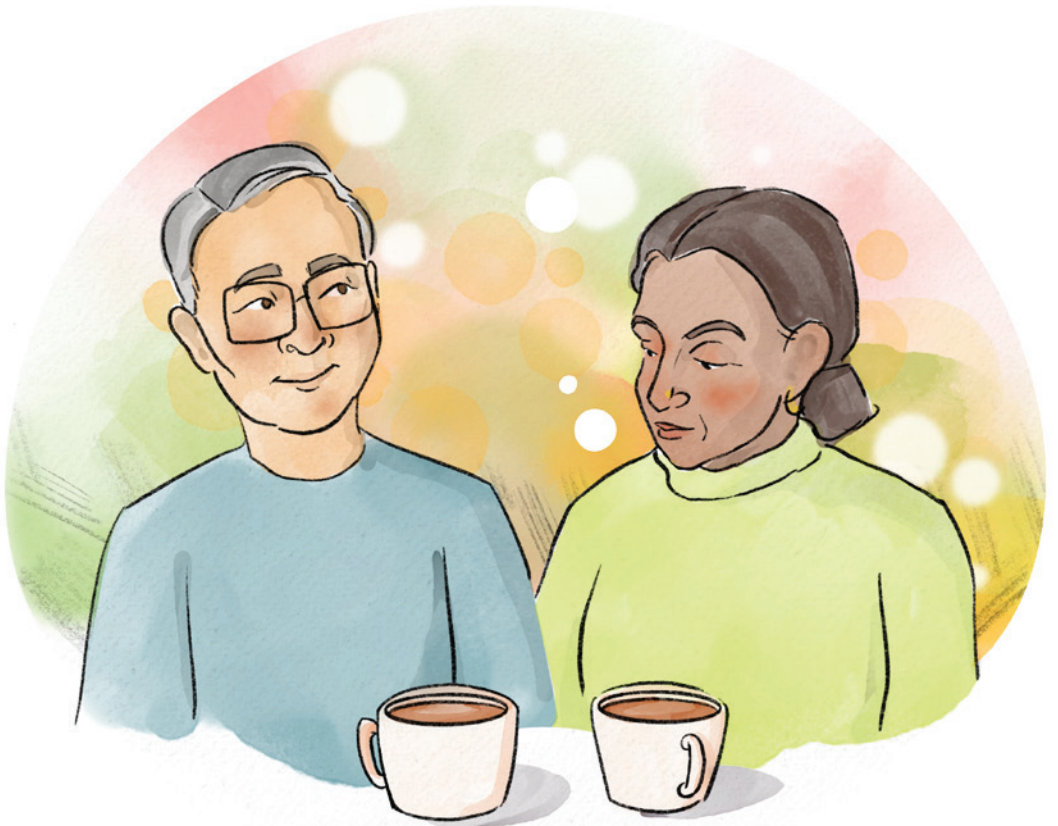


Autism and dementia



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This leaflet is for autistic people, their families and anyone who supports them. It has been developed by Dementia UK in collaboration with Autistica, King's College London and a lived experience group.

Autism and dementia are different conditions, but some people have both together. This guide explains the similarities, key differences, changes to look out for and how to find support.

We use the terms 'autistic person' and 'autistic people' in this guide. These are recommended by the National Autistic Society and are the preferred terms for many autistic people. However, we recognise that some people may prefer different terminology, such as 'person with autism'.

What is autism?

Autism is a lifelong difference in how a person experiences and interacts with the world. Every autistic person is different, but these are some of the things people might experience challenges with.

- **Communication:** many autistic people prefer clear and direct communication. Some autistic people may be non-speaking, non-verbal or communicate in other ways, such as writing, typing or using signs or pictures
- **Relationships and social situations:** social situations can sometimes feel confusing or overwhelming for autistic people. This may be because social cues and unspoken rules can be hard to understand, especially when there is a lot to take in
- **Changes in routines:** change can be stressful, and many autistic people value routines, clear plans and predictable environments

