



Understanding dementia

Your guide to understanding dementia and the range of services and support available.

krg.nsw.gov.au/dementia

Who is this information for?

This information is designed for people who have been given a diagnosis of dementia, and for their friends and families. It is designed to be a helpful starting point for you to get to know a little bit more about the condition and to help you access support, specifically in the Ku-ring-gai Council area. The information is correct at the time of printing.



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Dementia overview

What is dementia?

- Dementia describes a collection of symptoms caused by disorders affecting the brain.
- Dementia is not a normal part of getting older, and it isn't one specific disease. Instead, it's a broad term that covers the effects on people of a number of different medical conditions.
- Those conditions include Alzheimer's disease, vascular dementia, the Lewy body dementias and more.
- The effects of dementia vary from person to person, but generally, dementia affects your mood, memory, thinking and behaviour.
- Dementia can happen to anybody, but it is much more common after the age of 65.
- In Australia, more than 421,000 people live with dementia.
- There are things you can do to reduce your risk of developing dementia.
- There's currently no known cure for dementia, but there are treatments for many of the symptoms. Some people with dementia lead active and fulfilling lives for many years after their diagnosis.
- Researchers around the world are working on new treatments for dementia.

Younger onset dementia

Younger onset dementia is similar to other types of dementia. The symptoms of dementia and similar difficulties generally occur no matter what age the person is diagnosed. However, the condition can have a different impact on a younger person because they are more likely to be employed full time, raising a family or financially responsible for a family.

Some causes of early onset dementia are:

- Alzheimer's disease (the most common cause of dementia in younger people)
- Problems with blood flow to the brain (called vascular dementia)
- Deterioration to the front part of the brain (called frontotemporal dementia)
- Illnesses such as Lewy body, Parkinson's or Huntington's disease, Multiple Sclerosis or HIV infection
- Chronic overuse of alcohol over many years

More information on above conditions visit [healthdirect.gov.au](https://www.healthdirect.gov.au)





What is Chronic Traumatic Encephalopathy (CTE)?

CTE is a progressive terminal brain disease associated with repeated traumatic brain injuries (TBIs), including concussions and repeated blows to the head, causing the development of dementia symptoms.

The treatment of CTE is focused on symptom management and strategies to improve the person's quality of life. Some common treatment approaches include:

- Medications may be used to manage specific symptoms such as depression, anxiety, or sleep disturbances.
- Physical therapy can help manage motor problems such as difficulty with movement, coordination, or balance.
- Occupational therapy can help individuals with CTE manage daily activities and maintain their independence.
- Cognitive rehabilitation can help manage problems with memory, attention, and problem-solving.

It is important to note that while these treatments can help manage symptoms, they do not cure the condition or stop its progression.

Further information on CTE and resources visit:

- brainfoundation.org.au
- dementia.com.au



Key supports

Dementia Australia

- **Dementia Australia** is the national peak body supporting people living with dementia, their families and carers. Dementia Australia provides trusted information, education, support services, and also advocates to government and in the community for positive change.
- **National Dementia Helpline** provides 24 hour support, counselling and information on 1300 100 500. For help in languages other than English call 131 450.
- **Living with dementia program** is for people in the early stages of dementia, their family, carers and loved ones. It is about coping with change, relationships and communication, planning for the future and staying healthy.
- **The Dementia Guide** is the go-to resource for people living with dementia, their carers and families.

Website: dementia.org.au **Call:** 1800 100 500

Dementia Support Australia

- **Dementia Support Australia** delivers support that is tailored to your needs. The trained dementia consultants work with you to help determine the most appropriate support service.
- **Dementia Behaviour Management Advisory** service offers clinical support to carers of people living with dementia, where behavioural and psychological symptoms are impacting their care. Care can be provided at home or in a care home.

