment with activities and outings. The groups also provide respite for carers, so they can go shopping, go to appointments, play golf, learn a new skill, or catch up with friends.



Support groups and counselling services for people living with dementia and their family/carers

For Carer/Family	For Person Living with Dementia	
		<p>Central Coast Local Health District (CCLHD) Dementia and Behaviour Support Services (DABSS) – Carer Support Groups Carer Support Groups operate on a monthly basis in four locations across the Central Coast. The groups are for people who are supporting/caring for people living with dementia in the community. Groups provide information, education and support.</p> <p>Venues: Woy Woy, Erina, The Entrance, Lake Haven. Contact: Dementia and Behaviour Support Services (DABSS) Ph: 1300 725 565 Fax referrals to: 4320 9333 www.cclhd.health.nsw.gov.au</p>
		<p>Integrated Living Dementia specific day respite Centres at Gosford, Gorokan & Woy Woy on the Central Coast. These groups are to support people living with dementia to access their local communities. We deliver programs and are able to track client outcomes through these. Programs are designed to enable clients to use their current skills and abilities.</p> <p>Our centres run 5 x per week and are also respite for their carers. We also hold an informal carers' group online (via zoom) each Wednesday.</p> <p>Contact: Ph: 1300 782 896 www.integratedliving.org.au</p>
		<p>River Oak Social Club run by Hammond Care At Home Central Coast Contact: Ph: 1800 826 166 Email: RiverOakSocialClub@hammond.com.au</p>
		<p>Dementia Australia – National Dementia Helpline Information, counselling and support. Contact: Ph: 1800 100 500 www.dementia.org.au</p>
		<p>Carers Australia NSW – Counselling Contact: Ph: 1800 242 636 www.carersnsw.org.au</p>
		<p>Carer Gateway Support for carers through the provision of information, advice, help to get services, counselling and coaching. Contact: Ph: 1800 422 737 www.carergateway.gov.au</p>
		<p>CCLHD – Carer Support Unit and Carer Retreat A retreat for carers visiting people in hospital, offering support, resources, information, business facilities, parking, Tai Chi, meditation and refreshments.</p> <p>Contact: Ph: 4320 5556 Fax: 4320 5555 Email: CCLHD-CSUCC@health.nsw.gov.au Address: 91 Holden Street, Gosford (opposite Gosford Hospital). www.cclhd.health.nsw.gov.au</p>
		<p>River Gum Social Club Wyong Contact: Ph: 1800 826 166</p>

Support for carers

Caring for someone can be rewarding, however there can also be challenges. Carers may need to learn to balance looking after themselves while caring for someone else.

If you are a carer, seeking support from family and friends, and sharing your concerns with other carers is important. However, there may be times when you need to talk to a trained professional, who:

- Will understand how you are feeling
- Can help you to find solutions
- Can suggest services to support you and the person you are caring for

Carer Support Groups

Carer support groups provide an opportunity for carers to meet others going through similar experiences. Groups may also have guest speakers who can provide expert information on a range of topics.

CARER SUPPORT UNIT AND CARER RETREAT

02 4320 5556 or 02 4320 5557

CCLHD-CSUCC@health.nsw.gov.au

Mon-Fri from 9am to 4:30pm

If you are a carer of a patient in Gosford Hospital, you can take a break at the Carer Retreat. The Carer Retreat provides a place for carers to relax and re-energise and has a variety of information and resources to support the situation you may be going through

91 Holden St, Gosford, NSW, 2250

NATIONAL AUSTRALIA CARER GATEWAY

1800 422 737

Mon-Fri from 8am to 6pm

The Carer Gateway is a national phone service and website that provides advice, information, resources, and links to support services. The website includes an interactive service finder to help locate the nearest carer support services.

carergateway.gov.au

CARERS NSW AUSTRALIA

1800 242 636

Mon-Fri from 9am to 5pm

Carers NSW provides information, support and counselling to help improve the health, wellbeing, resilience and financial security of carers.

carersnsw.org.au

YOUNG CARERS

Ph: 1800 242 636

Mon-Fri from 9am to 5pm

Young Carers provides support for those under 25 years who are looking after someone in their family, taking them to appointments and/or doing the shopping or cooking. The website has stories from other carers, tips, resources and education scholarships.

<https://youngcarersnetwork.com.au/>


OUTREACH LIAISON WORKER FOR THE CENTRAL COAST AND HUNTER

Ph: 02 9289 4280

F: 02 9280 4755

M: 0437 986 903

keikoc@carersnsw.org.au



You can get information about dementia and carer support groups, including when and where they occur, by calling the National Dementia Helpline on 1800 100 500.

Social Groups

Helpful Resources for social support and activities for carers and health providers

A list of resources for social support across the Central Coast to assist health and care providers to support their patients and/or clients.

