

Camden Haven, Kempsey, Port Macquarie, South West Rocks, Wauchope

# **Important contacts**

#### Mind

Dementi	ia and Memory	Community	Centre	and	Dementia
Advisory	y Service				

A local team of health workers specialising in dementia.

- 02 6584 7444
- National Dementia Helpline

Free dementia advice, support and counselling. www.fightdementia.org.au/helpline

- 9am to 5pm Monday to Friday Closed on public holidays
- Dementia Support Australia

Free 24-hour dementia behaviour support helpline. Also known as Dementia Behaviour Management Advisory Service or DBMAS. www.dbmas.org.au

1800 699 799 24-hour helpline

#### Health

My GP	
	Hours:
	After hours:

Healthdirect

This is a free service staffed by a registered nurse who can provide health advice and information. www.healthdirect.gov.au

- 1800 022 222 24-hour helpline
- National Health Services Directory
  Online listing of local health services. www.nhsd.com.au

### **Services and support**

My Aged Care

The first point of access for most Aged Care Services in your area. www.myagedcare.gov.au

(1) 1800 200 422 8am t

8am to 8pm Monday to Friday 10am to 2pm Saturday

Commonwealth Respite and Carelink Centre

Emergency, short-term or planned respite care at home or in a residential care facility. www.crccfnc.org

1800 052 222

24 hours a day, 7 days a week

Carer Gateway

Connects you to local support services. www.carergateway.gov.au

1800 422 737 8am to 6pm Monday to Friday

Carers NSW

Carer information, support and counselling. www.carersnsw.org.au

1800 242 636 9am to 5pm Monday to Friday

Lifeline

24-hour mental health crisis support. www.lifeline.org.au

13 11 14



#### No Time Like the Present

Aunty Joyce Summers

The outer feature of the painting is the Tweed River and the marine life therein. The half green circles represent the mangrove roots of the Tweed River.

The concentric circles represent the services that can be accessed by people, friends and families who are affected by Alzheimer's. The waving lines between the circles show how services link to each other.

The centre of the painting shows a brain that is affected by Alzheimer's Disease. Words around the centre of the image are some feelings that a person with Alzheimer's may experience.

Aunty Joyce is a highly respected Aboriginal Elder who has worked tirelessly to educate the Tweed Community about her culture. She was born on Eukrebah Island in the Tweed River and from an early age her relationship with the river has been one of admiration of its beauty and colours.

We acknowledge the traditional custodians of Australia and their continuing connection to land, sea and community. We respect the Elders past and present and express our heartfelt apology for the injustices endured by Aboriginal people of our nation. We will continue to strive, day by day, for our thoughts and actions to reflect these truths and sentiments.

# Introduction

This Dementia Support Kit has been developed for:

- People with dementia
- People with changes in brain function or memory
- Family members
- Carers
- The community

#### The Kit includes:

- This book
- An Important Health Contacts fridge magnet
- Delirium Action Plan
- Printable resources for doctors
- A website where you can download a copy of the Kit: www.ncphn.org.au/dementia

This is not a complete list of resources or information. We hope it will help you start thinking about the support you may need now or in the future.

Everyone is unique, and support networks or living situations will be different for everybody. Don't hesitate to call the numbers listed to find answers to your questions. You can also look up more information online.

Remember that you are not alone. There are people you can talk to and different ways to get the support you need.

When mum was diagnosed I received lots of information regarding dementia as an illness, but nothing about support services. This Kit would have been so helpful for us.

Judy, cares for her mum with dementia

We gratefully acknowledge the people with dementia, their partners, family and carers who helped us to design this Dementia Support Kit. Their valuable contributions shaped this book into a truly local community resource.

For more information or to access an online version of the book, visit the North Coast Primary Health Network website: www.ncphn.org.au

This Kit was published in December 2017.

Information, services and support were correct at the time of publishing. This information does not replace advice from your doctor or medical professional.

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# **My Aged Care**

My Aged Care has been set up by the Australian Government to help find information about:

- Types of aged care services
- Eligibility for services
- Service providers
- The costs of services
- How to access services

Many Hastings Macleay aged care services need a referral from My Aged Care before you can use the service. Get a referral by visiting the My Aged Care website or calling them.



