

Living Well with Dementia MY JOURNAL





Country to Coast QLD is an independent, not-for-profit organization committed to building healthy, connected and resilient communities across the Central Queensland, Wide Bay and Sunshine Coast regions. We deliver the Australian Government's PHN Program and partner with health providers and the community to design and commission quality primary care services.

This journal belongs to

Name: Phone:

My Next of Kin is:

Name: Phone:

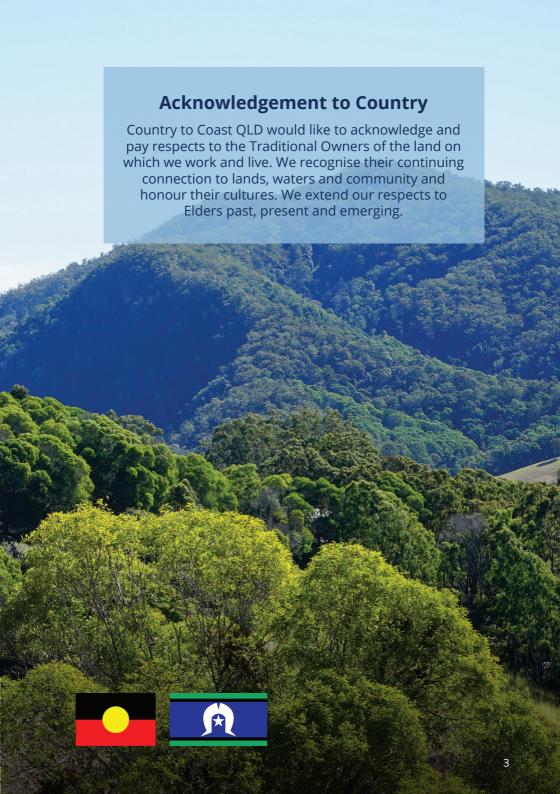
My "Go to person" is:

Name: Phone:









Use this journal to:



Keep track of appointments



Record questions you have for your health practitioner to help you get the most out of your appointment



Find carer resources and guidance



Complete monthly check ins



Record best contacts



Understand your dementia journey



Help locate Healthy Ageing resources



Find where to go for documenting Advance Care Planning and future self support



View websites with useful resources and information (Click icons- for online viewers only





The dementia journey

Use this as a guide to support your dementia journey



First changes noticed

Changes will occur over time and are not one off occurrences. These may include: memory problems, difficulty finding words, changes in personality and changes in day-today behaviours etc



Visit your GP

Visit your local doctor to determine the cause and significance of these symptoms



Medical tests

You may need medical tests. Check with your doctor



Referral to specialist

You may need to be referred to specialists



Contact Dementia Australia

Call the National Dementia Helpline (1800 100 500) for free telephone service providing information and advice



Contact My Aged Care

Call My Aged Care (1800 200 422) and organise an assessment to access funding and support



Initial management

Initial management of your symptoms



Access dementia supports services and networks

Your local doctor will support you to access dementia support services and networks as part of ongoing care management



Regular check-ups with your doctor

You may need regular check ups with your doctor and specialists as changes occur





Your health contacts

Name	C	Number
Local GP		
After hours GP		
Alter Hours de		
Pharmacist		
Nurse		
Specialist (e.g. geriatrician)		
Ambulance, fire, Police	00	00





Dementia resource list

Name Name	Number Number
Dementia Australia National Helpline	1800 100 500
Ozcare Dementia Advisory and Support Service	1800 692 273
Alzheimer's QLD 24/7 dementia helpline	1800 639 331
Carer Gateway	1800 422 737
My Aged Care	1800 200 422
Alzheimer's QLD carer support groups	3422 3000
Aged and Disability Advocacy Australia	1800 818 338
Carers QLD	07 3900 8100
Elder Abuse Prevention Unit	07 3867 2525 or 1300 651 192
Advanced Care Planning Advisory Service	1300 208 582
National Palliative Care Service Directory	07 3842 3242



Your national and local contacts

Add your necessary contacts here

Name	Number
Translating and Interpreting	131 450
National Relay Service	133 677
Health Direct	1800 022 222
Care Finders	1800 422 737
After hours GP helpline (speak to a doctor for free)	1800 022 222
Lifeline	13 11 14
Ambulance, fire, Police	000





Who can I talk to?

