ReMind UK

Getting ahead of dementia

The handy guide to living well with dementia

A post diagnosis resource for people living with dementia and those who care for them.

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Welcome

Welcome to ReMind UK's second edition of our resource guide and directory. This is a compendium of curated information for people affected by dementia. Our aim is to improve access to services and increase opportunities for people to build support networks.

This guide is designed to be dipped in and out of so please use the information whenever you need it, however please be aware that we will be updating this publication each year and details are accurate at time of printing but can change at any time. Always seek guidance from a medical practitioner as to what is most appropriate for your personal circumstances and those of your loved ones.

ReMind UK is an independent charity with over 35 years of experience dedicated to advancing research into dementia and other neurodegenerative conditions as well as providing high quality clinical care and support for people with dementia, their families and carers. We deliver a recognised Outstanding Memory Assessment service, lead and collaborate on essential research to improve health and wellbeing and find effective treatments for those impacted by dementia. We also deliver courses and events to support people living with dementia and those that care for them, helping to connect people with others with similar experiences.

This guide has been generously funded by the National Lottery's Building Communities Fund. As a charity we rely on the generosity of individuals, companies, trusts and foundations to support our work. To receive updates from ReMind UK including resources, events listings, news and opportunities to get involved, register your details by email at info@reminduk.org, give us a call on 01225 476420 or visit us online www.reminduk.org.

We hope you find this guide useful.

Melissa Hillier
Chief Executive Officer



"Remember, you are not alone. Your journey may be unique, but there are many others who have walked a similar path."

Lisa Genova

What is dementia?

Dementia is a descriptive term which indicates a progressive medical condition affecting the brain. It may result in difficulties accessing memories, thinking clearly or decision-making, affecting behaviour, sense of location or speech and therefore impacting everyday life.

Dementia is not one disease, but a term used to describe many different conditions affecting how our brains work. For example Alzheimer's disease, Lewy Body dementia, semantic dementia, frontotemporal dementia, vascular dementia and Creutzfeldt–Jakob disease are all types of dementia.



In the UK, 1 in 11 people over the age of 65 has a type of dementia, and 1 in 6 people over the age of 80. There are around 950,000 people living with dementia in the UK, with that number projected to rise to 1.1 million by 2030.

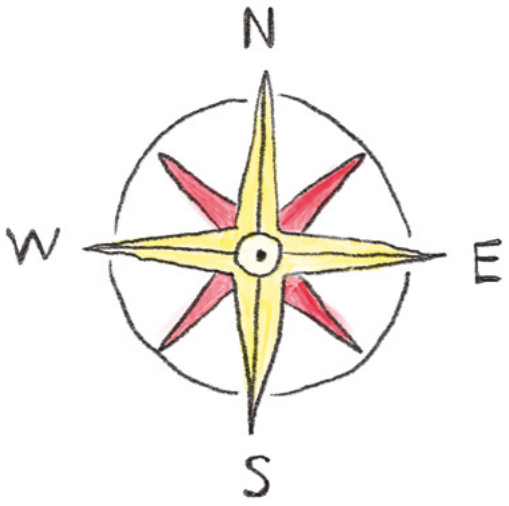
You can find out more about different types of dementia and symptoms from ReMind UK's website or other specialist dementia organisations such as the **Alzheimer's Society** or **Dementia UK**. There is also condition specific information at the ReMind UK Centre, based at Royal United Hospital, Bath.

If someone is diagnosed with dementia under the age of 65, this is classified as 'young onset' dementia. If you or someone you know is affected by young onset dementia you can seek support and access an online community at the **Young Dementia Network**.

There is also support available from the **Rare Dementia Support** website.

Someone develops dementia every three minutes. It's estimated that two-thirds of people with dementia are living in the community and are likely to be looked after by an unpaid family caregiver.

Diagnosis



It is important to remember that a diagnosis of dementia does not define who you are as a person. You are still the same person you have always been, and there are ways to continue living a fulfilling life with dementia.