YOUNGER ONSET DEMENTIA SOCIAL SUPPORT (YODSS) CENTRAL COAST

Social group for those diagnosed with Younger Onset Dementia, and their carers. YODSS meet at the Ourimbah RSL on the 2nd Friday each month from 2pm to 4pm.

Contact: Chris Jones 0424152257

Email: ceejay22@live.com.au

ROTARY FORGET ME NOT D-CAFÉ

Brisbane Water Rotary hold a social group in a safe and friendly environment, for people living with dementia and their family carers. Groups meet on the 2nd and 4th Mondays of the month at the CWA Hall in Umina from 10am–12pm.

Contact: Ph: Di – 0404 147 743 DiBartok@yahoo.com.au or Heather 0414 446 177

ROTARY DCAF DEMENTIA CAFÉ - KINCUMBER

Safe and friendly social gatherings for people living with dementia and their family carers. Held each Tuesday from 10am - 12pm at the Kincumber Neighbourhood Centre (K.N.C). Sponsored and run by the Rotary Clubs of Kincumber and Terrigal in conjunction with K.N.C.

Contact: Maggie Vincent - 0434 315 327

Other Community Support

WESTFIELD TUGGERAH SENSORY SUPPORT

Westfield Tuggerah aims to create an inclusive environment for customers, by offering a shopping experience where all customers feel welcomed and valued

Quiet Time - During Quiet Time hour, the lights are dimmed, music volume is adjusted alongside limiting some day to day activities. Many of our retailers participate by also dimming their lights, lowering their music and creating special offers just for Quiet Time.

When: Every Tuesday 10:30am-11:30am

Sensory Headphones – Sensory headphone kits are provided at no cost and can be hired from the concierge desk. Sensory headphones are designed to reduce stimulation in a shopping centre environment.

www.westfield.com.au/tuggerah/event/5igkNwDqq9cUgNOavKunrx/quiet-time

Ph: (02) 4305 5351

www.westfield.com.au/tuggerah/service/4Q1Zlw76aQU4OwokWkaIGC/accessibility

COLES SUPERMARKETS

Quiet Hour – Quiet Hour provides a low-sensory shopping experience by making changes in store, such as reducing noise and distractions.

When: Coles Quiet Hour times vary across different stores with some retail stores offering this every day.

www.coles.com.au/about-coles/community/accessibility/quiet-hour#NSW

WOOLWORTHS SUPERMARKETS

Quiet Hour – This program is designed to reduce anxiety and sensory stress for customers with specific needs, including dementia and Autism, by providing a quieter and less stimulating environment in store.

When: Every Tuesday 10:30am-11:30am at selected retail stores

www.woolworthsgroup.com.au/page/media/Latest_News/woolworths-rolls-out-quiet-hour-to-select-stores-across-australia

MCA ART PROGRAM

Art and Dementia program that aims to create new connections and life-enriching experiences through contemporary art for people living with dementia and their support networks.

www.mca.com.au/learn/art-dementia/

THE DEMENTIA SHOP

Online resources for dementia aids

www.dementiashop.com.au

TABTIMER

Online resources for dementia aids

www.tabtimer.com.au

M4DRadio

Music for dementia online radio station. A group of 5 themed radio stations available 24 hours a day, 365 days a year playing music that evokes memories.

www.m4dradio.com

AGELESS GRACE

Timeless Fitness for Body and Brain, Ageless Grace® is a fun, simple way to exercise – seated, standing or even lying down based on the science of neuroplasticity to work all parts of the body and brain.

www.agelessgrace.com.au

How can I get help?

If you need help at home, help caring for yourself, or want to know more about respite or residential care, the best place to start is **My Aged Care**.

When you call **My Aged Care**, the staff will ask you some questions so that they can work out what you need and what is the most appropriate next step for you.

If you require general support, **My Aged Care** can refer you to a suitable service at the time of the call. Otherwise, they can arrange for someone to visit you in your home, to work out what services are best for you.

MY AGED CARE

1800 200 422

Mon-Fri from 8am to 8pm

Saturday from 10am to 2pm

My Aged Care is a one-stop shop for anyone wanting access to services for people aged 65 years or older, or Aboriginal and Torres Strait Islander people who are 50 years or older.

My Aged Care provides information and advice about:

- How the aged care system works
- Types of services that are available, including help at home, respite care and residential care
- How to access services
- Eligibility criteria for services
- Fee estimators and the cost of services

The My Aged Care website allows you to search for services located near your home.

<https://www.myagedcare.gov.au/>

MY AGED CARE SERVICES OFFICER AVAILABLE AT SERVICES AUSTRALIA, WOY WOY

The My Aged Care face-to-face representative at Services Australia is the Aged Care Specialist Officer – ACSO

Contact: 1800 227 475

Email: acso.nwnsw@servicesaustralia.gov.au



Help at home

If you are able to manage but need some assistance with day-to-day tasks, or if you are a carer or family member and need help to look after a person living with dementia, you may be eligible for **help at home** through **My Aged Care**.