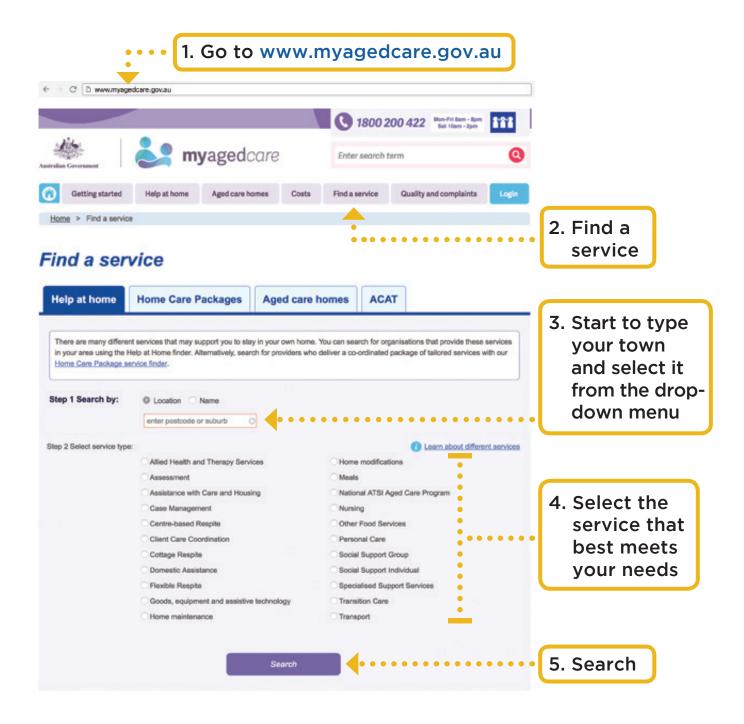
Visit www.myagedcare.gov.au

Call 1800 200 422

#### Aged care services include:

- Personal care like showering and dressing
- Transport
- Modifications to your home like hand rails or ramps
- Nursing, physiotherapy and other care
- Meals
- Household jobs like shopping, cleaning or gardening
- Social activities
- Respite services
- Permanent residential care

### Finding a service on the My Aged Care website



#### How to be referred to services

Call My Aged Care 1800 200 422

#### OR

Go online to www.myagedcare.gov.au/referral



Name the service you want a referral to



My Aged Care will decide whether you have a home visit from either the Regional Assessment Service (RAS)

#### or

Aged Care Assessment Team (ACAT)



The RAS or ACAT service will then visit and refer you to the services that are right for you

#### My Aged Care Video

The My Aged Care consumer video is a three-minute interactive video. It gives instructions on how to navigate the My Aged Care website.

Search 'my aged care consumer video' in Google to watch the video.

#### Languages other than English

There are many services and resources available in languages other than English.

#### **Translating and Interpreting Services (TIS)**

covers more than 100 languages.

Call **131 450** 24 hours a day, 7 days a week

for the cost of a local call

My Aged Care contact centre can organise an interpreter through TIS.

Call **1800 200 422** 8am to 8pm on weekdays

10am to 2pm on Saturdays

My Aged Care also includes information on aged care in other languages. Search 'My Aged Care other languages' in Google.

#### **Hearing impairment**

#### **National Relay Service**

People with hearing loss or a hearing or speech impairment can contact My Aged Care through the National Relay Service in two easy steps:

Step 1 Visit the National Relay Service website to choose your preferred access point: relayservice.gov.au

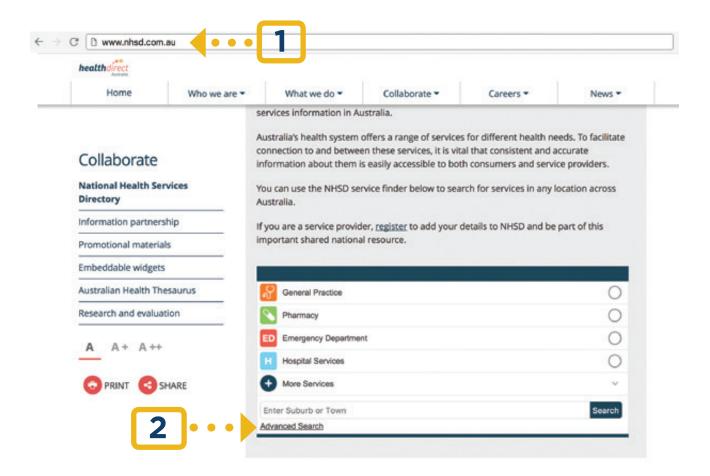
Step 2 Ask for My Aged Care on 1800 200 422

# **National Health Services Directory**

The National Health Services Directory lists local health services around Australia.

To find services for people with dementia in Hastings Macleay:

- 1 Visit www.nhsd.com.au
- 2 Click on Advanced Search at the bottom of the page:



- Type 'dementia' in the 'Can't find what you're looking for?' box.
- 4 Type your suburb or postcode and choose your location from the drop-down menu that appears.