Website: dementia.com.au **Call:** 1800 699 799

My Aged Care

- **My Aged Care** is your starting point to access government-funded aged care services for those over 65 years old. Whatever your situation, they can help get the support needed.
- You can receive government-funded help at home through the **Commonwealth Home Support Programme**, or a **Home Care Package**.

Website: myagedcare.gov.au **Call:** 1800 200 422

What home support services can I access?

If eligible to receive home support, there are different services that can help those who need to live independently at home.

These can include services to:

- connect with their community, like transport to appointments or activities, in-home social calls, and group activities
- help those eligible keep well and independent, like food provision or help with food preparation
- keep those eligible safe at home, like cleaning, home maintenance, and mobility aids
- help with showering or dressing
- help maintain mobility
- help manage medications
- help to care for a family member at home and respite care

You will need to apply for an assessment through **My Aged Care** to find out which of these services they're eligible to receive.

Website: myagedcare.gov.au/assessment **Call:** 1800 200 422

You can ask someone to speak on your behalf. This can be a family member, friend, a person you trust or an organisation.

Staff in all **Services Australia** service centres can also help with general information about My Aged Care services. They can also help you use the My Aged Care website and upload documents, as well as connect you with specialised assistance.

An Aged Care Specialist Officer can help you in more detail with aged care matters.

Call: 1800 227 475



Care Finder

Care Finder is a free, face to face service that supports vulnerable older people to navigate the aged care system and find support services to improve their quality of life. Care finders can help with both accessing services for the first time and changing or finding new services and supports.

Website: yourside.org.au **Call:** 8405 4484

National Disability Insurance Scheme (NDIS)

The NDIS can provide you with support and home services if the person diagnosed with dementia is under 65 years old.

The NDIS provides funding to eligible people with disability, including those with a diagnosis of dementia, achieve greater independence and an improved quality of life.

Website: ndis.gov.au **Call:** 1800 800 110



Caring for someone with dementia

Carer Gateway

Carer Gateway is the national service for unpaid carers, funded by the Australian Government to provide reliable services, support and advice for all carers. There are specific and tailored supports available to young carers under the age of 25. Carers can access dedicated services and supports to help manage daily challenges, improve health and wellbeing, and plan for the future.

Website: carergateway.gov.au **Call:** 1800 422 737

Carer Support - Northern Sydney Local Health District

Provide information, guidance and support to help in your caring role, information that is both practical and local, so you feel confident about finding the right services for your needs. Find out how you can connect to support and social groups and local **Dcaf's** (dementia friendly café's).

Website: nscarersupport.com.au **Call:** 9462 9488

NSW Companion Card

If support is needed to attend events, activities or venues, the diagnosed person might be eligible for a Companion Card. A Companion Card is a great way to continue participating in leisure activities and events with the support of a carer, at little or no additional cost. Present the card to a participating organisation and they will issue a second ticket for the companion at no charge.

Website: service.nsw.gov.au/transaction/apply-for-a-companion-card

Call: 1800 898 044

Respite care

Respite care supports the diagnosed person and their carer for short periods of time. It can give both parties both a break and can also the chance to meet new people.

Carer Gateway: carergateway.gov.au or 1800 422 737

Hammond Care: hammond.com.au



Legal and financial considerations

Planning for the future

Preparing a **Will** ensures your wishes are carried out and it makes known what your intentions are for distributing your assets.

An **Enduring Power of Attorney** is a legal document which gives a designated person the power to act on your behalf with regard to financial decisions.

An **Enduring Guardianship** is a legal document which allows a designated person to make decisions regarding your lifestyle, where you live, medical and health treatments you should receive.

An **Advanced Care Plan** gives you control over your life as you age.

For further information

NSLHD Carers Support Service

Website: nscarersupport.com.au

NSW Trustee and Guardians

Website: tag.nsw.gov.au

Service NSW

Website: nsw.gov.au/family-and-relationships/planning-for-end-of-life

Financial support and advice

Lifeline Financial Counselling

Ease financial stress with Lifeline H2H's expert financial counselling services. Their experienced and qualified team works to address immediate financial concerns, and significantly reduce stress and worry.

