



ACTION AWARENESS EAST MIDLANDS
FOR ALL OF YOUR TRAINING NEEDS & ASSISTANCE



A guide to dementia and how to provide effective support



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What is dementia?

Dementia is not a single disease but a collective term used to describe various symptoms affecting brain function. It primarily impacts memory, thinking, behaviour, and the ability to perform everyday activities. Millions of people worldwide are affected by dementia, making it a significant health and social concern. Dementia is progressive, meaning symptoms start out slowly and worsen over time. While it is most common in older adults, dementia is not a normal part of aging.

Types of dementia

Alzheimer's Disease – The most common form of dementia, accounting for 60–70% of cases. It is characterised by specific brain changes (the build-up of abnormal proteins, often referred to as plaques and tangles) and typically begins with memory loss and confusion.

Vascular Dementia – Caused by reduced blood flow to the brain, often after a stroke or series of small strokes. Symptoms can appear suddenly after a major stroke or more gradually after a series of mini-strokes. Difficulties with planning, concentrating, and slowed thought processes are common.

Lewy Body Dementia – Involves abnormal protein deposits (Lewy bodies) in the brain, affecting movement, cognition, and behaviour. People with Lewy Body Dementia may also experience visual hallucinations and fluctuations in alertness. Symptoms can overlap with Parkinson's disease.

Frontotemporal Dementia – Often affects people under 65 and is linked to changes in personality, behaviour, and language. This can include changes such as reduced empathy, impulsive behaviour, or difficulties with speech and understanding, depending on the part of the brain affected.

Understanding Alzheimer's Disease

Alzheimer's is a specific disease under the dementia umbrella. It involves the build-up of abnormal proteins in and around brain cells. Over time, this damages brain tissue and affects neurotransmitters (chemical messengers).

Common early signs include:

- Forgetting recent events or conversations
- Misplacing items
- Repeating questions
- Difficulty finding words
- Difficulty with problem-solving or planning
- Withdrawal from social activities

As the disease progresses, symptoms become more severe, affecting mood (such as depression or anxiety), behaviour (like agitation or aggression), and eventually physical functions (such as walking or swallowing). There is currently no cure for Alzheimer's disease. However, there are medications and other treatments that can help manage symptoms and improve quality of life. Researchers are actively working on new treatments and potential cures, and there are ongoing efforts to find ways to slow down or even prevent the progression of the disease

Risk Reduction and Brain Health

While age and genetics are factors in dementia, evidence suggests that a healthy lifestyle can help maintain brain health and potentially reduce the risk of developing some types of dementia. Consider these steps:

- **Regular Physical Exercise:** Aim for at least 150 minutes of moderate-intensity aerobic activity each week.
- **Healthy Diet:** A balanced diet rich in fruits, vegetables, whole grains, lean protein (especially fish), and healthy fats (like those in olive oil and nuts), similar to the Mediterranean diet, is beneficial. Limit saturated fats, sugar, and salt.
- **Stay Socially Active:** Regular engagement with friends, family, and community groups can help protect brain health.
- **Mental Stimulation:** Keep your brain active by learning new things, reading, doing puzzles, or engaging in hobbies that challenge you.
- **Manage Cardiovascular Health:** Control high blood pressure, cholesterol, and blood sugar levels (if you have diabetes). What's good for your heart is often good for your brain.
- **Avoid Smoking:** Smoking increases the risk of dementia. Quitting can reduce this risk.
- **Moderate Alcohol Consumption:** Limit alcohol intake to recommended guidelines.

It is worth bearing in mind that whilst these steps can help reduce the risk of developing dementia, they cannot guarantee staying dementia-free, they have been evidenced to be highly effective in research to date.

Diagnosing dementia

Getting effective treatment for dementia starts with a diagnosis, this is essential to help the individual receive the best possible care for the type of dementia they have. It can be scary seeking a diagnosis for the condition, but doing so can make a huge difference to the individual and those that care for them.

Early Signs and Symptoms

Spotting dementia early can make a big difference in planning care and improving quality of life. Look out for:

- Memory loss disrupting daily life
- Difficulty following conversations or plans
- Confusion about time or place
- Mood changes or withdrawal

- Struggling with familiar tasks

These symptoms may not mean dementia—but if they're persistent or worsening, it's worth seeking help. Consulting a GP is a good first step if you have concerns about yourself or someone else.

