

Living with dementia on the North Coast



HEALTHY
NORTH COAST

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NORTH COAST

An Australian Government Initiative

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Learning to live with dementia and steps on the journey

If you have recently been diagnosed with dementia, there is a lot of information and resources out there to help. While everyone's journey will be different, following Steps 1-5 in particular in the first six months after your diagnosis, can help you to plan ahead.

Steps on the journey

Step 1. Who can I talk with?

Step 2. Working with your local health teams

Step 3. Getting around

Step 4. Planning your future

Step 5. Staying healthy and active

Step 6. Staying safe

Step 7. Adapting as your health changes

Acknowledgement of Country

Healthy North Coast acknowledges the Traditional Custodians of the lands across our region and pays respect to the Elders past, present and emerging. We recognise these lands were never ceded and acknowledge the continuation of culture and connection to land, sky and sea. We acknowledge Aboriginal and Torres Strait Islander peoples as Australia's First Peoples and honour the rich diversity of the world's oldest living cultures.

What is dementia - how does it feel?

Dementia is a collection of symptoms affecting the brain. Over time, this can interfere with your normal social or working life and daily routines. Many people become affected by dementia, not just in Australia but around the world. Although you feel like it sometimes, you are not alone.

Learning to live with dementia is a journey. It is important for you and your family to understand dementia and prepare early for the health changes to come.

For many, finding out you or your loved one has dementia can trigger feelings like disbelief, shock, anger or sadness. Some people may feel relief that they now know what is happening to cause the symptoms. This information booklet is your guide to the dementia journey.

It starts with information about dementia and how people diagnosed with dementia and their families might feel. It then takes you to a number of steps along the way, which can be challenging, enjoyable and even exhausting.

To help manage your journey we provide you with local contacts and services to assist you. Remember, life is about the journey, not the destination, and dementia is no different.

There are many ways to live positively with dementia.

Find out more about dementia

Help sheets from Dementia Australia provide information on dementia, how it feels and ways to help.

About dementia:

www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-AboutDementia01-WhatIsDementia_english.pdf

About your feelings and adjusting to change:

www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-InformationForPeopleWithDementia06-FeelingsAndAdjustingToChange_english.pdf

Or take a look at the dementia guide:

www.dementia.org.au/resources/the-dementia-guide

Most Dementia Australia internet pages have drop-down boxes to translate the information into another language.

If you don't have access to the internet, phone the National Dementia Helpline and ask for copies of the help sheets and the Dementia Guide to be mailed to you.

Ph: 1800 100 500



Step 1. Who can I talk with?

There are a range of services you can talk with by phone or face-to-face.

Who can I talk with by phone?

Dementia Australia

Dementia Australia is a national organisation that can provide you with support, counselling, education, links to services, advocacy and information. Their post-diagnosis support service can help you understand the condition and plan for the future.

The Dementia Hotline operates anytime of the day or night, even on public holidays.

Ph: 1800 100 500

www.dementia.org.au

If you require the assistance of an interpreter, please call the **Translating and Interpreting Service**:

Ph: 131 450

If you are deaf or have a hearing or speech impairment, please call the **National Relay Service** and request a copy of the Dementia Guide. This guide is a comprehensive booklet to help you and your family understand your diagnosis better and plan for the future.

Ph: 133 677

Provides 24-hour health advice.

Healthdirect

Ph: 1800 022 222

www.healthdirect.gov.au

For families and carers

Carer Gateway (for family carers)

If you care for a family member or friend, then Carer Gateway could help you. Support for carers includes - planning, counselling, peer support, tailored support packages and respite services, emergency respite.

Ph: 1800 422 737

www.carergateway.gov.au

Carers NSW

Also provides carer information and support.

Ph: 02 9280 4744

www.carersnsw.org.au

Who can I talk with face-to-face?

Mid North Coast

Dementia support specialists can provide support for you and help you link into other services, such as family carer support groups and café connect. They also help with education, counselling and individual support.

Dementia Australia local offices:

Coffs Harbour

Ph: 02 6278 8902

(Tuesdays, Wednesdays and Thursdays)

Port Macquarie

Ph: 02 6584 7444

(Your call may be diverted to a Dementia Australia phone operator so ask for the Port Macquarie office)

Northern Rivers

Dementia Outreach Service (DOS):

This service consists of specialist health workers who can advocate for you through the diagnosis of dementia and provide education, online groups, support groups, referrals and linkages to other services.