The symptoms of dementia may get worse over time, so it is important to get a diagnosis as early as possible because, with the right medication, support, care, and proper planning, individuals can enjoy life to the fullest for as long as possible.

A diagnosis of dementia, or any other condition that may affect memory, can be a life-changing experience and for some, receiving a diagnosis can be a difficult and emotional. It is normal to feel a range of emotions, including anger, fear, and frustration. For others, the diagnosis may bring relief after a long period of worry and feeling that something 'isn't quite right.'

Sometimes people are frightened about what lies ahead and/or they can feel embarrassed about having a memory problem or worry about what people will think about them or be nervous about public stigma. Because of these worries, some people prefer not to talk about their diagnosis, or cope by avoiding situations where difficulties might be highlighted.

For some the shock can be so great that they prefer to keep the experience to themselves. For others, talking can help and they may want to share the news with family and friends.

While all these reactions are understandable, they can lead to people who have been diagnosed feeling lonely, isolated, and confused. In addition to emotional challenges, a diagnosis of dementia can bring significant life changes. You may have to adjust your career, retirement plans, or daily routines. These changes may feel overwhelming, and it can really help to seek support from loved ones, healthcare professionals, and community resources. It is important to remember that there are people to support you during this time.

There are many resources available to help individuals and their families navigate this challenging time, including support groups, educational courses, counselling or listening services, as well as social prescription and community services.

With the right support and resources, it is possible to maintain independence, stay engaged in meaningful activities, and enjoy precious time with loved ones.

What to Expect

A helpful list of things to expect is available on the Alzheimer's Association website: **Just Diagnosed/Alzheimer's Association**.

It is important to understand that when it comes to predicting how symptoms may progress, medical staff and clinicians can be limited in their ability to provide a precise projection. This is because there is huge variety in how quickly, or in what ways the functions of the brain will change over time.

Useful resources

Film (YouTube)
Watch an award-winning film '**The Impact of Diagnosis**' made by the Social Care Institute of Excellence about how people felt when they received their diagnosis.

Read
Read or listen to real life positive stories using the Living with Dementia Toolkit curated by the Dementia Engagement and Empowerment Programme (DEEP).

To read more about what care is provided, visit 'Help and Support for people with dementia' on the NHS website www.nhs.uk

Visit Dementia UK's website where they offer useful personal stories: www.dementiauk.org/information-and-support/stories/

The progression of symptoms will often depend on a variety of factors that are unique to each individual case. Factors which may impact progression of symptoms include age, overall health, and the severity of their condition. In addition, the specific type of brain condition and external factors can also play a role, as well as whether the patient responds well to appropriate medical treatment and support.

While it can be frustrating not to have a clear projection of how symptoms may progress, it is important to remember that professionals are doing their best to provide the most accurate information possible based on available expertise and research. And remember many others are facing a similar situation.

The ReMind UK Memory Clinic assesses a person's memory loss, and where appropriate can make a diagnosis and prescribe medication. For longer term support we have developed other ways for people with dementia and their loved ones to receive ongoing support through a range of courses, events, groups and peer support activities. Our Post Diagnostic programme of events relies on charitable funding as it is not paid for by the NHS.

When you receive a diagnosis you will be offered the chance to be referred to the Alzheimer's Society's Dementia Advisor Service. You can also self-refer. They can discuss local services and benefits you might be entitled to if you have a diagnosis of dementia. The Alzheimer's Society also has some useful information such as the "**This is Me**" document which helps health professionals provide more personalised care.

Living with dementia

It is important that you take steps to live as well as you can with the condition that you have been diagnosed with. You might consider some of the following:

- Communicate with family and friends - find ways which suit you to tell friends, colleagues and acquaintances. Keep them in the loop - they are your support network.
- Access support and guidance around financial and legal issues.
- Seek awareness of available treatments and support.
- Manage symptoms medically and socially (social prescription).
- Make decisions and plan for future decision-making.
- Where eligible, take up the opportunity to participate in research.
- Find practical solutions to difficulties you may be experiencing.
- Access support to help cope with stress and anxiety.
- Identify useful products and equipment to help with daily living.