How a Diagnosis is Made

Diagnosing dementia involves a combination of:

Medical History – Understanding the person's background, symptoms, their impact, and any relevant family medical conditions.

Cognitive Tests – Assessing memory, attention, language, and problem-solving skills to identify areas of difficulty.

Brain Scans – MRI or CT scans help identify visible changes in the brain, such as shrinkage or damage from strokes, and to rule out other conditions like tumours.

Blood Tests – To rule out other potential causes of confusion or memory loss, such as vitamin deficiencies, thyroid problems, or infections.

Referral to a memory clinic or specialist may be necessary. Specialists can conduct more detailed assessments and provide expert advice on diagnosis and management. Diagnosis can be challenging, especially in the early stages, but support is available throughout the process.

Living with dementia

Whilst dementia can significantly impact a person and their families lives it does not necessarily mean that everyone will need the same support, or lose their independence immediately. Due to the nature of dementia there may be times an individual is very clear and competent at looking after themselves whilst others they may require more support. It is important to monitor those with dementia over time and help make adjustments that support their independence wherever possible.

Daily Challenges

Living with dementia brings unique challenges. People may struggle with:

- Remembering names, places, or events
- Managing time or finances
- Recognising familiar people
- Navigating previously known spaces
- Finding the right words or understanding conversations.

These changes can be frustrating or frightening. However, with understanding and adaptations, many people continue to lead meaningful, connected lives.

Coping Strategies

Routine: Keeping a consistent daily schedule helps reduce confusion and anxiety. For instance, having meals, activities, and bedtime at roughly the same time each day can provide a sense of security.

Visual Aids: Labels on cupboards, clocks showing day and time, calendars, or photo boards of family members with names can provide helpful prompts.

Memory Books: Creating a scrapbook with photos and stories helps stimulate memory and supports conversations. Include important life events, favourite people, and past hobbies to encourage reminiscence.

Assistive Technology: Devices like talking clocks, GPS trackers, and medication reminders promote independence.

Therapeutic Activities: Music, gardening, or painting can provide joy and improve well-being. These activities can also offer non-verbal ways to connect and express oneself.

Stay Active: Light exercise like walking or stretching helps improve mood and maintain mobility.

Maintaining Independence

While support is key, many people with dementia want to remain as independent as possible. It's important to:

- Encourage decisions where appropriate
 - Involve them in daily activities
 - Adapt tasks to be manageable, rather than removing them altogether. For instance, if someone enjoyed cooking, they might still be able to help with simpler tasks like washing vegetables or setting the table, with supervision if needed.
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John's story

After John Hyde was diagnosed with frontotemporal dementia aged just 59, he had to retire from his job as a handyman. He immediately wanted to learn more about his condition and find ways to help others affected, so he signed up to Join Dementia Research.

Frontotemporal dementia is a relatively uncommon form of dementia that causes changes in language; such as speaking slowly, struggling to pronounce words correctly and difficulty speaking in coherent sentences.

It affects the front and sides of the brain (frontal and temporal lobes) and most cases start between 45 and 65 years of age.

Another common symptom is changes in behaviour, such as acting impulsively and being distracted easily. It can also cause memory problems, although this is often not as severe as with other forms of dementia, such as Alzheimer's disease.

John, of Clevedon, North Somerset, said: "At work, I started getting materials mixed up and forgetting my tools for certain jobs and things like that. My wife noticed it one day and she said 'you've come back home six times in the last hour to get tools.'

"So we went to the GP and they referred me to the local memory clinic. And then after two years of tests and scans, they diagnosed me with frontotemporal dementia.

"When I got the diagnosis I had a feeling of total relief. For ages I was wondering what was wrong with me, so to finally find out felt like a massive weight off my shoulders. I could finally plan what I was going to do about it."

John's diagnosis meant that he had to retire from his job, which mainly involved designing and building gardens. He wanted to keep himself busy after retirement so he decided to take part in dementia research.



He said: *“When I couldn’t do my job any more, I totally lost my purpose and was constantly looking for useful things to do. I wanted to learn more about what was affecting my brain and after finding out about Join Dementia Research, I knew I wanted to sign up straight away.*

“By doing research and medical studies through the Join Dementia Research website, I started to get my purpose back.”