Clarence Valley, Richmond Valley, Tweed Valley

Ph: 02 6620 6274

These services are not means-tested and many aspects of them are free.

To access these services, you will need a referral through My Aged Care. Dementia Australia/ DOS staff will talk to you about the services they offer and help with the My Aged Care referral. See Step 4 for more help with My Aged Care.

www.myagedcare.gov.au

My Aged Care Ph: 1800 200 422

Where can I go online?

Forward with dementia

Forward with dementia is a government-funded website that can guide you for the first year after diagnosis.

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

www.forwardwithdementia.au

The University of Tasmania runs online education sessions for people in the early stages of dementia, their families and anyone interested in learning more about dementia.

www.utas.edu.au/wicking/understanding-dementia

"What a difference in knowing there was support out there!"

Carer, Northern Rivers



Step 2. Working with your local health team

Your GP and other local health teams can help you along your journey with dementia.

General practice

Having a regular GP can help you manage dementia.

Below is a list of common questions you might like to ask your GP or practice nurse. This does not have to be done all in one appointment. In fact, it will be better to ask for three or four long consults and ask a few of your most pressing questions at each appointment.

If you can, take a family member with you and write down the answers to these questions.

What does this diagnosis mean?

Are there any treatments/medications available?

Can I take over-the-counter medications as well?

How should we plan for the future? For example, with an advance care directive, an enduring power of attorney, enduring guardianships, wills? Where will I live?

Can I still drive?

How might dementia affect my work life now and in the future?

What are the risks for people living with dementia?

What support is available?

How can I keep as healthy as possible - mentally, physically and socially?

What is a Chronic Disease Management Plan? Do I need one?

Should I have a pharmacist home medication review?

Should I get a referral to a specialist?

What supports are there for families?

When is my next appointment?

Other local health services

Other local services may be able to help. Talk to your GP to get the right referrals for you.

Geriatricians

A geriatrician can help with diagnosis, specialist medications, capacity testing for signing legal documents and local service knowledge. Currently geriatricians are based in Coffs Harbour, Port Macquarie, Lismore, Tweed Heads and the Gold Coast. There is also a geriatric telehealth option through Geriatric Care Australia.

Psychogeriatric service

This is a specialist community service that provides assessment, interim care coordination, education and support for older people who are having issues with maintaining mental health. This can include anxiety, depression, paranoia, hoarding or hallucinations. This NSW Health service is available in Port Macquarie and Coffs Harbour, and through a telehealth clinic in Pottsville.

Neurologists

These specialists can help with diagnosing conditions with the brain, spinal cord and nerves.

Allied health professionals

Occupational therapists, physiotherapists, dietitians, speech pathologists, audiologists, exercise physiologists, psychologists and counsellors can help make life at home easier and suggest ways to improve your fitness and healthy living.

Complementary therapies

Complementary therapies such as music therapy, art and gardening, can help improve quality of life and enjoyment.

Palliative care practitioners

Palliative care specialists and teams provide care to people as they approach end-of-life, particularly if they have complex needs, such as pain or nausea. Palliative care teams also provide support and advice to clinicians such as GPs.

On your journey

Before moving on to *Step 3 Getting around*, take a break and have a rest stop!



Step 3. Getting around

Driving for many older people is important to their way of life and represents independence. Over time, however, having dementia will affect your ability to drive. The changes will make it difficult to judge distances and the speed you are travelling, putting you and the people around you at risk of injury.

Steps to take

If diagnosed with dementia, you must notify Transport for NSW:

medicalunit@transport.nsw.gov.au

[Visit a Services NSW centre](#)

Ph: 13 22 13

Medical assessment

You will be asked to provide a medical assessment for Fitness to Drive from your doctor or health specialist. This may include a referral to a specialist occupational therapist driving assessor. Your doctor will help you find the closest one.

Other transport options

There are other ways to get around and stay active in the community.

Taxi subsidy scheme

Through Services NSW, eligible people can obtain discounts on taxi fares.

Ph: 13 77 88 (Monday to Friday 7am - 7pm)

www.service.nsw.gov.au/transaction/apply-taxi-transport-subsidy-scheme

Community transport schemes and other community services

These can be found through My Aged Care and can provide transport to appointments, shopping and social activities.

