



# Tweed Dementia Support Kit



Tweed Valley

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# Important contacts

## Mind

### ■ Dementia Outreach Service (DOS)

A local team of health workers specialising in dementia.

 **02 6620 6283**

### ■ National Dementia Helpline

Free dementia advice, support and counselling.

[www.fightdementia.org.au/helpline](http://www.fightdementia.org.au/helpline)

 **1800 100 500**

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](http://www.dbmas.org.au)

 **1800 699 799**

24-hour helpline

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## 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](http://www.healthdirect.gov.au)

 **1800 022 222**

24-hour helpline

### ■ National Health Services Directory

Online listing of local health services. [www.nhsd.com.au](http://www.nhsd.com.au)

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## Services and support

### ■ My Aged Care

The first point of access for most Aged Care Services in your area. [www.myagedcare.gov.au](http://www.myagedcare.gov.au)



**1800 200 422**

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](http://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](http://www.carergateway.gov.au)



**1800 422 737**

8am to 6pm Monday to Friday

### ■ Carers NSW

■ Carer information, support and counselling. [www.carersnsw.org.au](http://www.carersnsw.org.au)



**1800 242 636**

9am to 5pm Monday to Friday

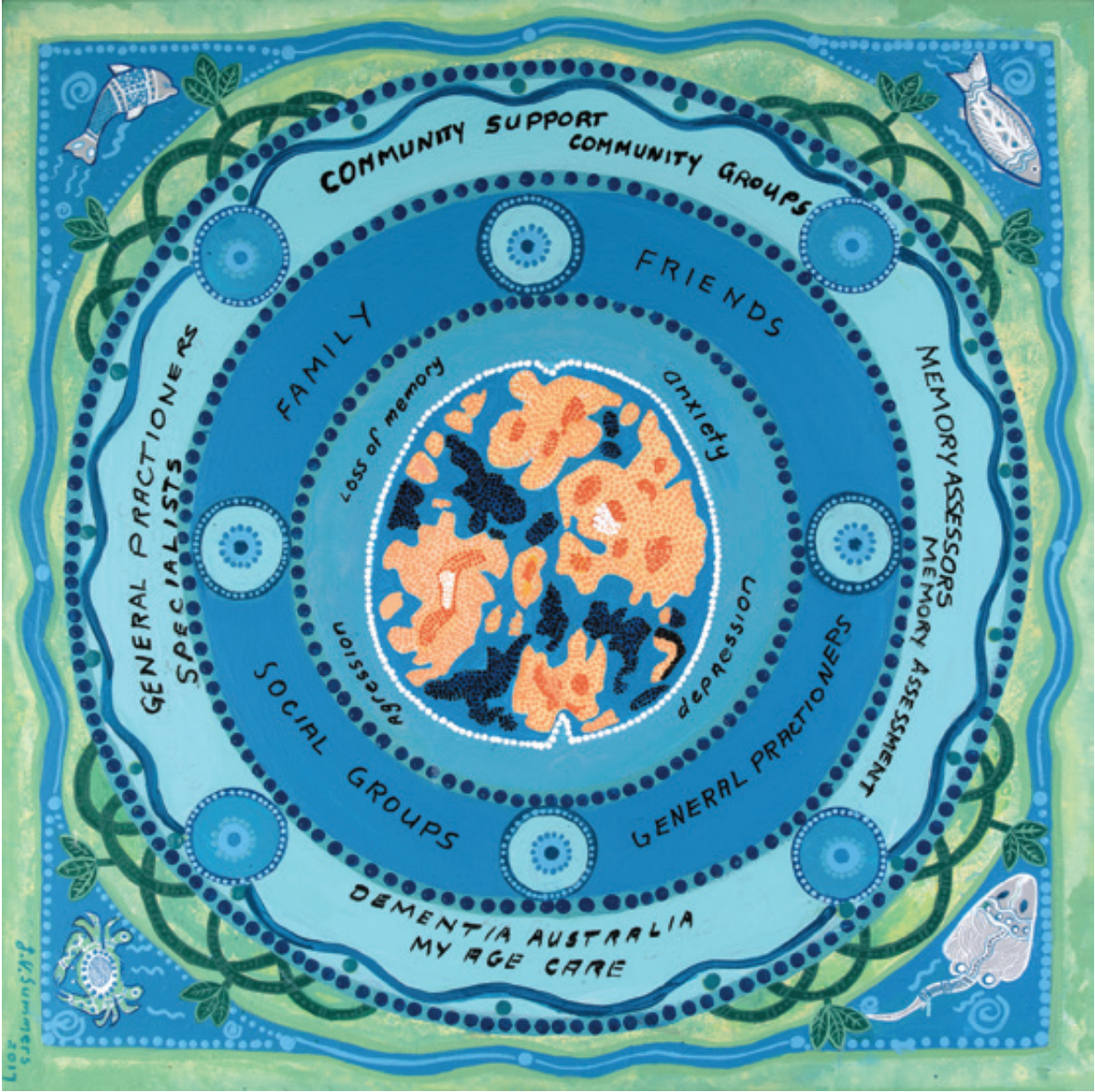
### ■ Lifeline

24-hour mental health crisis support. [www.lifeline.org.au](http://www.lifeline.org.au)



**13 11 14**





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## **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.*

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# Introduction

This Tweed Dementia Support Kit has been developed for:

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

This Kit was designed in partnership with the Tweed community to give information about local services and support in the Tweed Valley. 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](http://www.ncphn.org.au)

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.**

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“

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 Tweed 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](http://www.ncphn.org.au)

This Kit was published in August 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 Tweed Valley 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](http://www.myagedcare.gov.au)

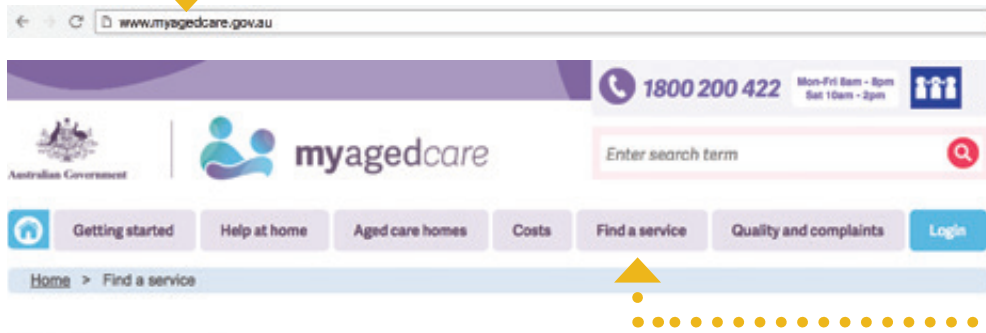
Call **1800 200 422**

### 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

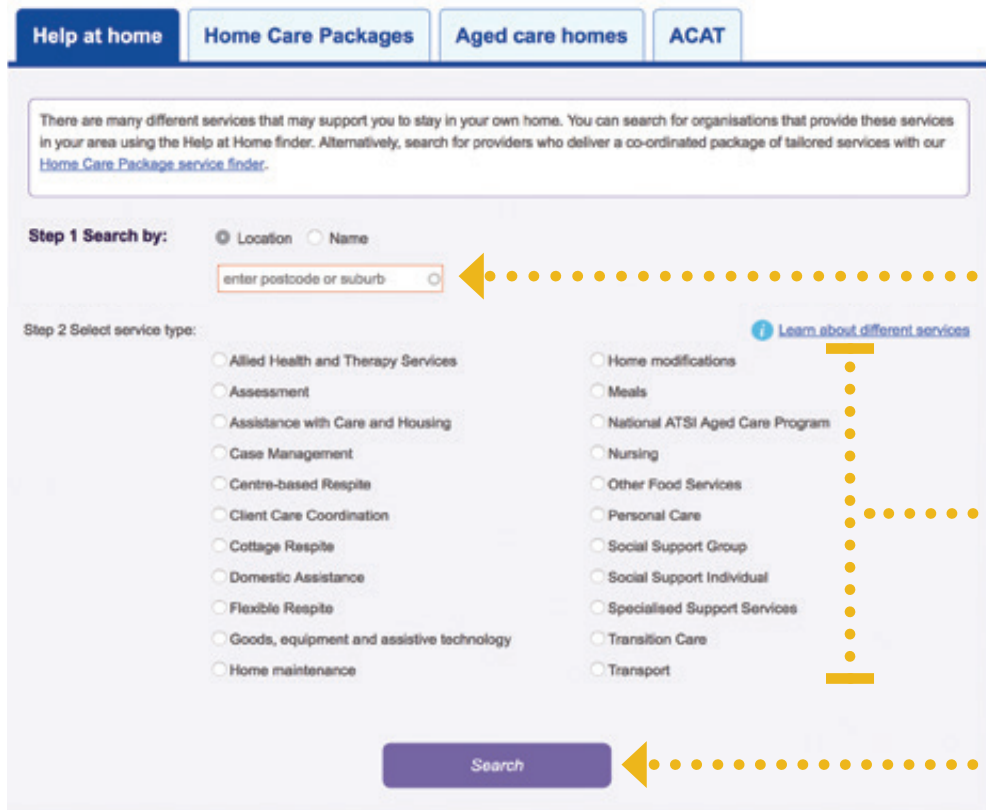
# Finding a service on the My Aged Care website