As John was diagnosed just before the Covid-19 pandemic, he took part in research studies remotely over Zoom calls.

This study is important because although many people with dementia seek medications, they can be concerned about side effects. Therefore, researchers at Leeds Beckett University sought opinions on how best to describe these medications for people with dementia.

He has also taken part in other studies, such as looking into the connection between photographs and memory and helping researchers make videos about dementia.

“If I can help make others less scared of their diagnosis and encourage them to keep asking questions about it and volunteering for studies, then actually their generation might come at it with the cure for it.

Alongside taking part in research, John also runs a YouTube channel where he gives regular updates on his condition. He has also begun writing picture books for children about dementia so that they can understand the condition better.

“If I can help the younger generations understand dementia better for the future, I feel like I’m doing a whole lot of good.”

Supporting someone with dementia

Supporting someone with dementia requires patience, understanding, and flexibility. The goal is to help them maintain their quality of life, dignity, and independence for as long as possible, while also ensuring their safety and well-being. Here are things to help you provide the most effective support possible:

- **Learn About Dementia:** Understanding the condition makes it easier to empathise and respond calmly. Seek information from reputable sources like the Alzheimer's Society or Dementia UK (listed in "Useful Contacts"). Learning about the specific type of dementia and its likely progression can help you anticipate changes and adapt your support strategies over time.
- **Communicate with Patience and Clarity:** Speak slowly and clearly, using short, simple sentences.
- **Minimise distractions when communicating.** Approach the person from the front and gently gain their attention, making eye contact.
- **Give them plenty of time to process what you've said and to respond.** Don't interrupt unless necessary.
- **If they struggle to find a word, offer a gentle prompt** if you know what they mean, but avoid constantly correcting them.
- **Use yes/no questions** if complex choices become overwhelming.
- **Listen actively to what they are saying**, even if it's repetitive or doesn't make complete sense. Often, there's an underlying emotion or need they are trying to express.
- **Acknowledge their feelings (validation)**, even if their reality seems different from yours (e.g., "It sounds like you're feeling worried right now").
- **Use non-verbal cues:** a warm tone of voice, a gentle touch (if appropriate and welcomed), and reassuring facial expressions can convey a lot.

- **If they repeat a question or story**, respond calmly or try to gently redirect their attention to a different activity or topic.
- **Create a Calm, Safe, and Supportive Environment:** Minimise noise, clutter, and too much background activity to reduce overwhelm and confusion.
- **Ensure good lighting**, especially in hallways, stairs, and bathrooms, to help with orientation and reduce the risk of falls.
- **Remove trip hazards** like loose rugs or unnecessary furniture.
- **Consider safety measures** such as alarms on outside doors if wandering is a concern, or locking away medications and hazardous substances.
- **Familiar objects**, photos, and a consistent routine can help the person feel more secure.
- **Encourage Choices and Foster Independence:** Offer options in daily life, such as what to wear or eat: "Would you like tea or coffee?" or "Would you prefer the blue shirt or the red one?"
- **Break down tasks into smaller, more manageable steps.** For example, when dressing, lay out clothes in the order they are put on.
- **Focus on the abilities they still have** rather than what they have lost. Encourage them to do as much for themselves as possible, providing support only when needed.
- **Adapt activities** they used to enjoy so they can still participate in a modified way.
- **Respect Their Identity and Dignity:** Acknowledge their past, achievements, and interests—dementia does not define who they are.
- **Talk to the person, not about them** as if they aren't present, even if you think they don't understand.

- **Engage them in conversations about their life**, memories, and interests. Use photo albums, familiar music, or objects from their past to spark reminiscence.
- **Support their personal care needs** in a way that respects their privacy and dignity.
- **Be Present, Engage, and Connect:** Even if words are forgotten, emotions and connection often remain. Spend quality time with the person.
- **Engage in activities** you can do together, such as listening to music, looking at photo albums, gentle gardening, simple puzzles, or going for a walk.
- **The power of touch**, like holding their hand, can be very reassuring and comforting if it's welcomed by the person.
- **Managing Changes in Behaviour:** Understand that behaviours like agitation, restlessness, aggression, or wandering can be a way the person is communicating an unmet need (e.g., pain, hunger, thirst, boredom, fear, or discomfort).
- **Try to identify triggers** for challenging behaviours. Does it happen at a certain time of day, or in specific situations? Keeping a diary can help.
- **Ensure they have regular health check-ups**, as physical illness or pain can significantly impact behaviour. If you are finding certain behaviours very difficult to manage, seek advice from their GP, a specialist, or organisations like Dementia UK for strategies.