Home Care Packages

If you have a Home Care Package, ask your service provider about transport for shopping, appointments or leisure.

Family and friends may be able to help with transport

Give family and friends the opportunity to provide you with practical help and chat to them about if and when they are available to help you get around.



Step 4. Planning your future

Another important activity after you receive your diagnosis is to plan for your future with your family.

Planning ahead

Planning for your future means you need to put in place all your legal protections, register with My Aged Care or the NDIS if under 65 years old, and have discussions with your GP and family about what you want at the end of your life. This may feel too soon for some people. You may be able to put in place some of the suggestions outlined below, but not all which is fine. Do what you can - it is important for you to voice what you want and to plan for the future.

Legal protections

Support with wills

Everyone should have a will. Having a will is the only way you can ensure that when you die, your estate will be distributed according to your wishes. Speak to a local solicitor or contact Services NSW.

www.service.nsw.gov.au/transaction/get-started-making-will

Enduring power of attorney

An enduring power of attorney gives someone you trust legal powers to look after your finances if you can no longer do so. It is important for your power of attorney to:

- understand your accounts and be signed up as a co-signatory on your accounts
- understand any pensions and be signed up with Services Australia as a co-signatory
- to be legally able to support you to manage all your financial matters.

Enduring guardianship

This allows someone you trust to make decisions about health and lifestyle for you if you can no longer make these decisions. Talk to a solicitor or speak to Services NSW.

Advance care directive

This written plan sets out the types of treatment and medical care you would want in the future. Talk to your doctor about having one prepared. These web resources can help you plan for the future.

www.health.nsw.gov.au/patients/acp/Publications/acd-info-form-book.pdf

www.dementia.org.au/information/about-dementia/planning-ahead-start2talk

The National Trustee and Guardian (NTAG)

NTAG has local offices and pop-up clinics to complete enduring powers of attorney and enduring guardianship free of charge for pensioners.

www.tag.nsw.gov.au

Support to live

For people over 65 years or 50 years if you are Aboriginal

My Aged Care

Register with My Aged Care as soon as possible to be assessed for services that can assist you. My Aged Care offers advice and resources about local aged care services that can support you to live well in your home and in the community. It is important to register early as some services can take up to six months or more to access.

You can call the contact centre for free on Monday to Friday, from 8am to 8pm, and on Saturdays from 10am to 2pm. The centre is closed on Sundays and national public holidays. Tell them you would like referrals to the local Dementia Australia service or Dementia Outreach Service and they will arrange an assessment to link you to these and other services.

Ph: 1800 200 422

www.myagedcare.gov.au

Services Australia

Aged Care Specialist Officers are located in Services Australia offices in Port Macquarie, Nambucca, Coffs Harbour, Grafton, Lismore and Tweed Heads. They can help you with the My Aged Care process and financial planning for aged care services. Office hours are Monday to Friday 8am to 5pm to book a face-to-face or virtual appointment.

My Aged Care will arrange a visit to you by either your local Aged Care Assessment Team (ACAT) or Regional Assessment Service (RAS) to understand your plans and needs and progress your request to receive services. It can take some weeks for this to happen, so starting this part of the journey as soon as possible after diagnosis.

Ph: 1800 227 475

www.servicesaustralia.gov.au/aged-care-specialist-officer-my-aged-care-face-to-face-services?context=55715

“Planning ahead was so important as it made life easier knowing what my husband wanted.”

Carer, Northern Rivers

For people under 65 years

While the majority of people who are living with dementia are over 65, people under 65 can also be affected. Help is available through Dementia Australia, the Dementia Alliances in Port Macquarie and Ballina, and the Northern Rivers Dementia Outreach Service. Their contact details are in this booklet. Help is also available through the NDIS.

The National Disability Insurance Scheme (NDIS)

The NDIS can provide all people with disability with information and connections to services in their communities, as well as information about what support is provided by each state and territory government.

Ph: 1800 800 110

enquiries@ndis.gov.au

www.ndis.gov.au

For war veterans

Department of Veteran's Affairs (DVA)

If you are a veteran, DVA may be able to assist with in-home support, nursing services and respite care.

You can call DVA between 8:00am and 5:00pm, Monday to Friday.

Ph: 1800 VETERAN (1800 838 372)

www.dva.gov.au/health-and-treatment/care-home-or-aged-care

End-of-life planning

When you are ready, it is important to talk to your family and GP about your end-of-life choices. Making your wishes known will allow your family to support your choices when you are not able to communicate what you want.