		Ģ	National Health SERVICES DIRECTORY
Find		More Services	
	Aboriginal Health Clini Chiropractic Dietetics Exercise Physiology General Practice Hospital Services Occupational Therapy Pharmacy Psychology  Can't find what you're loo  Search eg diabetes, surg	Diabetes Emergene General I Generalis Maternal, Optometr Physiothe	Educator cy Department Dental at Counselling Child and Family Health y erapy
Filter	Service Options		
	Preferences  My Health Record Ready No Appointment Required Telehealth Capable	Facilities  Accessible Parking Free Parking	Accessible Toilet Wheelchair Access
Location	Suburb or postcode	•• 4	<b>⊘</b> Search



# Mind



Dementia is the name given to a set of medical signs and symptoms caused by diseases that affect how the brain works. Dementia is more than just memory loss. It can also affect thinking, behaviour, communication and the ability to carry out daily tasks.



If you are experiencing changes with any of these abilities, it is good to see your GP early. Diagnosing dementia will require further investigations and may take some time. Referral to a medical specialist such as a geriatrician may also be required.

There are four main types of dementia:

- Alzheimer's disease
  Lewy body disease
- Vascular dementia
  Frontotemporal dementia

All types of dementia are progressive. This means the symptoms become worse over time. It is different for everyone and changes may happen over a few months or many years.

#### Dementia usually progresses through three stages:

#### Early dementia

A person may start to notice problems with memory or concentration. Friends, family or others may also notice these problems.

#### Moderate dementia

At this stage, the problems are more apparent and will interfere with everyday life. A person in this stage may act in unexpected ways, confuse their words, or be unable to recall personal details.

#### Advanced dementia

At this stage, a person is severely impaired and may need total care.

**Dementia Australia** has help sheets on the types and progression of dementia. You can access these help sheets at goo.gl/6PJCeq. You can also search 'dementia, Australia, help sheets' in Google.



# Port Macquarie 'Dementia Friendly Community'

Port Macquarie and the surrounding regions are aiming to be dementia-friendly communities. A dementiafriendly community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value.

Dementia Australia has developed a number of resources to assist all Australians to get a better understanding of what they can do to contribute to a dementia-friendly nation.

Call **02 6584 7444** or visit www.dementiafriendly.org.au

#### **National Dementia Helpline**

Call **1800 100 500** 9am to 5pm Monday to Friday Closed on public holidays

This is a free service. It provides advice, support and counselling for people with dementia, their carers, family and friends.

Visit www.fightdementia.org.au/helpline

# Diagnosis, Treatment And Care For People With Dementia PDF guide: www.tinyurl.com/y9nusv3j

This is a guide to the standard of care that should be available to all Australians with dementia. It lets you know what kind of care and treatment to expect and some questions to ask along the way.

You can find it by searching for the title in Google.



My mum's always been a knitter, but she can't follow a pattern any more because she just gets lost, so she makes up her own patterns now. She makes scarves and donates them to the local aged care services. It keeps her mind stimulated. It's just trying to find something that works for you.

Judy, cares for her mum

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## **Behaviour changes**

Changes in the behaviour of a person with dementia are very common. It may also be harder for people with dementia to tell others how they are feeling.

Common behaviour changes may include repetition, wandering or agitation. Behaviours may change for different reasons so always discuss these with your doctor to check for any medical causes.

If behaviours are worrying or causing problems, there is help available.



#### **Dementia Support Australia**

Call **1800 699 799** 24-hour helpline

Dementia Support Australia (also known as Dementia Behaviour Management Advisory Service or DBMAS) is a national free service funded by the Australian Government.

Dementia Support Australia provides support for the carers of people living with dementia whose behavioural and psychological needs are changing.

Visit www.dementia.com.au



#### **Education**

Learning about dementia can help people with dementia, their family and carers to understand the changes that are occurring in their daily lives.



#### **Local services**

Port Macquarie Dementia and Memory Community Centre provides information and education, activities and counselling. You can access a Younger Onset Key Worker and the Dementia Advisory Service. They also have a dementia library.

Call **02 6584 7444** 

**Note:** Some Dementia and Memory Community Centre Services will require a referral from **My Aged Care**. Contact My Aged Care on **1800 200 422** or visit www.myagedcare.gov.au

Tell them the service you would like to be referred to.

See page 10 for more information about My Aged Care.

There may also be other service providers not listed here that you can find through My Aged Care.

#### **National Dementia Helpline**

Call **1800 100 500** 9am to 5pm Monday to Friday. Closed on public holidays.