Supporting Children and Young adults

Dementia in a loved one can be particularly confusing, scary, and upsetting for children and young people. Open communication and reassurance are key.

Be Honest (in Age-Appropriate Ways): Explain that dementia is an illness that affects the brain and memory. For younger children, you might say, "Grandma's brain is not working as well as it used to, which makes her forget things sometimes." For older children, you can provide more detail.

Emphasise that it's not their fault and they can't "catch" dementia.

Answer their questions simply and honestly. If you don't know an answer, it's okay to say so and find out together.

Reassure Them: Let them know their loved one still loves them, even if they act differently, seem distant, or don't always recognise them. Explain that it's the illness causing these changes.

Address any feelings of guilt, fear (e.g., "Will I get it?"), sadness, or embarrassment they might be experiencing. Acknowledge that it's okay to feel these emotions.

Encourage Expression: Use drawing, writing, or talking to help them explore their feelings about the changes they are seeing.

Suggest journaling or talking to another trusted adult, like a teacher, school counsellor, or another family member.

Let them know it's okay to talk about their sadness, anger, or confusion.

Involve Them (Safely and Appropriately): Simple shared activities like looking at old photos, reading a story, listening to music, helping with a simple craft, or going for a short, supervised walk together can strengthen bonds and help them feel connected.

Choose activities that are enjoyable and suitable for both the young person and the person with dementia.

Ensure their involvement feels positive and helpful, not like a chore or overwhelming responsibility.

Offer Support and Maintain Routines: Let them talk about how they're feeling and ask questions whenever they need to. Remind them they're not alone.

Regularly check in to see how they are coping.

Try to maintain the child's or teen's own routines (school, hobbies, friendships) as much as possible to provide stability. Consider informing their school, with the child's consent if appropriate, so that teachers can be understanding and supportive.

Provide Resources: Look for books or online resources designed to help children and young people understand dementia. Some charities (listed in "Useful Contacts") may offer specific leaflets or web sections for younger audiences.



Legal and financial planning

Receiving a dementia diagnosis brings many questions about the future. It's sensible to consider legal and financial planning as early as possible, while the person with dementia still has the mental capacity to understand and make these important decisions. Early planning ensures their wishes are known and can be acted upon, providing peace of mind for both them and their family. This section provides general information; it is vital to seek professional legal and financial advice tailored to individual circumstances.

- **Lasting Power of Attorney (LPA):**

- An LPA is a legal document that allows a person (the 'donor') to appoint one or more people (the 'attorneys') to make decisions on their behalf. This is invaluable if the donor loses the mental capacity to make those decisions themselves in the future. It's important to set this up while the donor still has capacity.
- In England and Wales, there are two types of LPA:
 - **Health and Welfare LPA:** This covers decisions about your daily routine (e.g., washing, dressing, eating), medical care, moving into a care home, and life-sustaining treatment. It can only be used when the donor is unable to make their own decisions.
 - **Property and Financial Affairs LPA:** This covers decisions about managing bank accounts, paying bills, collecting benefits or a pension, and selling property. It can be used as soon as it's registered, with the donor's permission, even if they still have mental capacity, or it can be set to only activate if they lose capacity.
- **Choosing Attorneys:** Attorneys should be people you trust implicitly, like family members or close friends. You can appoint more than one.
- **Registration:** The LPA must be registered with the Office of the Public Guardian (OPG) before it can be used. This process takes several weeks.
- **Without an LPA:** If someone loses mental capacity without an LPA in place, an application may need to be made to the Court of Protection for someone to be appointed as a 'Deputy.' This process can be more complex, costly, and time-consuming than setting up an LPA.

- **Wills:**

- A Will sets out who you want to inherit your property and possessions (your 'estate') after you die, and who will be responsible for carrying out your wishes (your 'executors').
- After a dementia diagnosis, it's crucial to review an existing Will or make one if you haven't already. This ensures it accurately reflects your current wishes and is legally valid. The person making

or changing the Will must have 'testamentary capacity' (the ability to understand the implications of making a Will).