Website: lifelineh2h.org.au/get-support/financial-counselling

Call: 02 8287 1162 **Email:** csappointments@lifelineh2h.org.au

National Debt Helpline

If you feel overwhelmed by debt, contact a financial counsellor as soon as possible. Free service to assist you to get help early.

Website: ndh.org.au **Call:** 1800 007 007

Services Australia

Services Australia is a free service that can inform and educate you about financial issues for your current and future needs.

Website: servicesaustralia.gov.au/financial-information-service

Call: 132 300

NSW Photo Card

Apply at Service NSW to obtain a NSW Photo Card. Useful for proving identity when it comes to the time when someone may not have a valid driver's licence or passport.

Website: service.nsw.gov.au/transaction/apply-for-a-nsw-photo-card



Advocacy

Older Persons Advocacy Network

At some point, an older person may need a professional to advocate on their behalf. In these instances, the Older Persons Advocacy Network (OPAN) may be able to assist. This could be when you speak with health care, housing, welfare and financial service providers.

Website: opan.org.au **Call:** 1800 700 600

Seek support for elder abuse

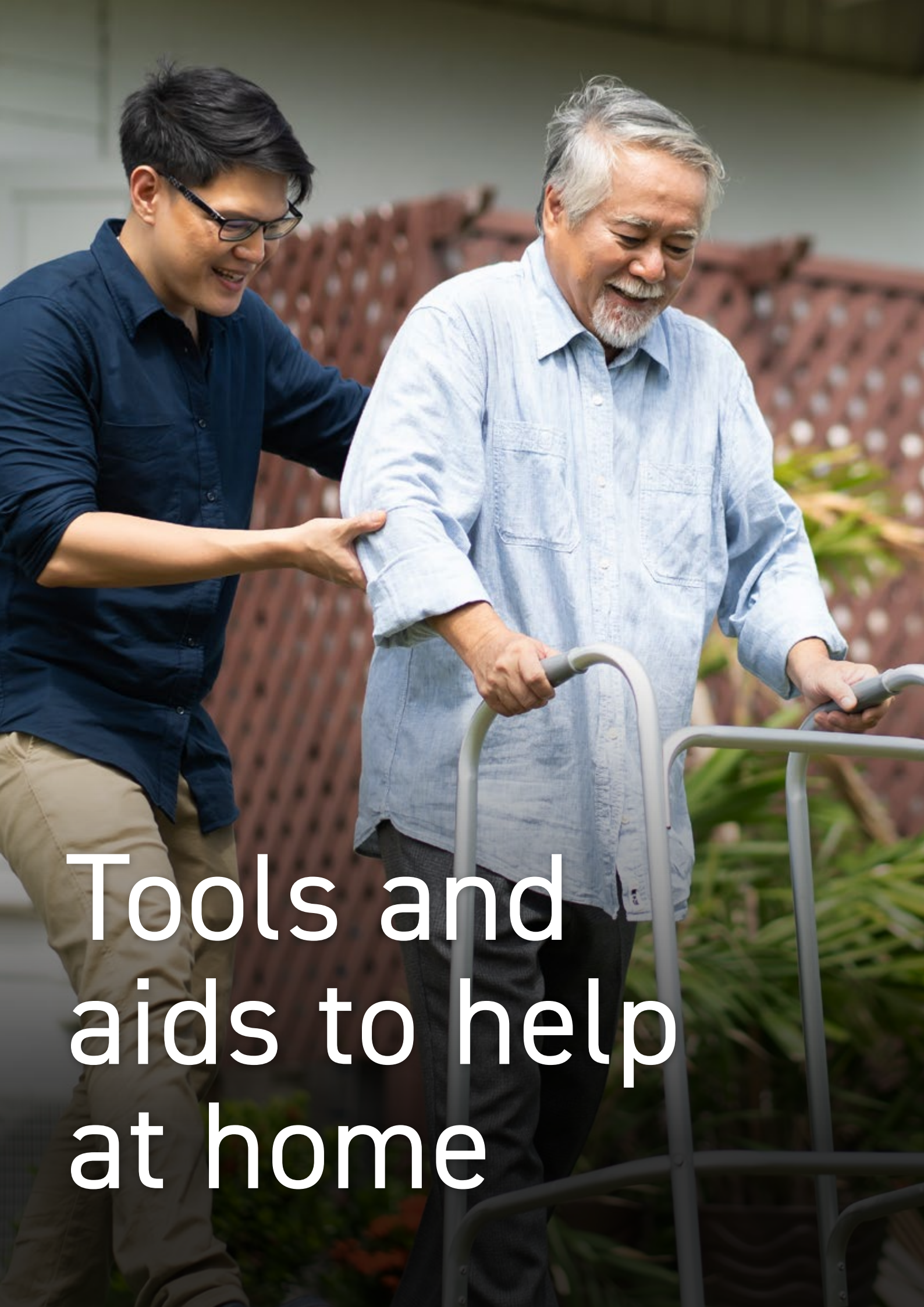
Elder abuse is the mistreatment of adults over the age of 60 who are abused, neglected, or financially exploited. Contact the **NSW Ageing and Disability Abuse Helpline** to learn more and report abuse.

