

Dementia Support Organisations and Services

Dementia Australia

www.dementia.org.au

Wide range of resources, courses, counselling and support, including post diagnostic support to assist with accessing NDIS funding.

- Helpline: 1800 100 500 | Monday to Friday, 8:00am - 8:00pm (except public holidays)

Specific links:

- Younger Onset Dementia Hub: yod.dementia.org.au/
- Family engagement counselling for YOD: www.dementia.org.au/get-support/family-engagement-counselling-younger-onset-dementia
- Counselling support: www.dementia.org.au/get-support/counselling
- Post-diagnostic Support: www.dementia.org.au/get-support/post-diagnostic-support
- Dementia Guide: www.dementia.org.au/get-support/dementia-guide
- Free access to digital books and resources: www.dementia.org.au/get-support/dementia-australia-library
- Peer support program: www.dementia.org.au/get-support/connecting-peers/get-peer-support

Alzheimer's WA

www.alzheimerswa.org.au/

Provide services, support, advocacy, resources education and training for people living with Dementia and their families

- Phone: 1300 66 77 88

Dementia Support Australia

www.dementia.com.au

Support for navigating changes in behaviour related to dementia

- Helpline: 1800 699 799 | (24 hours a day, 7 days a week)

It takes a Village program

An online series designed to empower and upskill carers to support a person living with dementia to remain at home for as long as possible. With a strong focus on wellbeing and self-care, carers will be equipped to navigate some of the complexities and challenges of supporting a person living with dementia.

www.dementia.com.au/it-takes-a-village-online-series-august-2025

McCusker Nurse

www.amanaliving.com.au/other-care-services/dementia-care/mccusker-nurse

Free service provided by experienced registered nurses, specialising in dementia, who can provide home visits and offer advice, support and reassurance; accurate information on resources available to you; and guide you to the dementia services most likely to help you.

- Email: mccuskernurse@amanaliving.com.au
- Phone: (08) 9424 6396

Forward with Dementia Website

www.forwardwithdementia.org

A resource following a diagnosis of Dementia for up-to-date information from clinicians and researchers, practical suggestions and stories from people with dementia and carers, and tools for people manage living with dementia.

Young Dementia Peer Support Group

Established in 2017, the Network has been shaped by a core group of carers to facilitate sharing of information, resources, lived experiences, support and practical help, social connection, and meet ups through events and other activities.

- Private Facebook page - to request to join, click on the link and answer the questions
www.facebook.com/groups/130789124306677/
- www.dementia.org.au/get-involved/dementia-friendly-communities/dementia-friendly-community-groups/young-dementia
- Contact: Vicki Barry | Phone: 0409 045 373 | Email: vicki.barry21@inet.net.au

YOD Special Interest Group

www.australiandementianetwork.org.au/special-interest-groups/yod-sig/

Australian Young Onset Dementia Special Interest Group (YOD-SIG) is a national network committed to research, policy, and clinical care to improve outcomes for people with young onset dementia and their families. YOD-SIG host webinars on topics to support people living with YOD and service providers.

- Webinars: www.australiandementianetwork.org.au/webinars/

YODWA Impact Network

ypinh.org.au/yodwa-joinus/

Working on a range of initiatives to encourage cross sector collaboration, service development, learning and information exchange. We have a growing membership of organisations and individuals committed to working together on system reform. Membership is free and open to WA based people with a living experience of YOD, stakeholders across disability, aged, health and community care.

My Dementia Companion

www.mydementiacompanion.com.au/

Online dementia service and information navigation tool. Carer version can be accessed through Carer Gateway.

Young People in Nursing Homes Alliance - Advocacy

ypinh.org.au/our-work/current-work/joint-solutions-leaders-summits/

Provide support and advocacy to people living with YOD in relation to NDIS funding

- Email: info@ypinh.org.au

Rare Dementia Support and Information

Rare Dementia Support Unit

www.raredementiasupport.org/

Rare Dementia Support Unit, University College London offers specialist social, emotional and practical support services for individuals living with, or affected by, a rare dementia diagnosis. Based in the UK there is access to information and support groups online.