1. Go to [www.myagedcare.gov.au](http://www.myagedcare.gov.au)



2. Find a service

## Find a service



3. Start to type your town and select it from the drop-down menu

4. Select the service that best meets your needs

5. Search

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## How to be referred to services

Call My Aged Care  
1800 200 422

**OR**

Go online to  
[www.myagedcare.gov.au/referral](http://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

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## 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](http://relayservice.gov.au)

**Step 2** Ask for My Aged Care on **1800 200 422**

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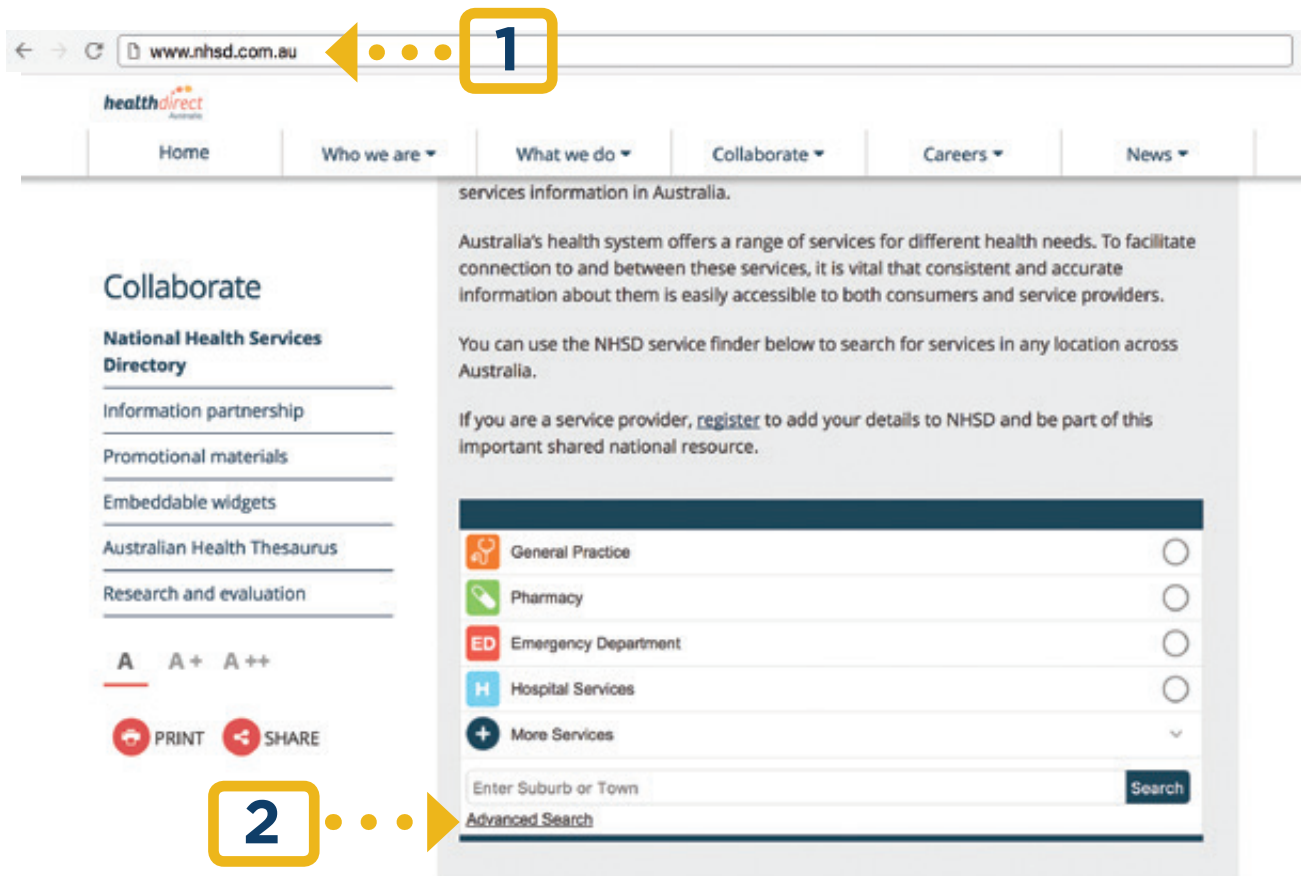
# National Health Services Directory