Website: ageingdisabilitycommission.nsw.gov.au **Call:** 1800 628 221

Seniors Rights Service

Seniors Rights Service supports older people with free legal advice, advocacy and information.

Website: seniorsrightsservice.org.au **Call:** 9281 3600



Tools and
aids to help
at home

The Australian National Equipment Database

The Australian National Equipment Database is where you can find tools and aids for people with dementia. Tools, aids and technology can help those diagnosed stay safe at home, stay independent and live at home for longer. It can also reduce stress for everyone including friends and family.

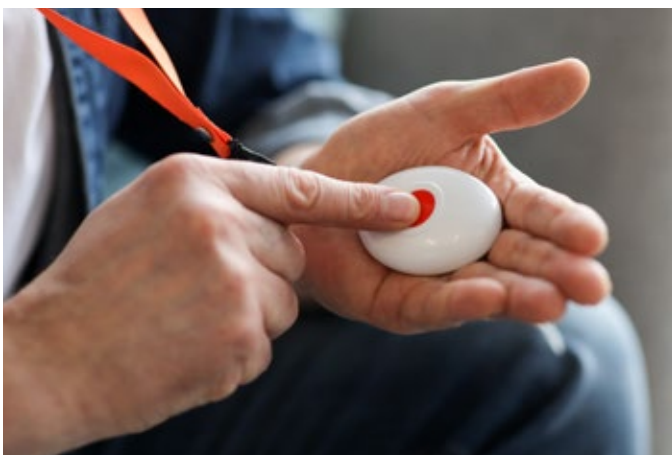
Tools include medication reminders and dispensers, date and time tools, items finders, digital photo books, safety devices such as personal alarms and communication tools.

Website: askned.com.au

Living at home alone

There are some changes that can be made to a home to make it dementia friendly. If there is a risk of falling, order an emergency response system. A special pendant or bracelet lets the affected person summon help if they fall and can't reach the phone.

Website: dementia.org.au/living-dementia/home-life/living-alone





Physical
and emotional
health



Nutrition

Eating a nutritious, balanced diet is vital for health. It keeps the body strong, helps fight off illness and prevent injury.

Website: dementia.org.au/living-dementia/staying-healthy/nutrition-and-dementia

Physical activity

Staying active and social can help improve skills and memory. Thirty minutes of physical activity each day can improve the way you think and feel, for ideas:

Website: activeandhealthy.nsw.gov.au

LiveUp can guide older people on their ageing journey. Explore a range of exercises, activities and assistive products designed to help older people take control of their ageing.