My Aged Care may refer you for a home visit with either the Regional Assessment Service (RAS), or the **Aged Care Assessment Team (ACAT)**.

During the home visit, you will be asked questions so that the assessor can work out which services you may be eligible for. The assessor will then assist in linking you to services in your local area.

Some services have a waiting period and for these services you will be added to the **National Queue**, until a service becomes available. While you wait, the assessor will ensure that appropriate, temporary services are able to help you.

When a service becomes available in your local area, you will need to choose the provider you would like to provide those services.

The **provider** will work with you to decide what help would best suit your personal needs. This information will be written into your **personal care plan** by the provider, and you will be given a copy of the plan.

If you can afford to do so, you will be asked to contribute to the cost of Home Care Packages, respite and residential care. The fees you are asked to pay will depend on your income and assets, as assessed by **Services Australia** or **Department of Veteran Affairs**.

**correct at time of print – Support at Home Program starts 1 July 2025*

1800 200 422

MyAgedCare.gov.au

What services can I access in my home?

Help at home is also known as either the **Commonwealth Home Support** or **Home Care Packages Program**.

These services are available to support you to continue to live independently within your own home and to remain socially active. The services also support carers and families to continue to care for someone living with dementia. If you want to know more about **Help at Home**, contact **My Aged Care**.

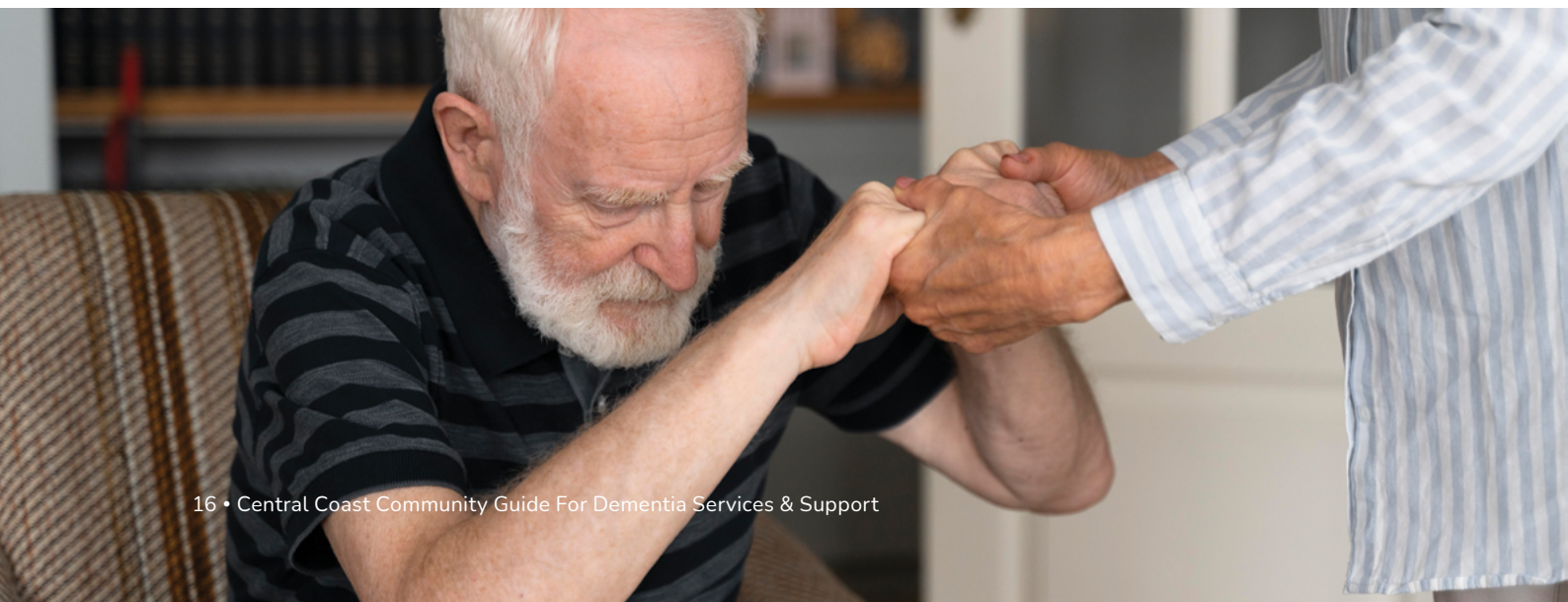
Help at Home services may include:

- **Allied Health and Therapy Services** - including Aboriginal and Torres Strait Islander Health Workers, Dietitians/Nutritionists, exercise physiotherapists, occupational therapy, podiatry, psychology, speech pathology
- **Domestic Assistance** - help with cleaning, clothes washing, shopping
- **Goods, Equipment and Assistive Technology** – car modifications, communication aids, reading aids, self-care aids etc
- **Home Maintenance** – major and minor repairs and maintenance, gardening
- **Meals and food services** – at home or at centre meals, food preparation, lessons, training and food advice
- **Personal Care** – assistance with showering and dressing
- **Social Support** - group support and activities in the community
- **Transport** - helping you get to appointments, go shopping, and get out and about
- **Assistance with Care and Housing** – financial and legal advocacy, assessment referrals, hoarding and squalor
- **Flexible Respite** – in-home day and night respite, host family day and night respite, mobile respite, centre based respite, residential respite etc
- **Sector Support and Development**

There are multiple service providers on the Central Coast

1800 200 422

MyAgedCare.gov.au



Respite care

Respite services can support someone living with dementia while their carer attends to everyday tasks (like shopping), goes to appointments or takes a short break. It also provides carers with an opportunity to care for themselves.