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

To find services for people with dementia in the Tweed Valley:

**1** Visit [www.nhsd.com.au](http://www.nhsd.com.au)

**2** Click on Advanced Search at the bottom of the page:



3 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.

The screenshot displays the National Health Services Directory interface. At the top right, the logo for National Health Services Directory is visible. On the left, a dark blue sidebar contains three sections: 'Find...', 'Filter', and 'Location'. The 'Find...' section includes a '+ More Services' button and a list of service categories with checkboxes, such as 'Aboriginal Health Clinic', 'Chiropractic', 'Dietetics', 'Exercise Physiology', 'General Practice', 'Hospital Services', 'Occupational Therapy', 'Pharmacy', 'Psychology', 'Audiology', 'Diabetes Educator', 'Emergency Department', 'General Dental', 'Generalist Counselling', 'Maternal, Child and Family Health', 'Optometry', and 'Physiotherapy'. Below this list is a section titled 'Can't find what you're looking for?' with a search input field containing the text 'Search eg diabetes, surgery, carer or Westmead Hospital'. A yellow box with the number '3' highlights the search input field. The 'Filter' section is titled 'Service Options' and is divided into 'Preferences' and 'Facilities'. 'Preferences' includes options like 'My Health Record Ready', 'No Appointment Required', and 'Telehealth Capable'. 'Facilities' includes 'Accessible Parking', 'Free Parking', 'Accessible Toilet', and 'Wheelchair Access'. The 'Location' section at the bottom features a 'Suburb or postcode' input field with a yellow box and the number '4' highlighting it, and a 'Search' button to its right.





# 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.





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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 <https://goo.gl/KZ5Eui>. You can also search 'dementia, Australia, help sheets' in Google.



## Local services

### Tweed Heads “Dementia Friendly Community” Project

Tweed Heads is aiming to be a dementia-friendly community where people living with dementia are supported to safely and easily access local facilities such as shops, clubs and groups.

This project has a committee made up of people with dementia, their carers and community organisations. This committee is working to increase awareness and support for people with dementia.

Call Dementia Australia on **(07) 5523 0731** for more information about how to be involved.

## 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](http://www.fightdementia.org.au/helpline)



“

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](http://www.dementia.com.au)



### Local service

**Byron Shire Respite Service** has a Challenging Behaviours Program. They provide respite care to people with dementia and challenging behaviours.

Call **02 6685 1619** or visit [www.byronrespite.com.au](http://www.byronrespite.com.au)

**Note:** To access Byron Shire Respite Service, contact **My Aged Care** on **1800 200 422**. Tell them you would like to be referred to the **Byron Shire Respite Service**.



## 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

#### Dementia Outreach Service

This is a team of health workers specialising in dementia. They support people in the early stages of dementia and their carers. The service provides a range of programs and education.

There must be a diagnosis of dementia to access this service.

**Note:** To access the Dementia Outreach Service, contact **My Aged Care** on **1800 200 422**.

**Tell them you would like to be referred to the Dementia Outreach Service.**

If you have any difficulties with referral, please call **02 6620 6283**.

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.