This is a free service. It provides advice, support and counselling for people with dementia, their carers, family and friends. Visit www.fightdementia.org.au/helpline



# Health



People with dementia can be at higher risk of other health conditions. It is important to have regular check-ups with your GP to monitor existing health issues and discuss any changes to your health. You may also be reviewed by your geriatrician or other medical specialists as required.



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Local services				
GP				
Name				
Phone				
Address				
After hour	After hours			
Other he	alth professionals			
Other he	alth professionals			
	•			
Name				
Name Role				
Name Role				

#### **Healthdirect**

Call 1800 022 222 24-hour line

Contact

This is a free service staffed by a registered nurse who can provide health advice and information.

Visit www.healthdirect.gov.au

## **Physical Activity**

Physical activity is any body movement that works the muscles and uses energy. It can include things like household chores and gardening as well as planned exercise. Physical activity and gentle exercise are beneficial for people with dementia. They can help:

- Keep the brain active
- Prevent muscle weakness and mobility problems
- Prevent health problems from inactivity
- Reduce anxiety and depression
- Increase social inclusion

Playing golf was so good for us - socially and to get some exercise as well. So when that had to stop 12 months ago, it was very hard for us, because then you're doing nothing. We now do lawn bowls and get all the trophies!





#### **Local services**

#### **Active and Healthy**

- You can find local Hastings Macleay gentle exercise and balance and strength programs on www.activeandhealthy.nsw.gov.au Enter your town or suburb in the "Find an Exercise Program" search box on left-hand side of the page.
- Call 1300 655 957 for a copy of the book "Staying active and on your feet" or order online at the above website.

#### **Physiotherapists**

- If you are attending physiotherapy, ask them about suitable physical activities.
- Call your local Community Health Centre to find out what physiotherapy services are available.
- There are also private physiotherapists listed in the phone book or online.

#### **Exercise physiologists**

- Visit www.essa.org.au and enter your postcode for local listings.
- Ask your GP about exercise physiologists who provide home visits or local groups.

Continued on the next page

# Going to hospital

Hospitals can be a foreign place, and sometimes hospital visits are unplanned. There are some simple ways you can ensure you are prepared for a hospital visit:

- Carry a list of your current medications on you at all times.
- Have the name of your doctor and their contact number written down.
- Have an emergency family contact number on you at all times.
- Keep a copy of your latest medical history, or ask your doctor to save it on your online My Health Record.
- Know who will feed your pets if you are ever away from home for a few days. Discuss this with them in advance and keep their name and phone number with you.
- If you have a home alarm, make sure a friend or family member knows the alarm code and number of the security company.
- Keep reading glasses or hearing aids in one place so you can pick them up quickly.



# Living



There are lots of services that can help people to stay independent as long as possible while living with dementia.

# **Safety**

It is important for everyone to feel safe and secure in their home and community. Dementia symptoms such as confusion, memory loss, disorientation and problems with mobility may affect personal safety.

An **occupational therapist** can provide an assessment of the home environment and offer suggestions on modifications and/ or aids and equipment to keep people safe and prevent falls.

**Personal alarms** can help bring peace of mind but still allow someone to live independently. Personal emergency response services are available. Companies providing these services can be found in your phone book or online.



#### **Local services**

#### **Occupational Therapy Assessments**

Camden Haven Community Health	02 6559 9003
Kempsey Community Health	02 6561 2790
Port Macquarie Community Health	02 6588 2882
South West Rocks Community Health	02 6565 9611
Wauchope Community Health	02 6580 8060
Occupational Therapy Australia Visit www.otaus.com.au to find a private occupational therapist.	02 9648 3225

#### **Safely Home**

This is a joint partnership between Dementia Australia and the Missing Persons Unit of the NSW Police. It provides accurate identification for people who may become lost or disorientated. Call **1800 100 500** for an information kit.



# **Driving**

Everyone has to stop driving at some stage. Having dementia may affect a person's ability to drive. It may mean a person needs to make the decision to stop driving earlier than expected. If you have a diagnosis of dementia, it is a legal requirement to notify the Roads and Maritime Service. This does not always mean you have to stop driving – you may need to do a driving test or speak with your doctor.



#### **Local services**

#### **Occupational Therapy Australia (OT Aus)**

Call 02 9648 3225 or visit www.otaus.com.au

Some occupational therapists provide driving assessments. Occupational Therapy Australia can help you find the nearest provider.

If you have concerns about driving:

- Speak to your doctor.
- Visit your local Roads and Maritime Service.

NRMA and Dementia Australia have also developed a guide to Staying on the Move with Dementia.