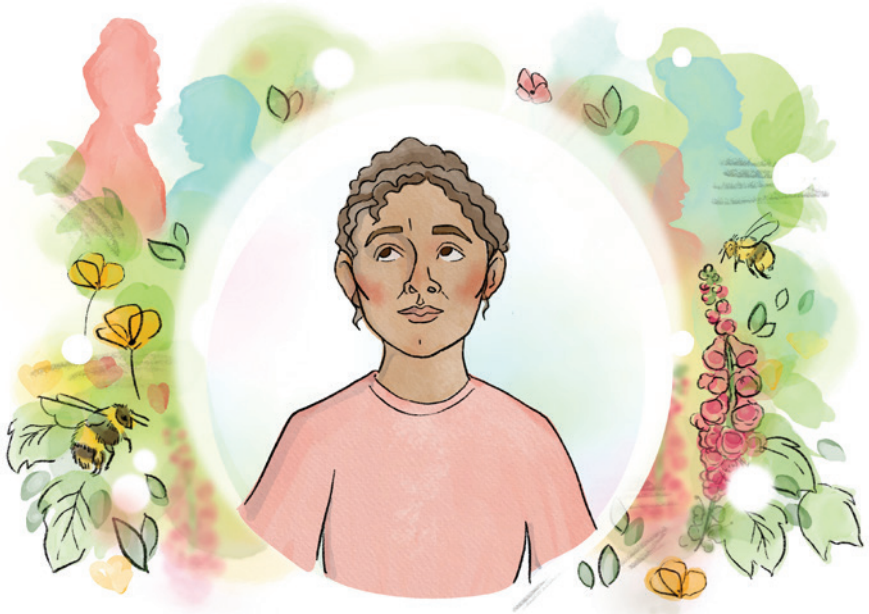


- **Sensory experiences:** bright lights, loud sounds, strong smells, certain textures or changes in temperature can feel overwhelming or even painful for some autistic people

Many autistic people are diagnosed as children, but sometimes autism is not diagnosed until adulthood. Some autistic people never receive a diagnosis. This might happen because they may change or hide their behaviours to fit in, meaning the signs of autism are missed. This is known as ‘masking’ or ‘camouflaging’.

Women and girls are less likely to be diagnosed with autism as their autistic traits might show up differently and are less well recognised.

Autism is not a learning disability, although some autistic people also have learning difficulties and disabilities.



What is dementia?

Dementia is a progressive condition that affects the brain and gets worse over time. It affects people's ability to remember, think and communicate, and can also lead to changes in personality, behaviour, mood and mobility. Over time, people with dementia will find it harder to manage everyday tasks.

There are many different types of dementia. The most common are Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia and mixed dementia (two or more types occurring together).

Dementia is most likely to affect older people, although it can also occur in younger people. When symptoms develop before the age of 65, it is known as 'young onset dementia'.

Symptoms of dementia

Dementia affects everyone differently and the symptoms will change over time, but common signs include:

- **Memory loss:** forgetting names and recent events; repeating questions; forgetting where things are
- **Cognitive changes (changes in thinking):** difficulty concentrating, solving problems or making decisions
- **Communication difficulties:** struggling to find the right words or follow conversations; difficulty reading and writing; for some people, becoming non-verbal in the later stages
- **Mood changes:** becoming more anxious, depressed, withdrawn, irritable or frustrated
- **Behaviour changes:** acting impulsively, or in ways that seem unusual or out of character
- **Struggling with daily tasks:** needing more help with familiar activities like cooking, shopping or getting dressed

Unlike autism, dementia always gets worse over time.

Understanding autism and dementia

Some autistic people will develop dementia, although we do not know if they are more likely to than non-autistic people. Autism and dementia can affect similar areas, such as communication, decision-making and behaviour. This can make it hard to tell whether changes are due to autism, dementia or both.

For example:

- An autistic person might already find words or communication challenging, so new language difficulties could be missed

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- If someone masks their autistic traits, dementia may make this harder, revealing behaviours that seem new or unexpected
- Difficulties with changes in routine, emotional responses and social understanding might be wrongly attributed to autism, when they could be signs of dementia

Noticing changes

Signs that someone might be developing dementia include:

- New or worsening memory problems, such as forgetting recent events or repeating questions
- Finding it harder to concentrate, solve problems or make decisions
- Struggling more than usual with communication, for example with finding the right words or following conversations
- Changes in mood, such as becoming more anxious, withdrawn or irritable
- Behaving in ways that are unusual or out of character
- Needing more help with daily tasks like cooking, shopping or getting dressed

These changes may be caused by something other than dementia, but if you have any concerns, you should speak to a GP. This means any other possible causes can be investigated, and if they are ruled out, a referral made for specialist dementia tests.

Diagnosing dementia in autistic people

Diagnosing dementia in autistic people can be complex, as traditional memory tests are not suitable for everyone, and dementia symptoms can show up and develop differently for each

person. However, if you notice possible symptoms of dementia, it is important to see a GP.