Always chat to your GP first for any medical concerns or queries. Ask them for any additional support services faceto-face in your region. Dementia Australia is another contact that can point you in the right direction.

Dementia Australia

A national organisation that can provide you with support, counseling, 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

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





Who can I talk to?

Health Direct

Provides 24-hour health advice

Ph: 1800 022 222

www.healthdirect.gov.au

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, counseling, peer support, tailored support packages and respite services, emergency respite.

Can help you to meet people who also care for a family member or friend. By sharing stories, knowledge and experience, you can learn from and support each other.

Carer Gateway offers two options to connect with other carers:

- <u>In-person peer support groups</u> meet with others in your local area who also care for a family member or friend
- Online community forum join the online written discussions to engage with other people who also care for a family member or friend.

www.carergateway.gov.au/about/peer-support-groups

Ph: 1800 422 737

www.carergateway.gov.au





Who can I talk to?

Translation and Interpreting Service

If you require the assistance of an interpreter, please call the

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

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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





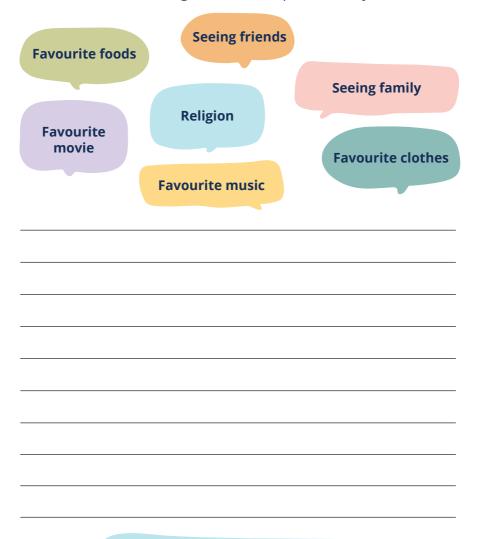
Add your additional contacts here:				





What is important to me

Make note of the things that are important to you.





Visit <u>Advance Care Planning Australia's website</u> and search for 'Queensland: Create your plan





Health and wellness appointments

Please make notes of your appointments such as doctors, podiatrist, massage, beautician, yoga, etc

Date	Time	Type of appointment	Clinic name



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Suggested health checks for living well

To keep you living well here are some suggested health checks







Suggested health checks for living well			

Health professionals, please record any other suggested health preventative checks on this list.





What to ask your health professional at your first appointment

Here are some suggestions. You don't need to ask all the questions. (Cross out the ones you don't want). You can also add your own questions

What should I do to stay independent?

Can you recommend any dementia support service for me and my partner/ supporter?

Is there a support group I can join?

I'm having trouble with... (add your own challenges e.g. forgetting appointments, getting lost, using my phone).

What can I do about these?

What should I do about my finances and legal matters?

How certain are you about my diagnosis?

How and what should I tell my family?

Can you write me a dementia care plan? (e.g., a Chronic Disease Management Plan)

Will I need to stop driving? If yes, how will I manage getting around?

Are there medications or exercises?





What I'm going to ask my health professional at my first appointment

Write questions here.		





Your first month checklist

Activities	Completed
Book into Dementia Australia's Post- Diagnostic support program through the National helpline phone number listed in the journal	
What type of dementia you have	
What drug and non-drug treatments are available	
What health professionals might be involved in your care	
Book a session with Dementia Australia through the national helpline listed in the journal	
Write a list of services and supports that could help improve your quality of life. Think about things that could help you live well at home, keep healthy and active and remain engaged in activities and hobbies	
Register with My Aged Care or the NDIS to learn about services and support that are available	
Tell your licensing authority and your car insurer about your diagnosis	

Use myhealth app for medications

Refer to myhealth app for medications.

Your pharmacist and GP are your best contact if you are unsure about your medications. Go to your contact list at the front of the journal.



The new myhealth app is a safe and easy way to access My Health Record on your mobile. Download it today. View and share important health information on the go. Search for 'my health gov' in your app store or scan the QR code.







Pin your prescriptions, referrals, pathology forms and lists to this page.