You can find it by looking up the title in Google.

## Younger people who have dementia

Younger Onset Dementia (or Early Onset Dementia) may be used to describe people under 65 years of age who have been diagnosed with dementia.



#### **Local services**

Dementia and Memory Community Centre Port Macquarie provides access to a Younger Onset Key Worker and the Dementia Advisory Service. They also provide information and education, activities, counselling and a dementia library.

Call **02 6584 7444** or visit goo.gl/vYtXpP

**Note:** to access some services from the Dementia and Memory Community Centre contact My Aged Care on **1800 200 422**.

Tell them you would like to be referred to the Dementia and Memory Community Centre.

See Page 10 for more information about My Aged Care. There may be other service providers not listed here that you can find through My Aged Care.

The National Disability Insurance Scheme (NDIS) supports people with a permanent and significant disability which affects their ability to take part in everyday activities. People with dementia under the age of 65 may be eligible for the NDIS.

Call **1800 800 110** to find out if you meet the eligibility requirements.

The **National Dementia Helpline** can provide information about meeting the NDIS eligibility requirements.

Call **1800 100 500**.



**Dementia Australia** has a national Younger Onset Dementia Key Worker Program to provide support to people with symptoms of dementia before the age of 65.

Call **1800 100 500** to be connected to a Younger Onset Dementia Key Worker.

**Dementia Australia** also has information for people with <u>Younger Onset Dementia</u>. You can search 'dementia, Australia, younger onset' in Google to find these.

#### The Lovell Foundation

The Foundation raises awareness about Younger Onset Dementia. Their website has lots of information and helpful links. Visit www.lovellfoundation.com.au



This Is My Family by Northern NSW author Barbara Chambers.

This is a book for children with a parent with younger onset dementia.

You can purchase it online. Search for the title and author in Google.

# Aboriginal and Torres Strait Islander people who have dementia

Dementia is one of the biggest health problems facing Australia today. Dementia is more than just memory loss. It can also affect thinking, behaviour, communication and the ability to carry out daily tasks.

#### **Local services**

Australian Unity Home Care Service provides help at home and other services. Call 1300 295 837 or visit www.australianunity.com.au/home-services/

Booroongen Djugun Limited, Greenhill via Kempsey provide community based services such as transport, community care packages, respite. Call **02 6560 2100** or visit http://booroongenjugun.com.au/

Hastings Macleay Community Transport provides transport for Aboriginal people with a disability or over 50 years old. Transport options include medical, shopping, podiatry, physiotherapy, hospital, cultural events and more. Call **02 6583 8644**.

Kempsey Aboriginal Meals on Wheels can also provide accompanied activities. Call 1800 283 666.

**Note** that referral to the above services will require an assessment through My Aged Care.

Call 1800 200 422 or visit www.myagedcare.gov.au

Ask for referral to these services by name.

See page 10 for more information about My Aged Care.



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#### **Local services**

**Aboriginal Medical Services (AMSs)** provide health care for Aboriginal people and their families. This includes:

- General practice, with a Registered Nurse and Aboriginal health practitioner
- Psychology
- Diabetes education
- Eyesight and hearing services
- Access to exercise classes

Durri Aboriginal Medical Corporation Medical Service, Kempsey. Call **02** 6560 2300 or visit www.durri.org.au

Werin Aboriginal Medical Corporation, Port Macquarie Call **02** 6589 4000.



# Wellbeing



Living with dementia may bring different feelings and emotions. It is important that you, and your family or friends, can talk about what is happening and how you are feeling.



My mum has dementia. Every time she goes on an outing, I can see the difference in her straight away and for the next few days. She is much more alert and happier. When we don't get out, I find she doesn't want to go out as much. So social support is very important for us. It's so good for mum to do regular social activities to keep her mind active.

Judy, cares for her mum

### **Social Life**

One of the best ways to exercise the brain is to talk to different people or try different activities. Everyone will have different interests. See below for some ideas of social groups or activities to try.



#### **Local services**

Dementia and Memory Community Centre Port
Macquarie provides activities, information and education.
They can also provide access to a Younger Onset Key
Worker and the Dementia Advisory Service.

Call 02 6584 7444 or visit goo.gl/vYtXpP

Parklands Cottage in Kempsey provides a social support program with a variety of activities.

Call 02 6562 7104 or visit www.parklandscottage.com.au





## **Local services**

**Omnicare** provides social support programs in Port Macquarie, Laurieton and Wauchope.

Call 1300 336 488 or visit www.omnicare.org.au

Note: To access these services contact My Aged Care on 1800 200 422 or visit www.myagedcare.gov.au

When known, ask for referral to these services by name.