Website: liveup.org.au **Call:** 1800 951 971

Healthy living for seniors

There are many organisations that welcome people living with dementia to their activities and groups. Some local examples:

AASHA Multicultural Hub

A monthly get-together in Gordon to enjoy music, food and good company.

Email: info@aashaaustralia.org.au **Call:** 0412 786 569

Active Seniors Gordon

Helping older people to improve their strength, flexibility and balance.

Website: activeseniors.net.au **Call:** 9499 4344

Dance Health Alliance

Have fun and maintain your well-being in a safe, inclusive environment.

Website: dancehealthalliance.org.au

Email: gwen@dancehealthalliance.org.au

Hornsby & Ku-ring-gai Circle Dancers

No experience needed to join in the dance. These can be gentle and reflective or lively and energetic.

Email: hornsbycircledancing@gmail.com

Hornsby Ku-ring-gai Parkinson's Support

Social activities for people living with Parkinson's disease and their carers.

Email: rdparkin@yahoo.com.au



Gordon Pymble Uniting Church

A variety of group activities each week.

Email: info@gpuc.org.au

Ku-ring-gai Council

Information sessions and social activities, including regular outings and chair yoga classes.

Website: krg.nsw.gov.au/seniors

Ku-ring-gai Home Library service

A free home delivery of books, magazines and DVDs to residents who are unable to visit the library.

Website: krg.nsw.gov.au/homelibrary **Call:** 9424 0478

Email: housebound@krg.nsw.gov.au

Sing Australia Gordon

Singing for everyone every Friday evening.

Email: singaustraliagordon@live.com

Stepping On Falls Prevention Programs

Strength and balance exercises, group discussions and presentations from expert guest speakers.

Website: nshp.com.au/SteppingOn **Call:** 9450 7050

Turrumurra Community Garden

Enabling people to grow vegetables and fruit in a friendly, shared community garden.

Email: info@tlcgarden.org.au



Social activities

Social activities challenge the brain and may slow down the progression of dementia symptoms. Social interactions also provide emotional support, reducing feelings of depression, anxiety and loneliness. For ideas and assistance please see the services below or those listed under healthy living for seniors.

DCaf

An opportunity for people with dementia and their carers to meet for a little exercise, a chat over a cup of coffee and generally enjoy a break from the confines of home.

Every Tuesday at 10:45am – Ku-ring-gai Fitness Aquatic Centre

Website: knc.org.au **Call:** 9988 4966

Hornsby Ku-ring-gai Community Transport

Hornsby Ku-ring-gai Community Transport can assist those affected to stay connected to family and friends, attend medical appointments, shopping trips and provide fun social outings.

Website: communitytransport.org.au **Call:** 9983 1611

Looking after your mental health

It is normal after a diagnosis of dementia to have a lot of strong feelings, both good and bad. Counselling can help you understand what you, or the person you care about, is going through.

Dementia Australia

Dementia Australia offers free, confidential, professional counselling for individuals, families, couples and professional carers at all stages of a dementia journey.

Website: dementia.org.au/get-support/counselling

Call: 1800 100 500

LifeLine

Lifeline's crisis support service is available to provide short-term support for people who are feeling overwhelmed or having difficulty coping or staying safe. It is confidential one-to-one support, with a trained Lifeline telephone crisis supporter.

Website: lifeline.org.au **Call:** 13 11 14 - available 24/7





Memory
changes

If you or someone you care for is experiencing difficulties with memory, know that they may not be signs of dementia. It could be memory loss as a part of normal aging.

If memory difficulties are concerning you it is best to be assessed earlier rather than later. The following organisations can assess memory changes.

Catholic Care's Memory Innovations Centre Waitara

The Centre assists people who may be noticing changes in their memory, have been diagnosed with dementia, or just to stay connected with others in the community. The professionally run programs focus on having fun, connecting with others and stimulating your brain.

