

Understanding autism and dementia

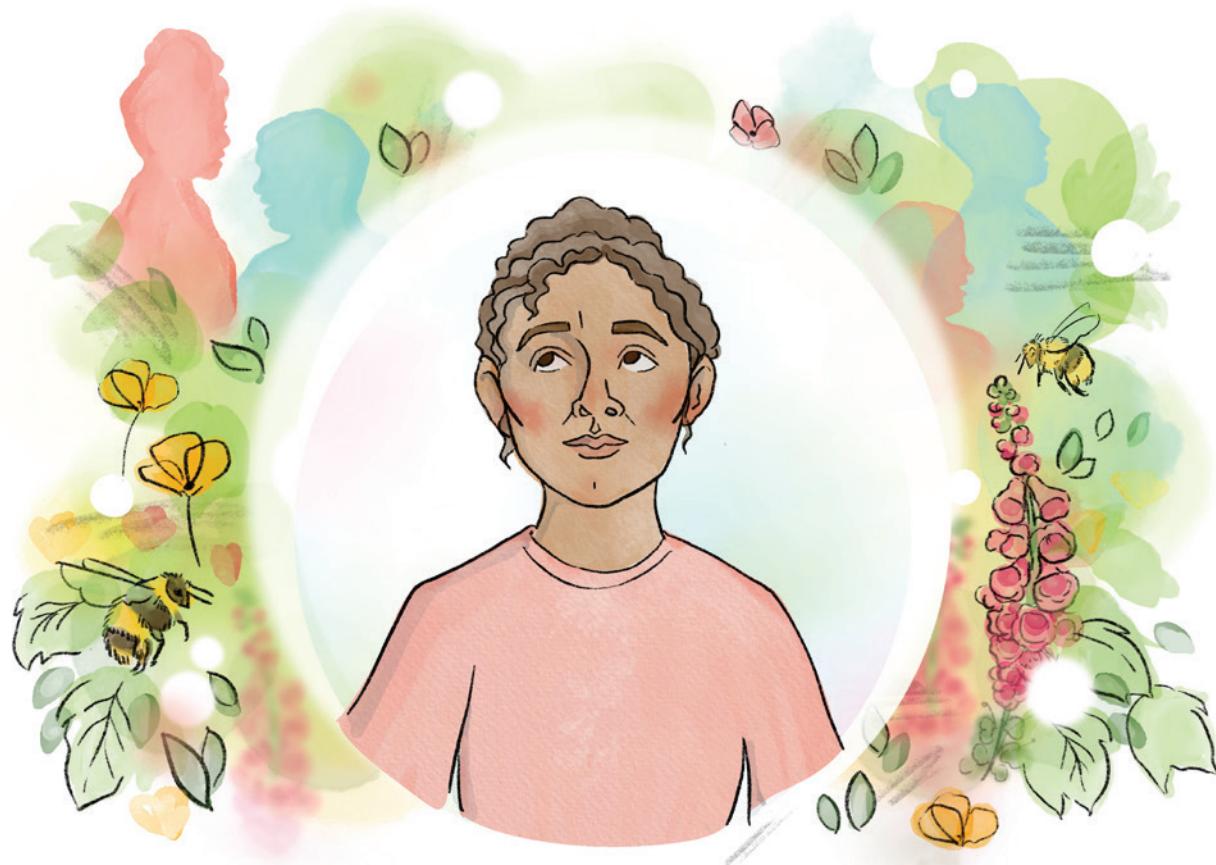
Who is this guide for?

This guide is for autistic people, their families and anyone who supports them.

Autism and dementia are different conditions, but some people have both together. This guide explains the similarities in the conditions, 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 terminology for many autistic people. However, we recognise that some people may prefer different terminology, including capitalising 'Autism'.





What is autism?

Autism is a lifelong difference in how a person experiences and interacts with the world. It can influence how someone communicates, builds relationships, adapts to change and responds to their surroundings.

Autism is different for everyone, and autistic people may think, feel and experience the world in ways that differ from non-autistic people, including in how they understand and connect with the world around them.

Autism may impact:

Communication styles and preferences: many autistic people prefer communication that is clear, precise and direct. Some autistic people may be non-speaking, non-verbal or prefer to communicate in other ways such as writing or using signs or pictures.