Being part of your community and making contributions to community initiatives can be very rewarding.

Dementia cafés, peer support groups, assistive technology, art and music therapy, movement, and physical activity can all play a role in helping people live better with memory conditions.

It is important not to feel isolated, groups help you socialise in a sympathetic environment.



Useful resources

My life, my goals
A practical guide full of hope to help you set and reach your goals, developed as a collaboration by Exeter University, Innovations in Dementia and Alzheimer's Society.

www.innovationsindementia.org.uk

AGE UK have produced a helpful list for daily living which can be accessed through the information and advice section on their website

General strategies include:
- Having a regular routine
- Keeping active
- Having 'the same place' to put things
- Breaking things down into small manageable steps
- Focusing on one thing at a time
- Reducing as many distractions as possible
- Getting support

www.ageuk.org.uk

Brain Health

As we age some cognitive decline is natural, but certain factors can speed up the process, such as smoking, excess alcohol, lack of exercise, sleep apnoea, obesity, untreated depression and social isolation.

There are ways to improve and maintain cognitive function as well as develop coping strategies for cognitive difficulties.

Regular exercise increases blood flow to the brain and may help support memory, attention, and decision-making.

The relationship between sleep and cognitive function is still being explored. It is thought that sleep consolidates memories and provides essential time out to rest and restore cognitive function. The NHS offers very useful sleep advice on their **Every Mind Matters** web pages.

Sleep apnoea is a known risk factor for developing dementia, due to the chronic reduced oxygen your brain is receiving when you are asleep. If you have concerns that you may have sleep apnoea it is advised to see your GP to discuss this further.

"The greatest glory in living lies not in never falling, but in rising every time we fall."

Source: Long Walk to Freedom (1995) by Nelson Mandela.

In terms of mental health if you struggle with overwhelm an effective approach can be to break tasks into smaller, more manageable steps. This can help reduce feelings of being overwhelmed and make it easier to focus on one task at a time, helping to reduce stress.

Additionally, practicing relaxation techniques and mindfulness may help improve cognitive function by reducing stress and increasing focus.

Puzzles & Brain Games

If you enjoy puzzles, teasers, riddles and brain games here are a few suggestions.

Reader's Digest online

- www.rd.com/knowledge/brain-games/

Brain Workout Puzzle
The Alzheimer's Society can send you a monthly Brain Workout Puzzle Pack delivered straight to your door. They ask for a voluntary donation which suits you.

- www.alzheimers.org.uk/get-involved/make-donation/donate-more-ways/brain-workout

The Activities Handbook
Has a useful section on online and digital activities.

- www.alzheimers.org.ukget-support/publications factsheets/activities-handbook-dementia-carers

Finally, it is important to maintain a healthy lifestyle overall. Eating a healthy diet and avoiding smoking and excessive alcohol consumption and managing stress can all help to protect cognitive function.

Research indicates that keeping your brain active by completing mentally challenging activities may also be beneficial.



Useful resources

The Dementia Toolkit

livingwithdementiatoolkit.org.uk

Brain Health Basics

www.alzheimersresearchuk.org/brain-health/brain-health-basics/

NHS – Mind Matters

nhs.uk/every-mind-matters/mental-health-issues/sleep/

Brain Health Network

Find out about steps you can take for brain health

https://brain.health/

Caring

You may not think of yourself as a carer, particularly if the person with dementia is a partner, parent, or close friend. However, post-diagnosis support and care are crucial for the wellbeing of both the person with dementia and their family and/or friends.

It is important to have access to support and resources, so that you can maintain your own health and wellbeing whilst caring for someone. You may find you need support with navigating resources and services available to both you and the person you're caring for, coping with symptoms and changes in behaviour, or some additional support with care.

Services such as day centres, home support and support groups offer valuable space for rest, time to talk to people in similar situations, or for free time for yourself and much needed respite from caring, and time to share.