See page 10 for more information about My Aged Care.

# **Feelings**

Experiencing changes due to dementia may lead to many different emotions. Feelings of shock, sadness, frustration, embarrassment, anger and loss are all common when dealing with memory changes. It is normal to experience a range of feelings.

Counselling is an opportunity to discuss feelings or issues related to dementia. People who may benefit from dementia counselling include:

- People in the early stages of dementia
- Carers of people with dementia
- Family such as spouse, partners and children
- Friends and other significant people



#### **Local services**

Talk to your GP for referral to local counselling or psychology services.

#### **Carers NSW**

Free carer information, support and counselling over the phone. Face-to-face counselling in the Hastings Macleay area can also be arranged.

Call **1800 242 636** 9am to 5pm Monday to Friday

Visit www.carersnsw.org.au

#### **National Dementia Helpline**

Advice, support and counselling for people with dementia, their carers, family and friends.

Call **1800 100 500** 9am to 5pm Monday to Friday Closed on public holidays

#### Lifeline

Mental health crisis support

Call **13 11 14** 24 hours, 7 days a week

Visit www.lifeline.org.au



# Support



Dementia can affect usual daily activities or tasks. Support in your home is available to help with some tasks like personal care, household chores and transport.
Other services can assist with respite arrangements or residential care.

# Help to live at home

My Aged Care will help you, or your family carer, to access local aged care services.



#### **Local services**

Call My Aged Care on **1800 200 422** or self-refer at www.myagedcare.gov.au/contact

See page 10 for more information about My Aged Care. There may also be other service providers not listed here that you can find through My Aged Care.

Many of the services listed in this book can help you navigate the My Aged Care website and phone service. Ask about this when you call the service.

My Aged Care can help you access support to manage better at home and improve your wellbeing. You may be eligible to receive individual services or a tailored package of services such as:

- Personal care like help with getting dressed
- Transport
- Simple modifications to your home like hand rails or ramps
- Nursing, physiotherapy and other care
- Meals
- Household jobs like shopping, cleaning or gardening
- Medication monitoring
- Social activities

These are government-funded aged care services.



Many organisations also provide privately funded services. If you are not eligible for the above services, or prefer to pay for your own services, you can visit www.myagedcare.gov.au and choose the "Find a service" tab.

This will give you a list of local organisations who may be able to provide private services.



#### **Local services**

National Health Services Directory (NHSD)

Visit www.nhsd.com.au

The NHSD lists local health services around Australia.

You can use the NHSD service finder on the above website to search for dementia services in the Northern Rivers area.

See page 14 for more information on the NHSD.

# **Transport**

Community Transport provides a range of affordable, flexible and accessible transport services. These are to support people who have limited or no access to private transport and difficulty accessing public transport.

They can be used to travel to medical appointments, shopping, social outings or other essential events.



# **Local services**

Hastings Macleay Community Transport provides transport for medical appointments, shopping, cultural events and more.

Call **02 6583 8644** or visit www.hmct.org.au



# **Meal delivery**

It may be getting harder to cook, or you may prefer to have some meals delivered for convenience and variety.



#### **Local services**

Meals on Wheels services are found in a number of areas across Hastings Macleay. They provide meals to your home and can provide their clients with other supports, such as social support, shopping service and cooking classes. Check with your local Meals on Wheels for availability.

Kempsey
Call **02 6562 1544**.

Port Macquarie Call **02** 6584 1463.

Wauchope Call **02 6585 2386**.

Omnicare Alliance Limited -Meals on Wheels Mid North Coast, Port Macquarie
Call **02** 6584 1115.

Open Arms Care Inc, Raleigh Call **02 6692 4470**.

Visit Meals on Wheels: http://nswmealsonwheels.org.au/Home

Or their Location finder: https://goo.gl/vSAr9P

# Respite and taking a break

Respite care provides a break for a person with dementia and their carer. It enables families and carers to have a rest, go out, attend to business or go on a holiday.

Many people find that a regular break means that they can recharge and avoid burn out. It also gives a person with dementia an opportunity to socialise and meet other people.

Respite care can happen at home or an overnight respite cottage, a day centre or residential care facility. Respite care may be for a few hours or longer, depending on need.



#### **Local services**

Commonwealth Respite and Carelink Centre can arrange for short term and emergency respite.

Call **1800 052 222 or 1800 059 059** for emergency respite support outside business hours.

Omnicare provides day respite programs.