Relationships and social situations: social situations can sometimes feel confusing,

overwhelming or tiring for autistic people. For example, an autistic person might enjoy one-to-one conversations but find large groups overwhelming. This could be because of things like difficulties with reading social cues, interpreting unspoken rules or processing lots of information at once. Some people may need more time alone, or access to a quiet area to recharge after social interactions.

Routines: change can sometimes be stressful or difficult. Many autistic people value routines, clear plans and predictable environments. Even small changes, like moving mealtimes or rearranging furniture, could have a big impact.

Sensory experiences: bright lights, loud sounds, strong smells, certain textures or changes in temperature can feel overwhelming or even painful for autistic people. This can affect how someone feels and responds in different places.

Diagnosing autism

Autistic people are often diagnosed as children. Getting a diagnosis as an adult is much less common. This might be because a person masks their autistic traits, or because they do not fit a stereotypical idea of what autism looks like.

Women and girls are less likely to be diagnosed with autism. This may be because their autistic traits can show up differently and are not as well recognised or understood.

Some autistic people never receive a diagnosis, but this does not mean their experience of autism is any less valid.

Everyone has a right to be understood and supported.

Autism is not a learning disability, although some autistic people may also have a learning disability. Being described as 'high functioning' does not mean the person does not experience challenges or need support related to their autism.

You can find out more about autism on the [Autistica website](#), and read more about how autism is diagnosed in the [NICE \(National Institute for Health and Care Excellence\) guidelines](#).

What is 'masking'?

Many autistic people 'mask' or 'camouflage' their traits to better fit in or avoid negative reactions from non-autistic people. For example, they might force themselves to make eye contact even if this is difficult for them, copy other people's social behaviours or rehearse what to say before taking part in conversations.

Some people are not diagnosed with autism until later in life – or at all – because they have learned to mask so effectively that their differences and difficulties go unnoticed, even by trained professionals.

Masking can be tiring and can take a toll on a person's wellbeing. Research has linked it to stress, burnout and poorer mental and physical health. If non-autistic people have a better understanding of autism, autistic people can feel more accepted and included, and feel less pressure to mask. Inclusion and acceptance help create environments where autistic people can be themselves, access the right support and live happier, healthier, longer lives.



What is dementia?

Dementia is a condition that can affect memory, communication, personality and behaviour. It gets worse over time and can make it harder for a person to manage everyday tasks.

The speed at which dementia progresses varies from person to person. In many people, the changes are gradual and can be well managed if they receive the right support that adapts as their needs and abilities change. Other people experience a more rapid progression.

The symptoms of dementia vary from person to person, but common signs include:

- Memory problems: forgetting recent events, repeating questions or losing track of where things are. Older memories may be less affected
- Cognition changes: difficulty concentrating, solving problems or making decisions
- Communication difficulties: for example, struggling to find the right words or follow conversations
- Mood changes: such as becoming more anxious, depressed, withdrawn 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



Autism and dementia together

Some autistic people may develop dementia. Both conditions 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
- 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 or social understanding might be wrongly attributed to autism, when they could be signs of dementia

Every person is different, so how symptoms present and develop will vary. That is why it is important to know what is typical for the person – and to seek help if something feels different or unusual.

Diagnosing dementia in autistic people can be complex. Traditional memory tests are not suitable for everyone and there are no specific tests for diagnosing dementia in autistic people. A thorough and sensitive assessment is important and should include input from people who know the person well. It also helps to work with professionals who understand both autism and dementia.

Types of dementia and their effects

There are many different types of dementia. The most common are:

- ➊ **Alzheimer's disease**
- ➋ **vascular dementia**
- ➌ **frontotemporal dementia**
- ➍ **dementia with Lewy bodies**

Dementia is more common in older people, but it can also affect younger adults. When symptoms start before the age of 65, it is called young onset dementia.

Each type of dementia can present slightly differently. This can sometimes make it hard to **➋ get a diagnosis**. Dementia can also be harder to diagnose in younger people or if the person has a rarer type with less typical symptoms.

Everyone experiences dementia in their own way. It is important to look out for changes and seek support if you have concerns.

Getting an early diagnosis can help with accessing support, planning for the future and maintaining quality of life.

Tip: knowing the person well and understanding what is usual for them can help you spot changes and seek advice as soon as possible.

Read more about the different **➌ types of dementia**, including **➍ young onset dementia**.

Reducing your risk of dementia

There is no guaranteed way to prevent dementia, but a healthy lifestyle may help reduce the risk, as well as supporting overall physical and mental health.