While respite care can be provided **in the home**, there are **day respite centres** which provide a safe, supported environment in the community. Day respite is a good opportunity for people living with dementia to get to know other people, be involved in activities, or go on outings.

Respite can also be arranged for **overnight or over a weekend**, either in the home, a cottage-style respite centre, or in a care facility. Some residential care facilities can offer respite for up to 63 days per year.

Respite care is available by contacting **My Aged Care** to arrange for an assessment.

Respite in the home

FLEXIBLE IN HOME RESPITE

Short term support in the home, allowing carers a break from the caring role. In home flexible respite is provided through the Commonwealth Home Support Program. Frail aged people; people living with dementia with carers and; those who have a carer still requiring access to employment, may be eligible for this government subsidised support.

Referral to My Aged Care for an assessment by the Regional Assessment Service (RAS) is required. There are multiple service providers on the Central Coast.

www.myagedcare.gov.au/getting-started/short-term-help

CARER GATEWAY

Carer Gateway provides information about respite options and other support services on the Central Coast and provides a link to those services and assists carers to access short-term and emergency respite support.

Ph: 1800 422 737 for all services including emergency respite

www.carergateway.gov.au/respite/what-respite

Out of home respite

COTTAGE RESPITE

Cottage respite is available overnight or over a weekend in a community setting.

A cottage respite referral code through My Aged Care is required through an assessment and approval by the Regional Assessment service (RAS) or the Aged Care Assessment Team (ACAT). If no other ACAT approvals are required the assessment would go to RAS.

If approval for permanent residential care, residential respite or a home care package is also needed then an ACAT assessment is required.

My Aged Care Ph: 1800 200 400

Cottage respite options on the Central Coast include:

JEAN MARION COTTAGE

The Jean Marion cottage, located in Narara on the Central Coast, was established by Hammond Care. It is a small suburban home that offers short term overnight respite care in a home-like environment for people living with dementia. A client contribution is charged; however this can be negotiated, depending on the person's circumstances and can be discussed with the service manager.

**Jean Marion Cottage Ph.: 4337 5850 Email: support@hammond.com.au
82A Reeves St, Narara NSW 2250**

COASTLINK OVERNIGHT RESPITE COTTAGES

Coastlink has two wheelchair accessible residential houses that provide a warm, friendly home-like environment for people with a disability.

The cottages can be used for overnight, planned or emergency accommodation. They were purpose built by Coastlink to provide much needed short term accommodation, respite and holiday options for people living or visiting the Central Coast. Each cottage has five bedrooms and can sleep up to nine people.

Fees - There may be various ways to apply for/access funding to help cover part of the cost. Call Coastlink to discuss funding/fees.

Coastlink Ph: 4321 1022 www.coastlink.org.au

RESPITE IN A RESIDENTIAL AGED CARE FACILITY

A short stay in a residential care home is available. People are eligible for 9 weeks respite per financial year. This can be extended by approval from ACAT in blocks of 21 days at a time. **Cost** - 85% of single aged pension.

Phone My Aged Care on **1800 200 422** for an assessment by the Aged Care Assessment Team (ACAT) for approval for residential respite.

Can book through My Aged Care. *However: If needing most costs covered by The Carer Gateway, respite is booked through the Carer Gateway staff. Carer Gateway do not reimburse if the Carer has self-organised the respite.*

**www.myagedcare.gov.au/respite-care?fragment=residential
www.carergateway.gov.au/respite/what-respite**

RESPITE IN THE COMMUNITY

1. CENTRE BASED DAY RESPITE

Centre based day respite usually takes place at a day centre or club. It offers structured group activities or outings that give people a chance to do things that they enjoy and talk with other people. Day respite often runs from 10am to 3pm and may include transport to and from the Centre.

Referral to My Aged Care (MAC) for an assessment by the Regional Assessment Service (RAS). Multiple service providers on the Central Coast.

Some Dementia inclusive day centres include:

Integrated Living - Gorokan, Woy Woy, Gosford **Ph: 1300 782 896**

Warnervale Wellness Centre - Hamlyn Terrace- Catholic Care **Ph 1800 225 474**

Coastlink Green Point - friendship group day centre.