These discussions can include what kind of care and treatment you would like at the end of life, as well as where you would like to die. If you are unsure how to have these discussions, the *What Matters to Me: Conversation Guide* and the *Palliative Care Australia discussion starter series* may be helpful.

www.health.gov.au/resources/publications/what-matters-to-me-conversation-guide?language=en

www.palliativecare.org.au/campaign/discussion-starters/

The teams who can guide you with this decision includes your GP or practice nurse and your

aged care or local palliative care service. Your team will discuss with you about the choice of dying at home, in a palliative care unit or in a residential aged care facility.

Local palliative care services

These services work in the community and are based out of the local hospitals or community health centres.

Port Macquarie

Ph: 02 6589 2100

Wauchope

Ph: 02 6580 8060

Kempsey

Ph: 02 6561 2790

Macksville

Ph: 02 6598 3500

Bellingen

Ph: 02 6659 5842

Coffs Harbour

Ph: 02 6656 7646

Grafton

Ph: 02 6641 8200

Lismore

Ph: 02 6620 2967

Murwillumbah

Ph: 02 6670 9400

Tweed Heads

Ph: 07 5506 7540

Hastings / Macleay Nightingale Program

Based in the Dementia Australia office in Port Macquarie, this model of palliative care provides a specialist nursing service free of charge to support people living with advanced dementia. They can provide strategies and advice for the person and their families focussing on promoting choice, well-being and forward planning.

To find out more or to access this service call the National Dementia helpline

Ph: 1800 100 500

Private services

These private services offer accommodation and care at the end of life.

Wedgetail Retreat, Dulguigan

Ph: 02 6672 8459

Honey Bee Homes, Coorabell

Ph: 02 8088 0773

Aged care homes

If you are considering a residential aged care home, My Aged Care provides a list of homes in your local area. It is also helpful to talk to an accountant or the Services Australia Aged Care Specialist Officers about financial considerations when moving into an aged care home. Phone Monday to Friday 8am to 5pm to book a face-to-face or virtual appointment.

Ph: 1800 227 475

www.myagedcare.gov.au/find-a-provider

Financial support

Financial supports can be found through Services Australia. This might include a carers payment instead of an aged care pension for families providing care. The carers allowance provides a weekly or fortnightly payment to carers. Contact Services Australia to find out if you are eligible and what supports can assist you. They are open Monday to Friday 8am to 5pm.

Ph: 132 717

www.servicesaustralia.gov.au/ageing



Step 5. Staying healthy and active

An important way to look after your health throughout your journey (whether you are living with dementia or are a family member) is to stay socially active. One way is to be with other people living the journey as well. There are many local groups available.

Join an alliance group

Dementia Friendly Community Alliance (Port Macquarie)

The Dementia Friendly Community (DFC) Alliance is made up of people living with dementia and family carers, along with enthusiastic volunteers and members of the community. Representatives from businesses, social groups, churches, local and state government, service organisations and aged care services, have all come together to help provide solutions to the challenges of living with dementia.

Dementia-friendly communities focus on improving the community inclusion and quality of life for people living with dementia.

 www.dementiafriendlypmq.com.au

Dementia Inclusive Ballina Alliance

The Dementia Inclusive Ballina Alliance is a not-for-profit community organisation working with the community to take action to improve the lives of people living with dementia and their carers.

The Alliance facilitates an activity program each Wednesday from 10am to 12pm at The Ballina Aeroclub for people living with dementia and their advocates. The cost is \$5 for members and \$7.50 for non-members.

They also facilitate a 'Dementia Café' on the second Monday of the month at Café Sebastian, Ballina Fair between 10am and 12pm.

 www.dib.org.au

dementiainclusiveballina@gmail.com

Or is a social group more for you?

Social groups encourage people living with dementia to be physically and socially active, and support other healthy activities like diet, nutrition and mind-stimulation games.

We hear some people say they are not ready to join a group yet, however, these services will help you receive support, information and early advice to assist you with your journey of living with dementia. They also help families have some time for themselves.

A referral through My Aged Care or the NDIS is required for these services.