To help yourself and your GP you can:

- Write down any concerns or changes you have noticed before the appointment
- Take notes during the appointment or ask someone to take notes for you, or ask for a written summary
- Use an NHS Health Passport, if you have one: this can help healthcare staff understand your needs better, especially if communication is difficult. Visit [england.nhs.uk/health-and-care-passport](https://www.england.nhs.uk/health-and-care-passport) for more information
- Request reasonable adjustments for your appointment, such as a longer appointment or seeing a GP with training in autism-informed care – you can do this by speaking to the GP’s receptionist or practice manager in advance

In the appointment, the GP should ask questions about the changes you have noticed and do some initial checks and tests, including requesting blood tests. These tests may reveal that there is another cause of the changes, such as depression or anxiety, an infection, a vitamin deficiency or menopause.

However, if other conditions cannot be ruled out, the GP should refer the person to a specialist – usually a memory clinic – for more assessments.

If an autistic person is diagnosed with dementia, they should be told which type they have and what will happen next – for example, what treatments might be available to help manage the symptoms, and where to find support.



Supporting an autistic person with dementia

If you support an autistic person who has dementia, these strategies may help:

- Make sure you communicate clearly and directly – see Sources of support on p10 for communicating with a person with dementia
- Keep routines predictable
- Create a calm and sensory-friendly environment
- Support their emotional wellbeing
- Look out for changes in behaviour or needs and respond to these accordingly – seek support from the GP if you have concerns about the changes you are seeing

- Involve other people who know the person well and can help support them
- Create a personal profile document such as a ‘life story’ to help professionals understand the person and their needs – please see Sources of support on p10

Where to find help and support

If you are an autistic person with dementia, or are supporting an autistic person with dementia, our specialist Admiral Nurses are here to offer advice and support on our Helpline and in online and phone appointments. Please see Sources of support on p11 for contact details.

You will also find more information on all aspects of dementia on our website: [▶ dementiauk.org](https://dementiauk.org)

Your local council or Adult Social Care Services are responsible for arranging support for daily living, care needs and access to community services. They can provide assessments and advice, and help coordinate care packages tailored to your needs. You can find the details of your local Adult Social Care Services at [▶ nhs.uk/service-search/other-health-services/local-authority-adult-social-care](https://nhs.uk/service-search/other-health-services/local-authority-adult-social-care)

Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, ‘Dementia: what next?’ at [▶ dementiauk.org/dementia-what-next](https://dementiauk.org/dementia-what-next)

To speak to a dementia specialist Admiral Nurse, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit [▶ dementiauk.org/book](https://dementiauk.org/book)

Dementia UK resources

Creating a life story

[▶ dementiauk.org/life-story](https://dementiauk.org/life-story)

Financial and legal guidance

[▶ dementiauk.org/financial-and-legal-support](https://dementiauk.org/financial-and-legal-support)

Getting a diagnosis of dementia

[▶ dementiauk.org/how-to-get-a-diagnosis-of-dementia](https://dementiauk.org/how-to-get-a-diagnosis-of-dementia)

Learning disabilities and dementia

[▶ dementiauk.org/learning-disabilities](https://dementiauk.org/learning-disabilities)

Looking after yourself as a carer

[▶ dementiauk.org/looking-after-yourself-as-a-carer](https://dementiauk.org/looking-after-yourself-as-a-carer)

Tips for communication

[▶ dementiauk.org/tips-for-communication](https://dementiauk.org/tips-for-communication)

Types of dementia

➤ dementiauk.org/types

Understanding autism and dementia (long-read version)

➤ dementiauk.org/autism

Autistica resources

Autistica is a research and campaigning charity that funds and shapes autism research and policy. Its mission is to create high quality evidence and make breakthroughs that enable autistic people to live happier, healthier, longer lives.

➤ autistica.org.uk

Molehill Mountain: a mobile app to help autistic people understand and manage anxiety

➤ autistica.org.uk/molehill-mountain

Tips Hub: a mobile app with autism tips and resources to make everyday life easier

➤ autistica.org.uk/get-involved/autistica-tips-hub

Illustrations by Alice Haskill Art in collaboration with the lived experience group.

**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:

0800 888 6678 or [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:

[▶ dementiauk.org/book](https://dementiauk.org/book)

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit [▶ dementiauk.org/donate](https://dementiauk.org/donate)
- Scan the QR code



Thank you.



dementiauk.org • info@dementiauk.org

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