A group is soon to start in Woy Woy as well **Ph: 4321 1022**

Hammond Care Social Club - Erina **Ph: 1800 826 166**

www.myagedcare.gov.au/respite-care?fragment=community

2. COMMUNITY ACCESS GROUPS

Community access groups: provide activities and outings to give people a sense of independence and some social interaction, while giving the carer a break. This may be provided individually or as part of a group.

Emergency Respite Care

NATIONAL AUSTRALIA CARER GATEWAY

1800 422 737

Mon-Fri from 8am to 6pm

The Carer Gateway is a national phone service and website that provides advice, information, resources, and links to support services. The website includes an interactive service finder to help locate the nearest carer support services.

carergateway.gov.au



Planning ahead

Dementia affects everyone differently. However, sooner or later the person living with dementia will need support to make decisions about their health, day-to-day living, finances and legal matters.

Planning ahead is very important. This ensures that important decisions are made while the person is able to make those decisions for themselves, and make their wishes known.

NSW law assumes that everyone has the mental capacity to make decisions. That is, they understand and weigh up information presented to them, make an appropriate decision, and clearly communicate their choices.

Capacity can however be affected temporarily because of illness or the effects of medication, or permanently affected due to conditions such as intellectual disability, dementia, mental illness, or brain injury.

Source: reproduced from NSW Government Planning Ahead Tools – Plan ahead for your future legal, health and financial decisions, www.tag.nsw.gov.au/.

START2TALK

Dementia Australia

Provides practical assistance with planning ahead by providing resources, tools and the information you need to make decisions and put them into action. The information is for anyone living in Australia.

<https://www.dementia.org.au/information/about-dementia/planning-ahead-start2talk>

Legal Matters



GUARDIAN

Guardian: A guardian is a substitute decision-maker with authority to make personal or lifestyle decisions about the person under guardianship. A guardian is appointed for a specified period of time and is given specific functions (e.g. the power to decide where the person should live, what services they should receive and what medical treatment they should be given). A private guardian may be appointed such as a family member or friend, provided the circumstances of the matter allow for this and they meet the criteria set out in the legislation.

Enduring Guardian: An enduring guardian is someone a person appoints to make personal or lifestyle decisions on their behalf when they are not capable of doing this for themselves. People choose which decisions they want the enduring guardian to make. These are called functions. People can direct the enduring guardian on how to carry out the functions. The appointment of an enduring guardian comes into effect when a person loses capacity to make personal or lifestyle decisions.

Public Guardian: The Public Guardian promotes the rights and interests of people with disabilities through the practice of guardianship, advocacy and education. The Public Guardian is a statutory official appointed by the Guardianship Division of the NSW Civil & Administrative Tribunal (NCAT) or the Supreme Court under the Guardianship Act 1987.

For more information:

- **NSW Civil & Administrative Tribunal (NCAT)**
www.ncat.nsw.gov.au/Pages/guardianship/guardianship.aspx Ph: 1300 006 228
- **NSW Trustee & Guardian and NSW Public Guardian – Planning Ahead**
www.tag.nsw.gov.au
Ph: 1300 887 529
- **LawAccess NSW** Ph: 1300 888 529 business hours. Provides free telephone information, including location of nearest Legal Aid office or Community Legal Centre.
lawaccess.nsw.gov.au
- Contact a solicitor
- Speak to a GP

 **WILL**

A will is a legal document that sets out who a person wants to receive their assets including jewellery, sentimental items, money and property when they die. Making a will is the only way people can ensure their assets will be distributed according to their wishes.

If someone dies without a will (intestate) the person's estate will be distributed according to a pre-determined formula, with certain family members receiving a defined percentage of the assets despite what the person may have wished.

For more information:

- **NSW Trustee & Guardian and NSW Public Guardian – Planning Ahead**
www.tag.nsw.gov.au
Ph: 1300 887 529
- **LawAccess NSW** Ph: 1300 888 529 business hours. Provides free telephone information, including location of nearest Legal Aid office or Community Legal Centre.
lawaccess.nsw.gov.au
- Contact a solicitor





POWER OF ATTORNEY

A Power of Attorney is a person who has legal authority to look after a person's financial affairs on their behalf. NSW Trustee & Guardian can prepare a Power of Attorney and act as the attorney under a Power of Attorney. When NSW Trustee & Guardian prepares a Power of Attorney, people can appoint either:

1. The NSW Trustee & Guardian to act as the attorney.
2. A person of their choosing to act as attorney and NSW Trustee & Guardian as substitute attorney.
3. A person of their choosing to act as attorney.

Enduring Power of Attorney: An enduring power of attorney is a legal document appointing an attorney or attorneys who can act on a person's behalf in financial matters under their instruction while they have capacity or without their instruction if they lose capacity.

Financial Manager: A financial manager is a legally appointed substitute decision-maker with authority to make decisions about and manage a person's financial affairs (e.g. their money, property and other financial assets, such as share portfolios) and their legal affairs (e.g. instructing a solicitor). A private financial manager may be appointed or a family member or friend, provided they are a 'suitable person' as required by the legislation.