Frontier

www.frontierftd.org

The FRONTIER Research Group is the largest specialist fronto-temporal dementia (FTD) clinic in Australia. It is based in Sydney and has online resources available.

Australian Frontotemporal Dementia Association (AFTDA)

aftda.org.au/

The AFTDA is a registered non-profit carer support organisation with a mission to:

- Establish and support Australian carer support groups for frontotemporal dementia (FTD) and related younger-onset dementias.
- Provide information, education, and support to those diagnosed with FTD and related disorders, their carers and families.

- Educate and work with clinicians to reduce diagnostic delays and improve outcomes of individuals with FTD.
- Advocate with government, peak dementia bodies and organisations for affordable quality care services for people with FTD, and support research and treatments in FTD.
- Increase public awareness about FTD and the needs of those with lived experience of FTD.

Frontotemporal Toolkit

ecdc.org.au/ftd-toolkit

Providing essential resources for awareness, diagnosis, and management of Frontotemporal Dementia.

Frontotemporal Peer Support Group - Dementia Support Australia

www.dementia.com.au/carer-conversations

The online groups are facilitated by health professionals with expertise in FTD and consultants from Dementia Support Australia who provide specific tailored advice on behaviour support for the changes that may be occurring as a result of this diagnosis. Run once a month, Carer Conversations are a safe space for you to share and learn.

Diagnostic Services

Neurosciences Unit - North Metropolitan Health Services

www.nmhs.health.wa.gov.au/Hospitals-and-Services/Mental-Health/Specialties/Neuro

The Neurosciences Assessment and Care Clinic (NACC) is an assessment and clinical management program for patients with a diagnosed or strongly suspected young-onset neurodegenerative condition (age of onset below age 65). Referrals into this clinic are for Neurology review. If considered relevant to the clinical management, patients may subsequently also be eligible to access input from Psychiatry, Social Work, Speech Pathology, and Clinical Neuropsychology.

- Phone: (08) 6159 6464
- Fax: (08) 9385 6813
- Email: Graylands.Neurosciences@health.wa.gov.au
- Location: Neurosciences Unit, Cnr Mooro Drive & John XXIII Avenue, Mount Claremont WA 6010

Private Neurology Services

Discuss with GP options for a Private Dementia Nurse with experience in Younger Onset Dementia.

Nursing Services

Neurological Council of WA - Neurocare Nurse

www.ncwa.com.au/help-for-you/ndis

Community neurological nurses providing high quality, patient-centred neurological nursing and health care navigation services to people of all ages living with any neurological condition or symptoms.

- Phone: 1800 645 771
- Email: hello@ncwa.com.au

Private Dementia Specialist Nurses

Discuss with GP options for a Private Neurologists with experience in Younger Onset Dementia.

Support for Carers

Carers WA

www.carerswa.asn.au/

Community neurological nurses providing high quality, patient-centred neurological nursing and health care navigation services to people of all ages living with any neurological condition or symptoms.

- Carers WA General Line: 1300 227 377
- Carer Gateway Services: 1800 422 737

YOD Bright Respite Program

brightwatergroup.com/home-care/brightrespite

BrightRespite is a 3-day, 2-night respite retreat set in the comfort of a hotel or resort. It is designed to refresh and empower carers while providing quality care and enriching activities for your loved one. BrightRespite is more than just a break – it's an opportunity for carers to gain vital skills, connect with others who share similar experiences, and rediscover balance in their caregiving journey.

Fully funded government program.

Continence Services

Therapy Focus – Community Aged Care Continence Services

www.therapyfocus.org.au/our-services/specialist-services/continence-toilet-training/

Bladder and Bowel Health Program focuses on prevention and management of bladder and bowel health issues, with qualified health professionals providing advice, assessment and continence management strategies.

- Phone: 1300 135 373

Information for Children and Young People about Dementia

Dementia in my Family website

dementiainmyfamily.org.au/

Online and interactive resources for children of all ages about Dementia and suggestions for relevant books.

Brightwater Resource for children and adolescents of people living with YOD

brightwatergroup.com/research/current-completed-research/keeping-us-in-mind

Y-Care

ycareofdementia.com.au/

Community for young carers of people living with dementia. Based in Sydney with online resources available.