Website: catholiccareddb.org.au/aged-care-support-services/memory-innovations-centre

Call: 9481 2659

Hornsby Ku-ring-gai Hospital Memory Clinic

When changes to memory have been identified by yourself, your family or a health professional. To access the service, the diagnosed person must have a GP referral to the memory clinic and live within the Hornsby Ku-ring-gai local government areas.

Email: NSLHD-HKH-outpatients@health.nsw.gov.au

General enquiries: 9485 6777 **Referrals:** 9485 6777

Royal North Shore Memory Clinic

Is a multidisciplinary diagnostic and treatment service for people with concerns about early memory loss or cognitive decline.

Email: NSLHD-RNS-AgedCare@health.nsw.gov.au

Call: 9462 9333

A hand is shown holding a large sheet of paper displaying a grid of brain MRI scans. The scans are arranged in a 3x3 grid, showing various cross-sections of a human brain. The background is dark and out of focus, suggesting a clinical or research setting.

Education resources

CHeBA (Centre for Healthy Brain Ageing)

Information and research projects that older people can participate in. Some projects focussed on CALD groups.

Website: cheba.unsw.edu.au **Call:** 9850 9882

Dementia Australia Library Service

Access to a comprehensive collection of print and digital resources about dementia. You can borrow books, articles, audio resources, e-books and DVDs.

Website: dementia.org.au/library

Macquarie University Lifespan Health and Wellbeing Research Centre

Information and research projects that older people can participate in.

Website: mq.edu.au/lifespan

Northern District Local Health

Provides online booklets with information on the physical comorbidities of dementia:

- At home with dementia
- Dementia handbook information for carers
- Falls prevention for people with dementia
- Memory problems booklet

Website: www.nslhd.health.nsw.gov.au/Search/Pages/default.aspx?k=Dementia

Call: 9850 8655

The Brain Foundation

Information on brain diseases, the latest research, fact sheets and resources.

Website: brainfoundation.org.au

University of Sydney Cognitive Decline Partnership Centre

Provides resources on clinical practice guidelines and principles of care for people with dementia. Also has a **Consumer Companion Guide**.

Website: cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/

Wicking Institute University of Tasmania

The Wicking Dementia Research and Education Centre is at the forefront of translational research and support for issues confronting people with dementia and their carers. The site offers free online courses on preventing and understanding dementia as well as understanding traumatic brain injury.

Website: mooc.utas.edu.au



Local support

Listed below are local organisations providing support and information to people living with dementia and their families. Please note this list is not exhaustive and there may be other organisations that can also help.

To find other organisations that provide services in the wider community, search the Community Directory.

Website: krg.nsw.gov.au/communitydirectory

Chinese Australian Support Services (CASS)

Provides a full range of information and support services for seniors in a range of languages including Chinese, Indonesian, Korean and Vietnamese.

Campsie

Website: casscare.org.au **Call:** 9789 4587

Email: info@casscare.org.au

Ku-ring-gai Neighbourhood Centre (KNC)

Provides information and access to a diverse range of in-home and community-based services for seniors and people living with a disability.

St Ives Village

Website: knc.org.au **Email:** info@knc.org.au

Call: 9988 4966

Northern Sydney Home Nursing Service (NSW Health)

Provides general home nursing care and support to seniors and people living with a disability and those living with a chronic illness.

Website: www.nslhd.health.nsw.gov.au/pach/Pages/NSHNS.aspx

Call: 1300 732 503

Richard Geeves Dementia Carers Support Group

Monthly support group for carers of people diagnosed with dementia. The group meets on the third Wednesday of the month 10.30am to 12pm.

North Turrumurra

Website: nscarersupport.com.au **Call:** 0434 323 411

Sydney Community Services

Provides information on, and access to, a diverse range of in-home and community-based services for seniors and people living with a disability.

Lane Cove

Website: sydneycs.org **Call:** 9427 6425

Email: support@sydneycs.org

Your Side

Provides information and in home support for seniors including **Commonwealth Home Support Program** and **Home Care Package** recipients.