NSW Trustee: When a person appoints the NSW Trustee & Guardian as attorney they offer either Future Assist or Active Assist.

Future Assist: A Power of Attorney designed to provide people with a safety net should unforeseen events occur.

Active Assist: A Power of Attorney where people are able to choose the level of assistance they require.

All of these documents can be drawn up by a solicitor, or can be drawn up and lodged with the Registrar of your local court house. These documents are also available on the start2talk website.

For more information:

- **NCAT**

<https://ncat.nsw.gov.au/case-types/guardianship.html>

Ph: 1300 006 228

- **NSW Trustee & Guardian and NSW Public Guardian – Planning Ahead**

www.tag.nsw.gov.au

Ph: 1300 887 529

- **LawAccess NSW** Ph: 1300 888 529 business hours. Provides free telephone information, including location of nearest Legal Aid office or Community Legal Centre.

lawaccess.nsw.gov.au

- Contact a solicitor

- Speak to a GP





ADVANCE CARE PLANNING

Advance Care Planning is a process that helps people to plan for future medical care. This process involves the person thinking about their values, beliefs, and wishes about what medical care they would like to have if they cannot make their own decisions.

An important part of the planning process is for the person to discuss their wishes with their family and other people who are close to them, as well as talking to their General Practitioner or other health professionals about any medical conditions they have.

People may also choose to write down their wishes in an Advance Care Directive, which outlines their specific treatment wishes.

For more information:

- **NSW Trustee & Guardian and NSW Public Guardian – Planning Ahead**
www.tag.nsw.gov.au
Ph: 1300 887 529
- **LawAccess NSW** Ph: 1300 888 529 business hours. Provides free telephone information, including location of nearest Legal Aid office or Community Legal Centre.
<https://www.lawaccess.nsw.gov.au/>
- www.cclhd.health.nsw.gov.au/patients-and-visitors/carer-support/carers-planning-ahead/advanced-care-planning
- Contact a solicitor
- Speak to a GP



ADVANCE CARE DIRECTIVE

An Advance Care Directive, which is sometimes referred to as a 'Living Will', is a document.

It should provide a clear statement that sets out a person's directions, including their wishes and values, that need to be considered before medical treatment decisions are made on their behalf. Discussions around these issues are best done with people who are important to the person and their doctor.

For more information:

- **NSW Trustee & Guardian and NSW Public Guardian – Planning Ahead**
www.tag.nsw.gov.au
Ph: 1300 887 529
- **LawAccess NSW** Ph: 1300 888 529 business hours. Provides free telephone information, including location of nearest Legal Aid office or Community Legal Centre.
<https://www.lawaccess.nsw.gov.au/>
- www.cclhd.health.nsw.gov.au/patients-and-visitors/carer-support/carers-planning-ahead/advanced-care-planning
- Contact a solicitor
- Speak to a GP



NSW CIVIL & ADMINISTRATIVE TRIBUNAL (NCAT)

The NCAT Guardianship Division makes decisions about people who have a decision-making disability. The Guardianship Division determines applications about adults who are incapable of making their own decisions and who may require a legally appointed substitute decision-maker.

For more information:

- **NCAT** <https://ncat.nsw.gov.au/case-types/guardianship.html> Ph: 1300 006 228

Palliative Care and End of Life Planning

Many people want to spend the end of their life in their homes, with friends and family around them, rather than be transferred to a hospital. Palliative Care is a service that provides care and support to people that chose to die in their home.

The goal of palliative care is to reduce suffering and manage symptoms being experienced by someone at the end of their life, including pain. Palliative care also provides specialised guidance, emotional and practical support to the carer, family and friends.

If you want to access palliative care services, talk to your doctor.

PALLIATIVE CARE AUSTRALIA

(02) 6232 0700 Business hours

The Palliative Care Australia website provides information and resources, as well as a service directory, so that you can find a service near you.

palliativecare.org.au

CCLHD ADVANCE CARE PLANNING

Resources are available at **<https://www.cclhd.health.nsw.gov.au/patients-and-visitors/carers-support/carers-planning-ahead/advanced-care-planning/>**

CCLHD PALLIATIVE CARE SERVICE

Ph: **4336 7777** is available for people in the community and in hospital.

A referral must be made by a medical officer (can be by a GP) and faxed to the Palliative Care Service on Fax: 4336 7773.

Website: **<https://www.cclhd.health.nsw.gov.au/services/central-coast-cancer-services/cancer-services/palliative-care-services/>**.

For referral criteria and referral form see Central Coast HealthPathways: centralcoast.healthpathways.org.au

ELDAC

www.eldac.com.au

ELDAC provides information, guidance, and resources to health professionals and aged care workers to support palliative care and advance care planning to improve the care of older Australians.