Monthly Journal Let's check in. It's time to journal Not Good Okay Good Great Amazing

Keep a note of your current symptoms, jot down unusual symptoms, what was something great today, thoughts and feelings, stories and any carers notes.



Remember your check in doesn't have to be about your health. It can be stories you have remembered, an interesting event you read or a social appointment you had.





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Suggestion for the month - make sure you are getting outside and enjoying the fresh air. Maybe try getting into the garden or going for a walk outside.







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How are vo	ou going this month?		11
	nd any overa halp at	n h	

How are you going this month? Do you need any extra help at home? Turn to page 7 for a list of support services.







Suggestion for the month - Have you joined a social group? Ask your GP or care for more information.



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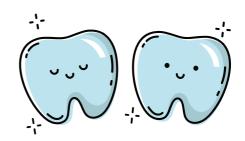
Suggestion for the month - Are you keeping up with your hobbies? Are there any new hobbies you would like to take up?







Suggestion for the month -Dental checks should be at least 2-3 times a year. Have you booked a dental check up yet?







Your 6 month checklist

Activities	Completed
Connect with local Dementia supports and services outlined in this journal (see pages 8-11)	
Assess your home environment. Make modifications to help you adapt to changes to your memory and thinking and keep you safe	
Assess your wellbeing. Keep your heart, mind and body active to look after yourself. Introduce exercise and healthy eating into your daily routine	
Organise regular check-ups with your doctor, dentist, optician and podiatrist. Consider having someone accompany you to appointments to take notes and ask questions or ask the practitioner to give you some written advice	
Make plans for your future. Consider any legal and financial matters, advance care directives and medical and healthcare wishes (pg. 39)	
Start to plan for when you may no longer be able to live at home. Research your options and eligibility for residential care	

		-

Suggestion for the month - Visit a café-style support program in your area. Ask your GP or call Dementia Australia (pg. 7) to help find a program near you.







Suggestion for the month - Establish a system for medication reminders.







Suggestion for the month - It is important to have a healthy diet for body and mind. Consider an appointment with a local dietitian for support.





Suggestion for the month - Keep your mind active to maintain health and wellbeing. You can exercise the mind by doing things you find challenging or trying new activities.







Suggestion for the month	
Suggestion for the month -	_ (
Did you know meditation and	
yoga reduces anxiety and depression. Are there any	
depression. Are there any	
classes near you?	





Suggestion for the month -Traveling with dementia comes with its challenges. To have the best possible experience, it's good to plan as much as you can in advance. Getting assistance from a travel agent can help reduce stress.







Monthly Check in

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Suggestion for the month -Keeping your activities low-key will help you to relax. If you usually go to church around this time but are unable to, consider online or televised services.



12 month review

Suggestion for the month - Are you connecting with culture and community? Visit or call your Local Aboriginal Medical Health Service (pg. 42-43).







Planning for your future

Advance Care Planning is for you and your family.

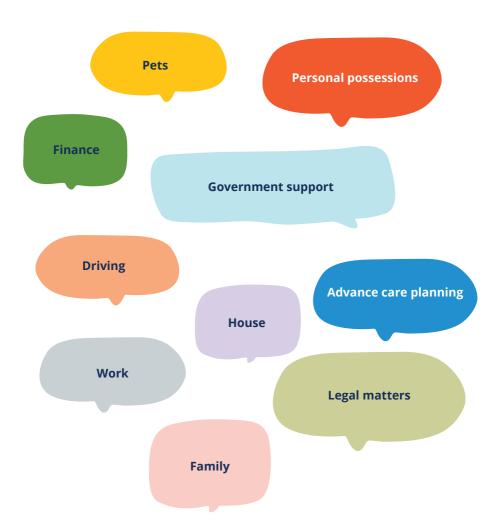
t is discussing your future and what matters most to you. t is important to make your plans and wishes known now. You can do this by having a conversation with those close to you and writing down your preferences.
Contact the Statewide Office of Advance Care Planning Call: 1300 007 227 or Email: acp@health.qld.gov.au





Let's talk...

It may be time to chat to your family and GP about your plans and wishes with...







Are you a carer?