Call 1300 336 488 or visit www.omnicare.org.au

**Omnicare** provides day respite programs in the Mid North Coast.

Call 1300 336 488 or visit www.omnicare.org.au

**Parklands Cottage Kempsey** provides centre-based day respite for residents of the Kempsey Local Government Area.

Call 02 6562 7104 or visit www.parklandscottage.com.au





**Macleay Valley Connections** provides day outings and short holidays and the Oasis day program.

Call 02 6562 2355 or visit www.macleayoptions.org.au

Calvary Star Of The Sea Respite Cottage Forster provides overnight community respite.

Call **02 6554 9480** or visit www.calverycommunitycare.org.au

Marrangbah Cottage Taree provides overnight community respite.

Call **02 6550 0788** 

Waratah Respite Services Coffs Harbour provides an overnight respite program.

Call 02 6648 3610 or visit www.waratahrespite.org.au

**Note:** referral to the above services will require an assessment through **My Aged Care**.

Call 1800 200 422 or visit www.myagedcare.gov.au

Ask for referral to residential care when contacting My Aged Care.

See page 10 for more information about My Aged Care.

#### **Guide: Getting the most out of Respite Care (PDF guide)**

A guide for carers of people with dementia. It helps with decision making and gives you information from a carer perspective.

Search 'getting the most out of respite care book' in Google to download the guide and print or read it online.

#### Permanent residential care

Deciding to find an alternative to caring for a person with dementia at home can be one of the most difficult decisions people with dementia, their families and carers will make.

Being prepared can help make this decision less stressful. Knowing about the services, government policies and costs of residential care beforehand can help you make the best decision.



#### **Local services**

There are a number of residential care providers in the Northern Rivers region.

My Aged Care can help you find local residential care providers.

An Aged Care Assessment Team (ACAT) assessment is required prior to any approval for permanent residential care.

My Aged Care will assist you to organise this assessment and help to look for government-funded aged care homes that meet your needs.

Call 1800 200 422 or visit www.myagedcare.gov.au

If you know what service you want, ask for this service by name when you contact My Aged Care.

See page 10 for more information about My Aged Care.



## **Palliative care**

Palliative care aims to maintain the comfort, choices and quality of life of a person at the end of their life. Care should provide emotional and practical support for people with a terminal illness and their families.



#### **Local services**

- Palliative inpatient care is available at Kempsey, Port Macquarie and Wauchope Hospitals.
- To access palliative assistance at home, see your GP for referral. Support at home includes symptom and pain management, social and bereavement support.



# Carers



Many people living with dementia in the community rely on a carer to support and help them. Family, friends and other support people may feel joy, stress and loss as they assist in managing changes, making decisions and coping with a caring role.



I'm a carer for my mum who has dementia. She likes the mental stimulation from doing puzzles and puzzle books. The puzzle books with the big writing are really helpful.

Judy, cares for her mum

There are a number of organisations who provide advice, support and counselling for carers and support people.



#### **Local services**

Commonwealth Respite and Carelink Centre supports carer relationships by providing access to information about local carer support services.

Call **1800 052 222.** 

Kempsey Carers Group Weekly Activity Centre for Older People and Carers. Includes morning tea, cards craft, music, lunch, bus pickup and delivery for \$3.00 per person per day.

Call **02 6566 5925**.

**Port Macquarie Dementia and Memory Community Centre** provides a monthly Carers support group for a small charge.

Call **02 6584 7444**.

**Note:** a referral is required from **My Aged Care** for some of the services at the Dementia and Memory Community Centre.

Call 1800 200 422 or visit www.myagedcare.gov.au

When known, ask for referral to these services by name.

See page 10 for more information about My Aged Care.





#### **Carer Gateway**

Call **1800 422 737** 8am to 6pm Monday to Friday

Carer Gateway is a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services.

Visit www.carergateway.gov.au

#### **NSW Companion Card**

The Companion Card is issued to people who have a significant, lifelong need for a high level of care to participate in community-based activities. The Companion Card allows a person's carer free entry into participating venues and events.

Visit www.nswcompanioncard.org.au for more information and an application form.

**Dementia Australia** has developed a **Support For Carers** practical guide.

There is also a dedicated section on their website for carers, family members and friends. Visit <a href="https://goo.gl/nmHK20">https://goo.gl/nmHK20</a>

They also have a number of wallet cards that can help when you are out in the community. Call **1800 100 500** to ask for some of these free wallet cards to be sent to you.

#### Dementia in My Family

A website to support children, family members and carers of people with dementia. Visit www.dementiainmyfamily.org.au



# Planning for the future



Planning ahead can help ensure that personal decisions are clear and controlled in the future.