Lorenzo's House

lorenzoshouse.org/

Non-profit social impact organization designed to empower the sons, daughters, children and families, affected by younger-onset dementia. Based in the United States with online resources and peer support groups.

Dementia Enabling Environments

Dementia Enabling Environments Project

www.enablingenvironments.com.au

Virtual Information Centre provides practical tips, guides and resources.

Adapting Your Home Free guide and checklist

www.enablingenvironments.com.au/downloads.html

DEEP (Alzheimer's WA)

My home, my life book

www.hammond.com.au/shop/dementia-and-aged-care/my-home-my-life

Practical ideas for people with dementia and carers. Colm Cunningham, Natalie Duggan & Agnes Houston.
Available through Hammond Care for \$19.99.

Dementia and Sensory Changes

Talking Sense book

[www.dementiacentre.com/resources/resource-category-2/74-talking-sense?filter\[tag\]\[\]=dementia-and-aged-care](http://www.dementiacentre.com/resources/resource-category-2/74-talking-sense?filter[tag][]=dementia-and-aged-care)

Living with sensory changes and dementia. Agnes Houston & Julie Christie. Free download or hard copy available.

Understanding Sensory Changes in Dementia video

m.youtube.com/watch?v=KHUiijkp-kj0

Falls Prevention

Stay on Your Feet

www.injurymatters.org.au/programs/stay-on-your-feet/

Falls prevention resources.

- Phone: 08 6166 7688

Community Safety

Safe & Found WA

www.safeandfound.org.au

An initiative introduced by Western Australia Police Force (WA Police Force) and Australia Medic Alert Foundation that supports people living with dementia or a cognitive impairment who might be at risk of becoming lost or reported as missing, by ensuring Police have immediate access to critical information to assist when undertaking search operations.

Assistive Technology - Indigo

www.indigosolutions.org.au

Specific advice for up-to-date technology (mobile personal pendant, GPS tracking devices etc) can be accessed through Indigo in Perth who offer a free 30-minute phone consultation.

- Email: help@indigosolutions.org.au
- Phone: 9381 0600
- Address: The Niche, Suite A, 11 Aberdare Road, Nedlands, WA, 6009 (Entrance on Hospital Ave.)

Dementia Activity Resources

Activities for Care

activitiesforcare.com.au/

Dementia Shop Australia

dementiashop.com.au/product/montessori-methods-for-dementia/

Dementia Education

Wicking Centre, University of Tasmania

mooc.utas.edu.au/

- Free online courses
 - Understanding Dementia Course
 - Preventing Dementia Course
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Dementia Training Australia

dta.com.au/

Dementia courses and resources

Dementia Australia

Dementia Australia Courses and Groups for people living with Dementia, families and carers

- www.eventbrite.com.au/o/dementia-australia-6584917001
 - www.dementia.org.au/professionals/professional-development-and-training/courses
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International Resources

Young Dementia Network UK

youngdementianetwork.org/

The Young Dementia Network is an online influencing community working collaboratively to improve lives. Launched in 2016 and driven by first-hand expertise and experience, the Network is now hosted by Dementia UK. Online resources and research available.

Media and Podcasts

Hold the Moment podcast

www.dementia.org.au/hold-the-moment

Good lived experience and carer content.

Talking Dementia with Heckle and Jeckle podcast

podbay.fm/p/talking-dementia-with-heckle-and-jeckle

Two women living with YOD – good content about the lived experience of Lewy Body and Semantic Variant Dementia.

Dementia in Practice

<https://podcasts.apple.com/au/podcast/dementia-in-practice/id1579299656>

Dementia Training Australia podcast hosted by GPs with good general content for GPs, Allied Health Professionals and people with living experience of YOD.

Brightwater YOD Services

brightwatergroup.com/disability/our-expertise/younger-onset-dementia

Brightwater addresses the unique needs of younger people with dementia through support and services including a multidisciplinary YOD Allied Health Team, Positive Behaviour Support, Support Coordination and Supported Independent Living Homes.

- Phone: 1300 223 968
- Email: welcome@brightwatergroup.com

Updates and suggestions to this list are welcome. Please send suggestions to:

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