Carer wellbeing matters too. Review this sheet to ensure you are looking after yourself as well.

Find your local dementia support group

Call the National Dementia Helpline in free call 1800 100 500 or use the <u>online service enquiry/referral request form</u>

Tailored support packages

These are designed to provide you with services and support specific to your needs to help you in your caring role. Call Carer gateway on 1800 422 737.

Self care

Self care is important for your mental health and wellbeing. There is support: Call Carer Gateway 1800 422 737.

You can even get financial help

You may be able to get payments from the Australian Government and receive cards and concessions that make many things cheaper for you and the person your care for.

Dementia Australia education programs

Join an education program specifically designed for families and cares to learn more and upskill.

Respite programs

Carers allow people living with dementia to remain home as long as possible however sometimes we need respite. To learn more: Call 1800 699 799.





Support for Aboriginal and/or Torres Strait Islander people living with Dementia

If you or your family are showing any early signs of dementia, make an appointment with your local health professional or your closest Aboriginal Community Controlled Health Organisation (ACCHO). Below is a list of ACCHOs / Aboriginal Medical Services within our CCQ region:



Central Queensland

Bidgerdii Community Health Service

Rockhampton Clinic

88 High Street, Berserker, QLD 4701

Ph: 1800 227 700

Blackwater Clinic

2 Seeman St, Blackwater, QLD 4717 Ph: 1800 219 000

Nhulundu Health Service

Gladstone Clinic

27-29 Goondoon St, Gladstone, QLD 4680

Ph: 07 4979 0992

Mount Morgan Clinic

63 Morgan St, Mount Morgan, QLD 4714

Ph: 1800 224 700

Yoonthalla Wellbeing Services

112 Munns Drive, Woorabinda, QLD 4713

Ph: 07 4935 0560





Support for Aboriginal and/or Torres Strait Islander people living with Dementia



IWC Ltd

Bundaberg Clinic184 Barolin St,
24 Fielding St,

Bundaberg, QLD 4670 Gayndah, QLD 4625 Ph: 1300 492 492 Ph: 07 4161 4800

Galangoor Duwalami Primary Healthcare

Hervey Bay ClinicMaryborough Clinic7-11 Central Ave,Shop 1, 87-89 Bazaar St,Pialba, QLD 4655Maryborough, QLD 4650

Ph: 07 4194 5554 Ph: 07 4184 9966



North Coast Aboriginal Corporation for Community Health

Gympie Clinic Head Office

31 Excelsior Rd, 8/8 Innovation Parkway, Gympie, QLD 4570 Birtinya, QLD 4575

Ph: 07 5329 5872 Ph: 07 5346 9800





Interpreter support and resources for those who have English as a second language

Dementia Australia has developed multiple resources translated into 38 languages. If you need an interpreter you can contact the Translating and Interpreting Service on 131 450.



Click on the icon to find information in your language of choice or search 'information in other languages' on the <u>Dementia Australia website</u>





About this journal

Country to Coast, QLD has created this Living Well Journal - Dementia edition to support those people diagnosed with dementia and their carers to live well.

The Dementia Journal is customisable to cater to the unique needs of each individual facilitating communication, connection, with a supportive community, and progressive tracking towards personal goals. It encourages mental, physical and social wellbeing and empowers those with dementia to live well. It encourages mental, physical and social wellbeing and empowers those with dementia live well

If you have any feedback on your experience using this journal, or have suggestions for improvement, please send an email to:

Older Persons Health - olderpersonshealth@c2coast.org.au





Thank you to the people living with dementia, their families and service providers who guided the development of this journal. Funding was provided by The Australian Department of Health and Ageing.

Country to Coast is an independent, not-for-profit organisation proudly delivering the Primary Health Network (PHN) program on behalf of the Australian Government, Commonwealth Department of Health. Our support covers the Sunshine Coast, Central Queensland and Wide Bay regions of Queensland.

While the Australian Government helped fund this document, it has not reviewed the content and is not liable for any incident or consequential damages resulting from use of or reliance of the material.

Links are correct at time of publishing. There are many more resources, tip sheets and information available on dementia. We recommend Dementia Australia as your first reference point to continue your journey.

Dementia Australia Ph: 1800 100 500 www.dementia.org.au









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