### 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](http://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.



## Local services

**GP** \_\_\_\_\_

Name \_\_\_\_\_

Phone \_\_\_\_\_

Address \_\_\_\_\_

After hours \_\_\_\_\_

## Other health professionals

Name \_\_\_\_\_

Role \_\_\_\_\_

Contact \_\_\_\_\_

Name \_\_\_\_\_

Role \_\_\_\_\_

Contact \_\_\_\_\_

## Healthdirect

Call 1800 022 222 24-hour line

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

Visit [www.healthdirect.gov.au](http://www.healthdirect.gov.au)

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## 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!

*David*

”





## Local services

### Active and Healthy

- You can find local Tweed Valley gentle exercise and balance and strength programs on [www.activeandhealthy.nsw.gov.au](http://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](http://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



## Local services

### CHEGS

Community Health Education Groups (CHEGS) is a not-for-profit organisation offering a variety of workshops and exercise classes in Northern NSW.

Call **0423 956 585** or **0410 496 908**

Visit [www.chegs.org.au](http://www.chegs.org.au)

### Feros Care

Feros Care's Health and Wellness team provides a range of programs, therapies and services to support people to remain active in your own home or in the community. The following services may be offered in the Tweed Valley:

- Physiotherapist, exercise physiologist, occupational therapist and podiatrist assessment and treatment.
- Strong Foundations - a home-based falls prevention and mobility program.
- Forever Young - a group exercise program for people over 65.

For more information and to discuss the suitability of classes call Feros Care on **1300 763 583** or search 'Feros Care, health and wellness' on Google.



## Local services

### Meals on Wheels Tweed

Meals on Wheels Tweed provides Balance Improvement classes every two weeks. They can also help with transport to and from the classes. You must be a Meals on Wheels Tweed client.

Call **02 6674 2205** or visit [www.tweedmeals.org](http://www.tweedmeals.org) for more information.

**Note:** to access Meals on Wheels and some Feros Care programs, you will need to contact My Aged Care.

Call **1800 200 422** or visit [www.myagedcare.gov.au](http://www.myagedcare.gov.au)

**Ask for referral to these services by name.**

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.

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## 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.

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## 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

##### Tweed Heads Community Health

Call **07 5506 7540** for referral to an occupational therapist

##### Occupational Therapy Australia

Call **02 9648 3225** or visit [www.otaus.com.au](http://www.otaus.com.au) to find a private occupational therapist.

#### 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](http://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 a guide to [Staying on the Move with Dementia](#).

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

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## 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 Outreach Service (DOS)**

A local team of health workers specialising in dementia.

Call **02 6620 6283**

**Note:** To access the Dementia Outreach Service contact My Aged Care on **1800 200 422**.

**Tell them you would like to be referred to the Dementia Outreach Service.**

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.

#### **National Disability Insurance Scheme (NDIS)**

The 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**.





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**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 [Younger Onset Dementia](#). 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](http://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.

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## 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 North Coast Aboriginal Branch** provides help at home with cleaning, personal care and other services.

Call **1300 295 837** for further information.

**Canowindra Tweed Byron Aged & Disabled Aboriginal Corporation** provides services including short-term respite (using Cedric House) and Home Care Packages. Call **(07) 5523 0311** or email [ablagedcare@bigpond.com](mailto:ablagedcare@bigpond.com)

**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](http://www.myagedcare.gov.au)

**Ask for referral** to these services by name when contacting My Aged Care.

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.



## Local services

### **Bugalwena General Practice**

Provides comprehensive health care for Aboriginal and Torres Strait Islander people and their families. Services include general practice, psychology, diabetes education, hearing services and access to exercise classes and aqua aerobics.

Call **07 5513 1322** or visit [bugalwena.org.au](http://bugalwena.org.au)

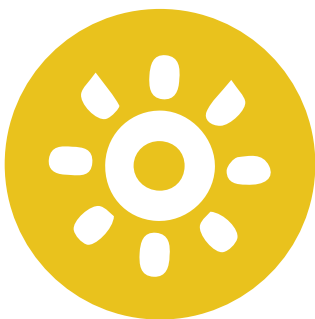
**Dementia Australia** has [helpsheets](#) for Aboriginal and Torres Strait Islander People who have dementia.

Search 'Aboriginal and Torres Strait Islander dementia resources' in Google or call **1800 100 500**.