The ELDAC Care Model is a guide to help aged care staff and health professionals meet the needs of older Australians coming to the end of their life. It reflects national policies and practices in palliative care.

ELDAC has five toolkits to help your practice:

- Primary Care
- Home Care
- Residential Aged Care
- End of Life Law
- Working Together



It is important to talk to the GP and family/carer/guardian when the prognosis is poor, or when health is deteriorating to ensure that end of life planning is discussed with the person.

Life planning documents may include an Advance Care Plan or an Advance Care Directive (ACD). See <https://www.cclhd.health.nsw.gov.au/patients-and-visitors/carer-support/carers-planning-ahead/advanced-care-planning/> for more information.

If the person is wishing to remain living at home during this time, it will be crucial to have a GP who can do home visits when required and to sign a death certificate when that time comes.

Financial advice and support

SERVICES AUSTRALIA

13 27 17

Mon-Fri from 8am to 5pm

Services Australia provides financial support, including a carer's allowance, to anyone who is eligible. They also have financial counsellors that can assist with financial difficulties. An assessment may be required if you are accessing Home Care Packages, respite care, or residential care. humanservices.gov.au

DEPARTMENT OF VETERANS AFFAIRS (DVA)

1800 555 254

If you or your partner has served in the Australian defence force, you may be eligible for financial support or benefits, household help, medical equipment, home or health care. A DVA assessment may be required if you are accessing Home Care Packages, respite care, or residential care.

dva.gov.au

FINANCIAL INFORMATION SERVICE

13 23 00

Mon-Fri from 8am to 5pm

Provides free advice to help you understand your options, plan for retirement, and make informed decisions about your finances.

humanservices.gov.au

MONEY SMART

This website contains practical tips, a financial calculator, budget planner, planning for retirement, and information on how to avoid scams.

moneysmart.gov.au

SALVATION ARMY

Emergency Financial Assistance

1300 371 288

Mon-Fri from 9am to 5pm

Financial or material assistance, and support for people in crisis.

salvos.org.au

Other Support Services

SENIORS RIGHTS SERVICE

Seniors Rights Service is an advocacy service for older residents of nursing homes, hostels and retirement villages and people receiving Community Aged Care Packages.

Seniors Rights Service promotes and protects the legal rights of each person.

Contact details: Ph: **1800 424 079** or **9281 3600** Level 4, 418A Elizabeth Street, Surry Hills NSW 2010 www.seniorsrightsservice.org.au

OLDER PERSONS ADVOCACY NETWORK (OPAN)

The Older Persons Advocacy Network's free service supports older people and their representatives to address issues related to Commonwealth funded aged care services.

Contact details: Ph: **1800 700 600** www.opan.com.au

NSW ELDER ABUSE HELPLINE & AGING & DISABILITY COMMISSION

The Helpline offers a free service that provides information, support and referrals relating to the abuse of older people living in the community across NSW. This service places the safety of the older person first, is confidential and callers remain anonymous.

Contact details: Ph: **1800 628 221** <https://eapu.com.au/elder-abuse-helpline/>

Ageing and Disability Abuse Helpline **1800 628 221** (Mon-Fri 8.30am-5.00pm)

<https://www.ageingdisabilitycommission.nsw.gov.au/>

LEGAL AID AND ELDER ABUSE

Legal Aid NSW's Elder Abuse Service assists older clients on the Central Coast at risk of, or experiencing elder abuse. Clients must be over 65 years, or over 50 years for our Aboriginal clients. They must live on the Central Coast. The service has lawyers and a social worker working together to support the client. We can help with a range of legal problems that affect older people. You can contact the service.

Contact details: Ph: **4324 5611**

Office location: **Gosford**

AGED CARE QUALITY AND SAFETY COMMISSION

The Aged Care Quality and Safety Commission provides a free service for anyone to raise their concerns about the quality of care or services being delivered to people receiving aged care services subsidised by the Australian Government.

Contact details: Ph: **1800 951 822**

info@agedcarequality.gov.au

www.agedcarequality.gov.au



HOME MEDICINES REVIEW (FOR THOSE LIVING ALONE)

A program funded by the Australian Government and Pharmacy Guild where local GPs and Pharmacists work together to review and help individuals manage medications at home.

[www.nps.org.au/consumers/managing-your-medicines#getting-a-home-medicines-review-\(hmr\)](http://www.nps.org.au/consumers/managing-your-medicines#getting-a-home-medicines-review-(hmr))

ALTERNATIVE TRANSPORT OPTIONS

The Staying on the Move with Dementia resource provides information on alternative transport and how to access them.

www.dementia.org.au/resources/dementia-and-driving-nsw

DRIVING

Links to provide information about licensing requirements and guidance for the difficult transition from driver to non-driver.

<https://www.dementia.org.au/resources/dementia-and-driving>

EHEALTH RECORD

My Health Record is a secure online summary of a person's health information.

www.myhealthrecord.gov.au/internet/mhr/publishing.nsf/content/home

NATIONAL CONTINENCE HELP LINE

Information about managing continence including the continence aids payment scheme.