Port Macquarie

Omnicare hosts social support groups at four day centres:

Port Macquarie (Morton Centre)
Port Macquarie (Greenmeadows)
Kempsey (Parklands Cottage) and
Wauchope (Bain Park)

Ph: 1300 336 488

www.omnicare.org.au

Coffs Harbour

Waratah Respite Services provides social support groups and centre-based respite care at Woolgoolga and Coffs Harbour.

Ph: (02) 6648 3610

www.waratahrespite.org

Grafton

Liveable provides a Sunshine Club that allows you to connect with your community. Transport to and from the venue from your home may be able to be included.

Ph: 1800 289 927

www.livable.org.au/service/social-clubs-support

Lismore

St Carthages, Senior Day Club offers a wide variety of activities.

Ph: 1300 761 833 or 6620 0000

Ballina

CPL provides centre-based respite care and social support groups.

Ph: 1800 275 753

www.cpl.org.au/services/seniors/getting-out-community

Byron

Byron Shire Respite Service hosts Carers Coffee Club on the fourth Wednesday of the month at Brunswick Heads.

The service specialises in dementia care and provides centre-based respite, social support groups and individual flexible respite.

Face-to-face counselling support for family carers is also available.

Ph: 02 6685 1629

www.byronrespite.com.au

Tweed

Lifefridge offers social groups where people are supported to engage in social and lifestyle activities.

Ph: 1800 043 186

www.lifebridge.org.au

For families and carers

Coffee and Chat Group is a monthly social group for carers and past carers.

Contact Kath Storey on

Ph: 0408 670 630 or 02 65826008 for information on the following:

- Port Macquarie carers coffee morning - fourth Thursday of the month and other services
- Port Macquarie carers dinner group - second Tuesday evening every two months
- Laurieton carers coffee morning - fourth Friday of the month
- Laurieton carers lunch group - second Friday every two months.

The cost is covered by participants.

Other ways to stay healthy

Ensure you eat a well-balanced diet

www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-CaringForSomeone13-Nutrition_english.pdf

If you need help, talk to your doctor about a referral to a dietitian.

Stay physically active

Do something you enjoy, like taking a walk in the bush or on the beach, joining a gym or getting involved with local sporting groups. Playing bowls, table tennis and tennis or joining a walking group are all good ways to stay active. You can also speak to your doctor about referrals to an exercise physiologist or physiotherapist. The active and healthy website provides a list of local exercise programs for older people.

www.activeandhealthy.nsw.gov.au

Routine health checks

It is important to maintain routine checks with your GP and dentist, have your eyesight and hearing checked, and don't forget those important vaccinations! When life gets busy, we tend to forget these, but as we age, these checks become more important to keep us in the best possible health.

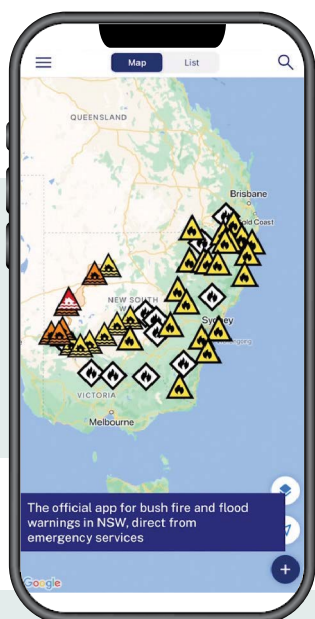
On your journey

Before moving on, take a rest stop and ask yourself how you and the family are going? It's important to keep checking in with each other.

Preparing for Natural Disasters

We live in areas that are prone to natural disasters so it's important to plan ahead and be ready. Download these apps to receive warnings in your local area. This Guide from DCRC and QUT can also help you prepare.

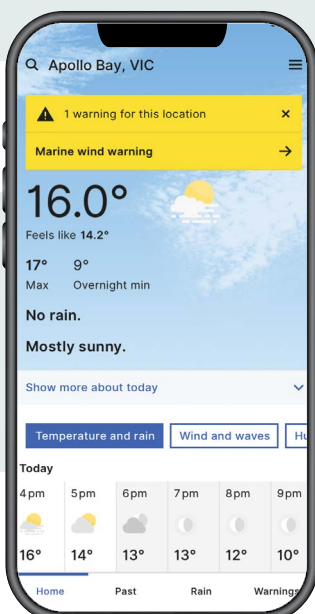
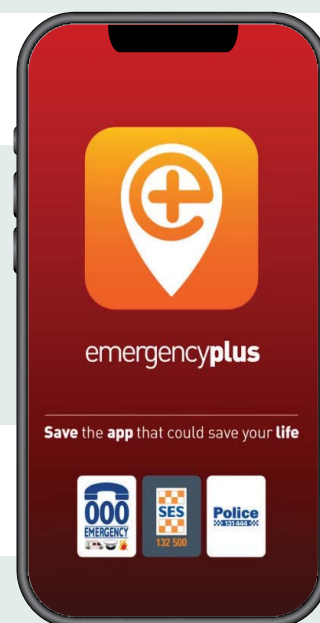
www.dementiaresearch.org.au/resources/carer-ready-guide/