# 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*



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## 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

**Lifebridge Australia** offers centre based programs, Community Access Groups and social groups. They are based in Kingscliff.

Call **1800 043 186** or visit [www.lifebridge.org.au](http://www.lifebridge.org.au)

### Byron Shire Respite Service

Has a centre based day respite program which operates from Monday to Friday. They are based in Brunswick Heads and receive referrals from the Tweed Valley.

Call **02 6685 1619** or visit [www.byronrespite.com.au](http://www.byronrespite.com.au)

**Dementia Outreach Service** offers 'Café Connections' social groups in the Tweed Valley. These are social groups for people who have been diagnosed with dementia and their support person to enjoy a coffee and conversation.

Call **02 6620 6283**

### Meals on Wheels Tweed

Provides social support for their Meals on Wheels clients including transport to and from social activities.

Call **02 6674 2205** or visit <https://goo.gl/zM4H5U>

Continued on the next page



**Please note** that referral to these services will require an assessment through My Aged Care.

Call **1800 200 422** or visit [www.myagedcare.gov.au](http://www.myagedcare.gov.au)

**Ask for referral** to these services by name when contacting My Aged Care.

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.

### **Tweed Valley social groups**

- **Tweed Shire Council** – produces a number of brochures listing social, arts and exercise activities for seniors in the Tweed region. They also support a Seniors Festival, held once a year.

Call **1300 292 872** or visit <https://goo.gl/p83UaX>

- **RSL Day Clubs** – call your local RSL to find out about their Day Clubs.
- **University of the 3rd Age Tweed Coast**  
Email [tweedcoastu3a@gmail.com](mailto:tweedcoastu3a@gmail.com)

## **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.

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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 Tweed Valley area can also be arranged.

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

Visit [www.carersnsw.org.au](http://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](http://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.

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## 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](http://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.

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](http://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](http://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 Tweed Valley area.

See page 14 for more information on the NHSD.

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## Transport

Community transport provides a range of community transport services and programs to support people who have limited or no access to private transport and difficulty accessing conventional public transport.

Community transport services are affordable, flexible and accessible. They can be used to travel to medical appointments, go shopping, for recreation or social outings, and to attend other essential events.



### Local services

**Tweed Byron and Ballina Community Transport** provides transport services to people who live in the Tweed, Byron, and Ballina shires.

Call **1300 875 895** or visit [community-transport.org.au](http://community-transport.org.au)

**Note:** To access Community Transport contact My Aged Care on **1800 200 422**.

**Tell them you would like to use Tweed Byron Ballina Community Transport and they will send a referral.**

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.



## 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

Meals on Wheels Tweed is based in Kingscliff and provides meals to the Tweed Coast, from Pottsville to the border and inland to Bilambil. They also provide social support and Balance Improvement classes for their clients.

Call **02 6674 2205** or visit [www.tweedmeals.org](http://www.tweedmeals.org)

#### Meals on Wheels Murwillumbah

Meals on Wheels Murwillumbah provides meals to the rest of the Tweed Valley.

Call **02 6672 8866**

**Note:** To register for services from Meals on Wheels contact **My Aged Care on 1800 200 422**.

**Tell them you would like to register for Meals on Wheels.**

Call either of the numbers above for help with the referral process. See page 10 for more information about My Aged Care.

#### Private meal delivery

There are also a number of private companies who provide meal delivery services. These are listed online.

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## 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.

### **Guide: Getting the most out of Respite Care**

A guide for carers of people with dementia. It helps with decision making and gives you information from a carer perspective. Visit <https://goo.gl/uipHUx>

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



## Local services

**Lifebridge Australia** offers day respite. They have centre-based programs, Community Access Groups and social groups. They are based in Kingscliff.

Call **1800 043 186** or visit [www.lifebridge.org.au](http://www.lifebridge.org.au)

**Byron Shire Respite Service** has a centre-based day respite program which operates from Monday to Friday. They are based in Brunswick Heads and receive referrals from the Tweed Valley.

Call **02 6685 1619** or visit [www.byronrespite.com.au](http://www.byronrespite.com.au)

### **Overnight Respite House**

Provides overnight respite for people with dementia in a caring, safe and relaxed environment.