Chatswood

Website: yourside.org.au **Call:** 1300 134 332

Email: customer care@yourside.org.au

Village Chef

Village Chef by Meals on Wheels produce a high standard of meals you can have delivered to your home. They are produced locally in their Turrumurra kitchen using locally sourced and fresh ingredients.

Website: villagechef.com.au/our-service **Call:** 1300 361 287

Dementia specific in-home services

Catholic Community Services - Dementia Care

In home support and residential aged care.

Macquarie Park

Website: catholicealthcare.com.au/homecare/about-our-services/dementia-services/

Call: 1800 225 474

Group Homes Australia

This model of care is an alternative to traditional aged care facilities. Smaller care environments have been proven to increase quality of life, reduce rates of depression and reduce hospitalisation for people living with dementia.

Website: grouphomes.com.au **Call:** 1300 015 406

HammondCare

In home support, residential care and dementia support services.

North Turrumurra

Website: hammond.com.au **Call:** 1800 776 112

UPA Sydney North Region

In home support and residential aged care.

Wahroonga

Website: upa.org.au **Call:** 9450 8300

Dementia specific respite care

Lucinda Cottage HCAH (Hammondcare At Home)

Overnight respite cottage.

Wahroonga

Website: hammond.com.au/location/hammondcare-lucinda-overnight-respite-cottage

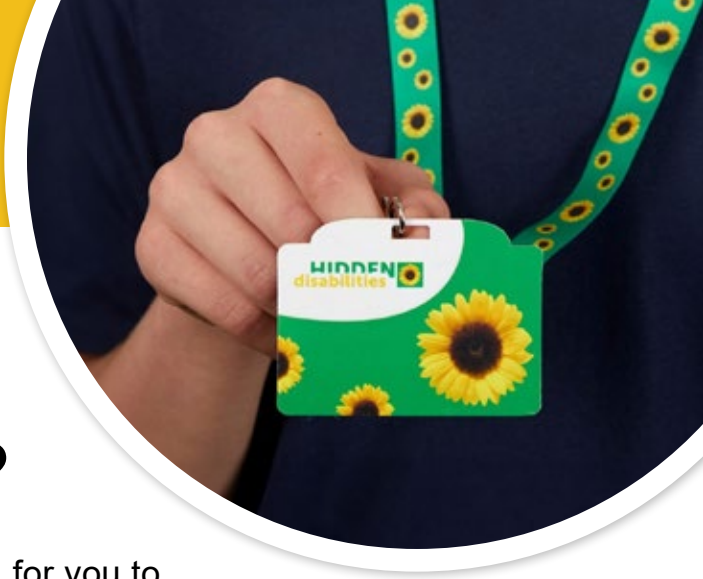
Call: 9488 2288

Residential care

My Aged Care provides a list of residential care possibilities and details about each.

Website: agedcareguide.com.au





What is the Hidden Disabilities Sunflower?

The Hidden Disabilities Sunflower is a simple tool for you to voluntarily let others know that you have a disability or health condition that may not be immediately apparent – and that you may need a helping hand, understanding, or more time in shops, at work, on transport, or in public spaces.

Free lanyards are available at all Ku-ring-gai Council library branches, customer service centre at Council Chambers and at the Wildflower Gardens.

At the time of printing the following large organisations have trained staff to recognise the lanyard and provide extra assistance if required:

- Art Gallery of New South Wales
- Australian Museum
- Australian National Maritime Museum
- International Convention Centre Sydney
- Macquarie Centre
- Museum of Contemporary Art
- Sydney Airport
- Sydney Dance Company
- Taronga Zoo Sydney
- Westfield Hornsby



Website: hdsunflower.com/au/

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Ku-ring-gai Council

For more information contact Ku-ring-gai Council community services
on 9424 0000 or krq@krq.nsw.gov.au

krq.nsw.gov.au