Hazards Near Me NSW



Emergency Plus



The BOM Weather app





Step 6. Staying safe

Dementia can affect your walking and balance. If you notice this, it is important to see your GP and get a referral to your local physiotherapist.

Walking

If you notice changes in your mobility and balance, it is important to see your GP and get a referral to your local physiotherapist. They can assess you for a walking aid and provide you with some strengthening exercises to help improve balance. Many local physiotherapists and the local health district run groups to prevent falls.

To find a local program go to:

www.activeandhealthy.nsw.gov.au/find-a-program

How to get up safely if you have a fall:

www.stayonyourfeet.com.au/over60/what-if-i-do-fall/get-up-off-the-floor

Feeling safe at home

There are many tricks to being safe at home, and these apply to all older people, particularly people living with dementia. Below is a list of resources and local services to help you stay safe at home.

Adapting your home

Dementia Australia's help sheet outlines a number of ways to make living at home easier for someone with dementia.

www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-Environment01_AdaptingYourHome_english.pdf

Safety issues - caring for someone in the home

www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-CaringForSomeone03-SafetyIssues_english.pdf

Dementia Outreach Service (DOS)

Have good understanding of needs in the home and simple modifications to promote independence.

Technology

Equipment and technology will assist you in being safe. Good examples are clever watches that talk to you if you fall or get lost, and equipment in the home to make living easier.

www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-Environment02_SupportiveAids_english.pdf



Step 7. Adapting as your health changes

As your health changes your family will notice that there are things you do well and other things you need help with. Stay focused on what you can do and let family and services support you to live each day to its fullest.

Stay focused on what you do well

As your health changes, you and those around you may notice changes in what you do well and how you manage your day-to-day needs. Having the help of family and friends where you need it can lessen stress and feelings of being overwhelmed. It's important to focus on what you can do and develop your network of helpers so you remain as active as possible.

Your GP or the nurse looking after you will run regular short memory tests with you. The results will show what you can do well and your health professional will discuss these with you and your family.

Your support team may include:

- your family and friends
- your GP and or nurse
- your specialist doctor/s.

Unfinished planning?

If you haven't taken Step 4 in your journey yet about your choices in end-of-life care, now is definitely the time. The teams who can guide you with this decision include your GP or practice nurse, and your aged care or local palliative care service.

Your team will discuss with you your options of either dying at home, in a palliative care unit or in a residential aged care facility.

"I used to think I could do everything myself, but accepting some help and support was the best thing I ever did!"

Mid North Coast resident living with dementia

Dementia Support Australia (DSA)

DSA provides help anytime of the day or night, even on public holidays for carers of people living with dementia, where personalities and behaviour are changing.

Some of the changes may be difficult to understand. This service can help with working out why and offering ways to help.

Ph: 1800 699 799

dsa@dementia.com.au

www.dementia.com.au

Dementia Australia provides a help sheet on understanding changes to behaviour.

www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-ChangedBehaviours02-ProblemSolving_english.pdf

Acknowledgement

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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. Links are correct at time of publishing.

Resources:

There are many more resources, tip sheets and information available on dementia. We recommend Dementia Australia as a reference point to continue your journey:

www.dementia.org.au/resources/help-sheets#caring-for-someone-with-dementia

On your journey

We hope these steps have helped you and your family adjust to life with dementia. Now it's time to keep living and enjoying life.

This image shows a single sheet of white paper with horizontal blue lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



Healthy North Coast is an independent, not-for-profit organisation proudly delivering the PHN program in North Coast NSW. We are committed to improving the health of our communities through quality primary health care.

The PHN program is an Australian Government Initiative.

hnc.org.au

enquiries@hnc.org.au

ABN: 18 154 252 132