Call **02 6687 3502**

(FSG Australia manages the Respite House)

### **Commonwealth Respite and Carelink Centre (CRCC)**

Call **1800 052 222** 24 hours a day, 7 days a week

CRCC will link you to local respite services including:

- Emergency respite
- Flexible short-term respite
- Planned respite care
- Respite at home or in a residential care facility

Visit [www.crcfcnc.org](http://www.crcfcnc.org)

Continued on the next page



## Local services

**Please 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](http://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.

### **Respite in a residential facility**

Call My Aged Care on **1800 200 422** (or self-refer online) to ask for an ACAT assessment. If approved, clients are eligible for up to 63 days respite care in a residential facility yearly.

See My Aged Care "Find a service" tab to find local residential facilities for respite care.

## 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 Tweed 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](http://www.myagedcare.gov.au)

**If you know what service you want, ask for the 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 The Tweed and Murwillumbah 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*

”

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



## **Local services**

### **Carers NSW**

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

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

Visit [www.carersnsw.org.au](http://www.carersnsw.org.au)

### **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](http://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](http://www.nswcompanioncard.org.au) for more information and an application form.



## Local services

### Dementia Outreach Service (DOS)

Call **02 6620 6283**.

A local team of health workers specialising in dementia. Offers 'Café Connections' social groups and carer education in the Tweed Valley.

**Note:** To access the Dementia Outreach Service contact My Aged Care on **1800 200 422**.

**Tell them you would like to be referred to the Dementia Outreach Service.**

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.

**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 <https://goo.gl/nmHK2o>

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.

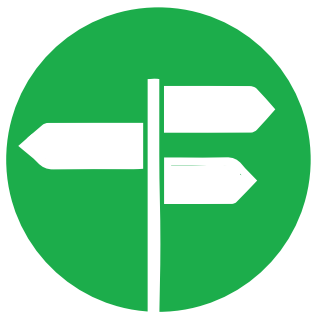
### Dementia in My Family

A website to support children, family members and carers of people with dementia. Visit [www.dementiainmyfamily.org.au](http://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.



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## 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, Lismore

Call **1300 364 103**

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

### Northern Rivers Community Legal Centre

Call **02 6621 1000** or **1800 689 889**.

9am to 4pm Monday - Wednesday, Friday

2pm to 4pm Thursday

Provides education and can advise in relation to Guardianship Applications.

Visit <http://northernriversclc.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](http://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](http://www.start2talk.org.au)





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## 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](http://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.

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## Phone book

Active and Healthy	1300 655 957
Dementia Australia NSW	07 5523 0731
Australian Unity North Coast Aboriginal Branch	1300 295 837
Bugalwena General Practice	07 5513 1322
Byron Shire Respite Service	02 6685 1619
Canowindra Tweed Byron Aged and Disabled Aboriginal Corporation	07 5523 0311
Carer Gateway	1800 422 737
Carers NSW	1800 242 636
Commonwealth Respite and Carelink Centre (CRCC)	1800 052 222
Community Health Education Groups (CHEGS)	0423 956 585 / 0410 496 908
Dementia Behaviour Management Advisory Service (DBMAS)	1800 699 799
Dementia Friendly Community Project	07 5523 0731
Dementia Outreach Service (DOS)	02 6620 6283
Dementia Support Australia	1800 699 799
Feros Care	1300 763 583
Health direct	1800 022 222
Lifebridge Australia	1800 043 186
Lifeline	13 11 14

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Meals on Wheels Murwillumbah	02 6672 8866
Meals on Wheels Tweed	02 6674 2205
My Aged Care	1800 200 422
National Dementia Helpline	1800 100 500
National Disability Insurance Scheme (NDIS)	1800 800 110
Northern Rivers Community Legal Centre	02 6621 1000 / 1800 689 889
NSW Companion Card	1800 893 044
NSW Trustee and Guardian	1300 364 103
Occupational Therapy Australia	02 9648 3225
Roads and Maritime Services (RMS)	13 22 13
Safely Home	1800 100 500
Translating and Interpreting Services	13 14 50
Tweed Byron and Ballina Community Transport	1300 875 895
Tweed Heads Community Health	07 5506 7540
Tweed Shire Council	1300 292 872
Younger Onset Dementia Key Worker	1800 100 500





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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.