It is a good idea to:

- Register with your local carers centre or organisation.
- Take care of your own health and wellbeing.
- Make sure you're registered as a carer with your GP.
- Apply for a carers assessment.
- Check if you are eligible for benefits for carers.
- Find out about training courses that could help you.

Local Carers' Centres offer information, advice and support to unpaid carers - those looking after partners, friends or family members due to old age, illness, disability, mental health difficulties or addiction.

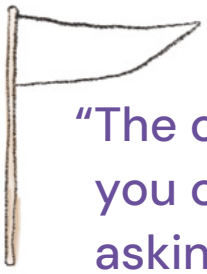
Carers can become exposed to an increase in normal levels of physical tasks and emotional stress which can put their physical health at risk. The national back pain charity, **BackCare** is working to help UK carers support their physical health and prevent problems before they arise.

At ReMind UK, we encourage you to refer yourself to your local Carers Centre, or support service to benefit from what's available. All local authorities or independent carers charities will offer different services depending on where you live.

We have not included information on Home Care Agencies, Nursing Homes or Residential Homes in this guide, but you can find guidance on these, as well as home care support at B&NES' AGE UK's comprehensive **'Your Guide to Later Life.'**

At some point you may need some assistance. This may range from a companion to offer company, to full personal care at home.

Do not hesitate to ask for help if it will make your life easier.



"The only mistake you can make is not asking for help."

– Sandeep Jauhar

Useful resources

ReMind UK run carers days and events throughout the year.

www.reminduk.org

The Carers' Centre in Bath

Monday - Friday, 9am - 1pm

0800 0388 885
(leave a message)

support@banescarerscentre.org.uk

Or register directly

https://banescarerscentre.org.uk/adult-joining-form/ntr

Dementia Carer Counts

Virtual Carers Centre

www.dementiacarers.org.uk/vcc/

Carers Trust

https://carers.org

The Jointly app

This app is supported by Carers UK and was created by carers to help with managing day to day activities. It works by combining group messages and to-do lists with medication lists and calendars to make coordination between those who share care as easy as text messaging. It can be down loaded on the App Store or Google Play.

https://jointlyapp.com

The Alzheimer's Society

The Alzheimer's Society run a Carer Information and Support Programme (CrISP), providing support and relevant information in a group environment.

www.alzheimers.org.uk

ReMind UK courses, events and activities



The ReMind UK Centre, based at the Royal United Hospital in Bath, offers a range of support opportunities for people affected by dementia.

Cognitive Stimulation Therapy is a seven-week program for people with mild to moderate dementia to stimulate memory in an interactive and engaging way. CST is evidence based and recommended by NICE (The National Institute for Health and Care Excellence).

Dementia Courses for Carers. These are one or half day events for people looking after someone with a diagnosis. Expert speakers provide information about support services and practical advice and carers can share their stories.

Chat, Make and Move Courses
Ten-session programmes of activity aimed at supporting those who are newly diagnosed and developing longer term local support groups. The courses help people affected learn new things, enjoy themselves, and participate in gentle exercise, creativity, and wellbeing activities.

We also offer a seasonal events programme of varied activity.

Come along on your own or with a friend, family member or carer.

For more information email
✉ info@reminduk.org

Course feedback:



"This has really opened doors for me, it has been very therapeutic."

"I really enjoyed it. I loved the singing as well. Everyone is so friendly and kind. I would recommend it to anyone. It is the full package!"

"The ReMind UK Centre makes such a positive contribution to all of our lives, and we are very grateful for the opportunities you offer."

Top Tips

This section is a collection of top tips, curated by carers and ReMind UK's Lived Experience Advisory Panel.

- **Legal** – ensure you have wills and you have **lasting power of attorney (LPA)** - both for finance, and importantly, for health and welfare. These are now separate and were previously known as 'enduring power of attorney'.

- **Medical** – Maintain communication with your GP about any medications prescribed and any queries you may have. Medication, where appropriate, can help delay the onset of symptoms.

- **Falls** - prevention is key. See the NHS website.