Contact details: Ph: **1800 330 066**

<https://www.continence.org.au/get-help/national-continence-helpline>

RSPCA COMMUNITY AGED CARE PROGRAM – FORMALLY KNOWN AS PETS OF OLDER PERSONS SERVICE (POOPS)

RSPCA NSW understands that to an elderly owner, a pet can mean everything. Our Aged Care program aims to keep pets and their elderly owners happy, healthy and together in their own homes for as long as possible. To do this, we assist elderly pet owners over the age of 65, Indigenous pet owners over the age of 50 and palliative care patients of any age.

- Services our Aged Care program offers include: temporary foster accommodation and/or emergency pet boarding if the owner requires medical treatment, respite or other assistance
- assistance with veterinary treatment
- home visits to assist the elderly with basic pet care
- assistance with pet grooming
- assistance with transport to and from the local veterinarian
- a volunteer network to assist with dog walking and short periods of in-home care if the owner requires medical treatment, respite or other assistance

Contact details: RSPCA Community Programs helpline **(02) 9782 4408**.

The helpline operates Monday to Friday, 9am – 5pm During weekends and public holidays contact the RSPCA Contact Centre on **(02) 9770 7555**.

www.rspcansw.org.au/what-we-do/working-in-communities/community-aged-care-program/

CCLHD – CARER SUPPORT UNIT AND CARER RETREAT

The Central Coast Support Groups and Services Directory developed by the Carer Support Unit lists a range of other support services.

www.cclhd.health.nsw.gov.au/patients-and-visitors/carer-support/

Contact details: Ph: **4320 5556** Fax: **4320 5555**

91 Holden Street, Gosford (opposite Gosford Hospital).

Email: **CCLHD-CSUCC@health.nsw.gov.au**

www.cclhd.health.nsw.gov.au/patients-and-visitors/carer-support/

FINANCIAL INFORMATION SERVICE

An Australian Government Service that can help assist an individual make current and future financial decisions.

Contact details: Ph: **132 300**

www.humanservices.gov.au/individuals/services/financial-information-service



SUPPORTED WAGE SYSTEM – AUSTRALIAN GOVERNMENT

A system when people are unable to find or keep a job at full wages due to the effect of disability on their workplace productivity.

www.jobaccess.gov.au/supported-wage-system-sws

EMPLOYMENT ASSISTANCE FUND

Employers may be eligible for financial help from the Australian Government for equipment, modifications and services to support employees with a disability.

www.jobaccess.gov.au/employment-assistance-fund-eaf

ACCESSING SUPERANNUATION

For circumstances where a person with dementia can apply to access money in their superannuation fund early

<https://www.servicesaustralia.gov.au/who-can-access-their-superannuation-early?context=21971>

ACCESSING AUSTRALIAN GOVERNMENT PAYMENTS AND SERVICES

Individuals may be eligible for payments and services if unable to work or are limited in the amount of work they are able to do as a result of having younger onset dementia.

<https://www.servicesaustralia.gov.au/health-and-disability>

THE AGEING AND DISABILITY ABUSE HELPLINE

1800 628 221

Mon-Fri from 9am to 5pm

Provides information, support and referral for anyone who suspects, witnesses or experiences abuse. Elder abuse includes physical, psychological, emotional, sexual or financial abuse.

If it is an emergency call

Triple Zero (000).

ageingdisabilitycommission.nsw.gov.au

nswadc@adc.nsw.gov.au

LOCAL COUNCILS

Provide valuable, local information on community services in your area.

OLDER PERSONS ADVOCACY NETWORK

1800 700 600

Mon-Fri from 9:30am to 4:30pm

Provides advocacy, expert advice and information for people who are unhappy with government funded home care, community care or residential care services.

opan.com.au

SENIORS RIGHTS SERVICE

1800 424 079 Business hours

Provides free legal advice and assistance for older people.

seniorsrightsservice.org.au

ACKNOWLEDGEMENTS

We would like to thank the New England Dementia Partnership for allowing us to base this booklet on their booklet entitled **Memory Problems and Beyond– New England and North West NSW.**



EMERGENCY CONTACT NUMBERS – 24 HOUR

Ambulance, Fire, Police
Phone: **Triple Zero (000)**

Lifeline (crisis support)
Phone: **13 11 14**

Dementia Support Australia (behaviour support)
Phone: **1800 699 799**



CONTACT NUMBERS – BUSINESS HOURS

Dementia Australia – National Dementia Hotline
Phone: **1800 100 500**

Emergency Respite Care
Contact Carer Gateway: **1800 422 737**

My Aged Care
Phone: **1800 200 422**

National Disability Insurance Scheme
(Younger Onset Dementia)
Phone: **1800 800 110**

CENTRAL COAST DEMENTIA ALLIANCE

Email: Central-Coast-Dementia-Alliance@hneccphn.com.au