Talking with family and carers will also help them to know your wishes. There are people and organisations who can help with money, legal and medical arrangements.



# **Legal matters**

Planning ahead can make it easier for families and carers to manage the affairs of a person with dementia. It may also mean that the person with dementia can participate in the planning and make sure that their wishes are carried out in the way that they would like.

Wherever possible, get advice while the person with dementia can still participate in the discussion and is legally competent to sign any documents.

Some things to think about:

#### Enduring Power of Attorney

An enduring power of attorney is a legal arrangement that enables a nominated person to look after the financial affairs of another person should they become unable to do so.

## Enduring Guardianship and Administration

An Enduring Guardian is someone appointed to make lifestyle, health and medical decisions for a person if they are not capable of doing so. An Enduring Guardian may make decisions about living, support at home and medical treatment.

#### Advance Care Directive

This is a written document expressing the wishes of the person with dementia about medical treatment.

#### Finances

You may need to plan ahead to protect your money and set up your finances so they can continue to be managed responsibly if you can no longer do this yourself.



#### **Local services**

**NSW Trustee and Guardian** provides information and support including will preparation, power of attorney, enduring guardianship, and storage of wills. They can meet at Port Macquarie, Macksville and Kempsey.

Call 1300 360 466 or visit goo.gl/8MyotT

You can discuss wills, powers of attorney and enduring guardianship.

Mid North Coast Community Legal Centre - Port Macquarie provides legal information, referral, advice, education and advocacy and representation for vulnerable clients.

Call 02 6580 2111 or visit http://mncclc.org.au/

**LawAccess NSW** provides Legal Aid in NSW which can include information, face-to-face advice, and court assistance.

Call 1300 888 529 or visit www.legalaid.nsw.gov.au

The Australian Government **Moneysmart** website has a useful helpsheet: Memory loss, dementia and your money

Search 'Memory loss, dementia and your money' in Google.

#### Start2talk Dementia Australia

Helps you plan ahead in six simple steps with worksheets and resources.

Visit www.start2talk.org.au



#### **Dying to Talk**

Dying to Talk encourages Australians of all ages and levels of health to talk about dying. They have a discussion starter toolkit which supports you to plan ahead, prepare and discuss your wishes for the future.

Visit www.dyingtotalk.org.au

#### **Advance Care Directive**

A NSW Government package with:

- An Advance Care Directive form to complete.
- An Information Booklet to help you complete your Advance Care Directive.

Visit https://goo.gl/mjxxuU or search 'making an advance care directive' in Google.

# **Phone book**

Aboriginal Medical Service, Durri	_02 6560 2300	
Aboriginal Medical Service, Werin	02 6589 4000	
Active and Healthy	1300 655 957	
Australian Unity Home Care Service	1300 295 837	
Booroongen Djugun Limited	_02 6560 2100	
Calvary Star Of The Sea Respite Cottage	_02 6554 9480	
Carer Gateway	1800 422 737	
Carers NSW	1800 242 636	
Commonwealth Respite and		
Carelink Centre1800 052 222 or 1800 059 0	59 (after hours)	
Dementia Australia Advisory Service	_02 6584 7444	
Dementia Outreach Service	_02 6620 6283	
Dementia Support Australia	_1800 699 799	
Healthdirect	1800 022 222	
Kempsey Carers Group	_02 6566 5925	
LawAccess NSW	1300 888 529	
Lifeline	13 11 14	
Marrangbah Cottage	_02 6550 0788	
Meals on Wheels Kempsey	02 6562 1544	
Meals on Wheels Port Macquarie	02 6584 1463	
Meals on Wheels Wauchope	_02 6585 2386	
Meals on Wheels Omnicare, Port Macquarie	02 6584 1115	
Meals on Wheels Raleigh	_02 6692 4470	
Macleay Valley Connections	_02 6562 2355	
Mid North Coast Community Legal	02 6580 2111	
My Aged Care	_1800 200 422	

National Dementia Helpline	1800 100 500
National Disability Insurance Scheme (NDIS)	1800 800 110
NSW Trustee and Guardian	1300 360 466
Occupational Therapy Australia	02 9648 3225
Omnicare	1300 336 488
Parklands Cottage, Kempsey	02 6562 7104
Safely Home	1800 100 500
Translating and Interpreting Services (TIS)	131 450
Transport Hastings Macleay	02 6583 8644
Waratah Respite Services Coffs	02 6648 3610
Younger Onset Dementia Key Worker Program	1800 100 500

Notes		




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While the Australian Government helped fund this document, it has not reviewed the content and is not responsible for any injury, loss or damage however arising from the use of or reliance on the information provided herein.