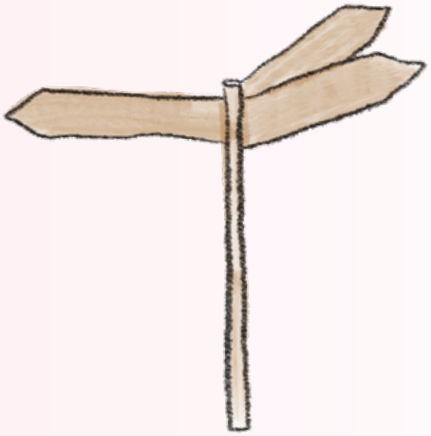
⊛ www.nhs.uk/conditions/falls/

B&NES NHS has a Falls Ambulance for people over the age of 65 years who fall over at home. The Falls Rapid Response Team, includes a specialist paramedic and an occupational therapist.

⊛ https://bathnesshealthandcare.nhs.uk/clinics-and-treatments/falls-service/falls-service-support-and-information/

- **Social services** – ask for a Care and Support Assessment by Social Services. For more info on carers rights and care and support assessments speak to HCRG group, and or your local carers organisation.

  It's important they assess both of you as they can assess needs and register you as a carer with your GP. Contact your local authority or local carers centre to get a carers assessment.



Useful resources

This is Me

- www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me

In Case of Emergency (ICE) – First Response

Download emergency contacts on to your mobile phone.

- www.firstresponsefirstaid.co.uk



- **Finances** – apply for an Attendance Allowance when you are ready - paint a picture of the worst day. Keep copies to send out as you will be asked for it frequently. Get help from Citizen's Advice Bureau if you are not sure – it is a long form! This is a gateway for some other benefits such as a discount on council tax.

  The Disability package is like a puzzle... you need Doctors' notes, medical letters, certificates and blue badges, and you need to keep going with it all.

- **Give your GP Practice a copy of Power of Attorney (PoA) over health.** Keep a copy of your PoA in your bag, you will need it again and again. Also give a copy of it to the bank, even if it is a joint account.

- **Discuss things for the future** – you can agree and sign a RESPECT form with your GP – paramedics will then try to treat at home whenever possible, which may be helpful for someone with dementia.

- **Prepare an Emergency Plan** in case something should happen to you – the carer. (Carers Centres may provide a pack). Get a **Lions Club sticker** for your front door – this alerts the Emergency Service that you are a carer.

- **Think about who can help** – neighbours, family and friends. Local support for carers may be available. The Alzheimer's Society can offer regular contact to support you. Local churches and village halls often offer something.

- **A healthy diet and hydration are important** so check and keep a note of what your loved one is eating and make sure they drink enough – this is essential if they are prescribed medication. Look out for any unmet causes which may influence behaviour such as constipation, pain, temperature.

- **Don't put your life on hold.** Seize the moment. Getting out in the fresh air, taking exercise, seeing people and doing things help to delay the progress of the disease. There are lots of ways to stimulate your brain - Singing for the Brain is just one and it can be surprisingly uplifting. Find groups or activities and peer support opportunities which you enjoy.

- **Take time out.** Don't beat yourself up. Both of you should be able to relax. Be kind to yourself and each other. If the short-term memory is failing, dig into the past and talk about things that happened before. This part of the memory is likely to be functioning better. Make a book of memories and photographs to enjoy together.

- **Consider a free home fire and safety visit**, offered by Avon Fire and Rescue or your local Fire Service.

- **Create one key overview document with a list of contacts** for dentists, doctors, medications. A good starting point for this is a 'This is Me' document available from the Alzheimer's Society website.

  Leave it in an obvious place and copy it a few times.



"Bread and butter, love, and warmth
I love toasted tea buns!
Warm slippers and grandmothers.
The person who has
never been foolish
Is the most foolish.
If music be the food
of love PLAY ON
In the company of good friends
One is never alone"

A poem co- created at our Toast, Tea & Poetry Group
November 2023



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