- Seek advice from a solicitor to ensure the Will is drafted correctly and is legally sound.

- **Benefits and Entitlements:**

- Investigate any state benefits or allowances the person with dementia or their carer may be entitled to. These can help with the costs of care and daily living. Key benefits in the UK may include:

- **Attendance Allowance:** For those over State Pension age who need help with personal care or supervision due to illness or disability.

- **Personal Independence Payment (PIP):** For those under State Pension age who need help with daily activities or getting around.

- **Council Tax Discounts, Exemptions, or Reductions:** Depending on circumstances, a reduction in Council Tax may be available.

- **Carer's Allowance:** For people who spend at least 35 hours a week caring for someone with substantial caring needs.

- Organisations like Age UK, Citizens Advice, Alzheimer's Society, Dementia UK, and the government's official website (gov.uk) can provide information and help with applications.

- **Advance Decision to Refuse Treatment (ADRT):** Also sometimes known as a Living Will or Advance Directive, an ADRT is a legally binding document (if made by someone with capacity, aged 18 or over, and it meets certain requirements) that allows you to state which specific medical treatments you wish to refuse in the future, in case you lose the capacity to consent or refuse at that time.

- **Advance Statement (of Wishes and Preferences):** This is a written statement that sets down your preferences, wishes, beliefs, and values regarding your future care. It is not legally binding in the same way as an ADRT for refusing treatment, but healthcare and social care professionals have a duty to take it into account when making decisions in your best interests.

- It's important to discuss these documents with your family, GP, and any other relevant healthcare professionals.

- **Managing Bank Accounts and Bills:**

- Consider simplifying finances, for example, by setting up Direct Debits for regular bills.

- While the person with dementia has capacity, they could consider adding a trusted person to their bank account (e.g., a joint account or a third-party mandate), but it's vital to understand the implications and take advice.

- An LPA for Property and Financial Affairs will allow attorneys to manage bank accounts and finances once registered and activated as appropriate.

- **Pensions and Investments:**

- Review pension arrangements and any investments. Understand how they can be accessed or managed if capacity is lost.
- A financial advisor can help, and attorneys appointed under a Property and Financial Affairs LPA can manage these if the donor loses capacity.

- **Paying for Care:**

- Arranging and funding care can be complex. Care can be provided at home or in a care home, and funding can come from various sources including local authority support (means-tested), NHS funding (e.g., NHS Continuing Healthcare, which is for primary health needs, not social care), or self-funding.
- The rules around paying for care are complicated and vary. It is highly recommended to seek specialist financial advice from an accredited later life financial advisor (e.g., one with SOLLA - Society of Later Life Advisers - accreditation) to understand your options.

- **Seek Professional Advice:**

- The information here is a general guide. It's essential to seek independent legal and financial advice from qualified professionals, such as solicitors specialising in elder law or Wills and Probate, and independent financial advisors specialising in later life planning. They can help you understand how the law applies to your specific situation and make informed decisions.

- **Note on UK Jurisdictions:**

- Please be aware that the laws and terminology for arrangements like Powers of Attorney and adult safeguarding differ between England & Wales, Scotland, and Northern Ireland. This guide primarily reflects the system in England and Wales. If you live in Scotland or Northern Ireland, you should seek advice specific to your region. The principles of planning ahead are, however, important across all parts of the UK.

Organisations like the Alzheimer's Society, Dementia UK, and Age UK (see "Useful Contacts") can provide more detailed information and signpost you to appropriate legal and financial advice services.



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Useful Contacts

Alzheimer's Society

Website: www.alzheimers.org.uk

Helpline: 0333 150 3456

Support groups, advice, and information.

Dementia UK

Website: www.dementiauk.org

Helpline: 0800 888 6678

Access to Admiral Nurses for specialist dementia support.

Age UK

Website: www.ageuk.org.uk

Advice and information on dementia care, benefits, and daily living.

NHS Dementia Services

Website: www.nhs.uk/conditions/dementia

Overview of diagnosis, treatment and care pathways.

Carers UK

Website: www.carersuk.org

Help and advice for those caring for someone with dementia.

Young Dementia Network

Website: www.youngdementianetwork.org

Samaritans

Website: www.samaritans.org

Helpline: 116 123 (available 24/7)

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