Steps you can take:

Eat a balanced diet: include foods that are low in fat and sugar and high in fibre, and aim to eat at least five portions of fruit and vegetables each day.

Be physically active: for example by walking or swimming, or through daily activities like gardening or housework.

Stay connected: spend time with family, friends and/or online or in-person community groups.

Manage long-term health conditions: taking any medication that is prescribed, attending regular check-ups and ensuring healthcare professionals understand your support needs can all help you stay healthy and feel more in control.

Take part in activities you enjoy such as hobbies, creative projects, sport or anything else that makes you feel good.

Manage stress: find ways to relax and look after your mental wellbeing.

Limit alcohol: stay within recommended guidelines.

Avoid smoking: research has shown a strong link between smoking and dementia.

A GP can give advice on lifestyle choices and changes that have a positive impact on physical and mental health. They may be able to offer a health check or additional support if you have concerns.

Read more about **➌ reducing the risk of dementia**.

When to seek help

If you notice any changes in yourself, or in the person you support or care for, that you do not understand, it is important to seek help. You are not alone.

Book an appointment with a GP if you notice changes such as:

- new or worsening memory problems, such as forgetting events or repeating questions
- finding it harder to concentrate, solve problems or make decisions
- struggling more than usual with communication, for example 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

It is important to remember symptoms like these do not necessarily mean a person has dementia – they could be caused by stress, burnout, infection, medication side effects or another health issue. However, it is best to seek help if you are concerned.

Tip: talk to someone you trust. This could be a friend, family member, support worker or advocate. They can help you decide what to do next.

What to expect at the GP

If you have any concerns about possible symptoms of dementia, your GP can explore what is happening and should carry out some simple checks, such as a basic memory test. They may also refer you to a memory clinic for more detailed tests.

To help your GP, you can:

- write down any changes or concerns beforehand
- bring your **NHS health passport**, if you have one, to your appointment: this will help healthcare staff understand your needs better, especially if communication is difficult or you are in a new environment
- bring someone who knows you well to your appointment. They can help describe the changes and support communication between you and the doctor
- take notes, or ask the person you are with to take notes, or ask for a written summary

You can request reasonable adjustments to help make healthcare appointments easier and more accessible, such as having longer GP appointments or seeing a health professional with training in autism-informed care. However, these adjustments are not always applied consistently across NHS services.

If you experience any difficulties requesting reasonable adjustments, you can contact

Patient Advice and Liaison Service (PALS): a free service to help you resolve concerns or problems with your NHS treatment. Your GP surgery can provide details. If you prefer, you can contact an independent advocacy organisation like **VoiceAbility**.

Tip: you can also speak to your GP about an autism NHS health check.

Supporting autistic people with dementia: advice for carers

While there is currently no cure for dementia, the right treatment, support and coping strategies may help to manage the symptoms and make daily life easier.

There is no one-size-fits-all approach to supporting someone with dementia. It may involve some trial and error and learning as you go. Additionally, the person's support needs and preferences may change as their dementia progresses. However, support should always respect their comfort, dignity and preferences. Wherever possible, include the person in decisions about their care and support.

Strategies that might help:

Use clear and direct communication: using plain language, written notes or visual supports (such as pictures, symbols or colour-coded schedules) can make things easier to understand. Some people may also find emojis or gesture-based prompts helpful. Our tips for [communicating with a person with dementia](#) may be useful.

Keep routines predictable: many autistic people and those with dementia find comfort and stability in routine. Sudden changes can be disorientating and distressing. Try to keep daily activities, surroundings and people as consistent as possible. If change is needed, explain it clearly in advance using the communication tips above.

Create a calm and sensory-friendly environment: autism and dementia can both affect how someone experiences sound, light, textures and other sensory input. Adapt the environment to the person's preferences where possible. This could include using soft lighting, offering quiet spaces or making sure clothing feels comfortable.

Support emotional wellbeing: dementia may increase a person's anxiety, leading to emotional responses like frustration or withdrawal. Being calm, patient and reassuring may help to reduce [distress](#). Activities that are enjoyable or calming, such as listening to [music](#), engaging

with nature or taking part in hobbies, can be helpful. Familiar items, such as photographs or a favourite mug, may provide comfort.

Notice changes in behaviour or needs: it may be hard for the person to explain or show how they feel. Small changes in mood, appetite, sleep or behaviour could point to discomfort, pain or distress. Knowing what is 'usual' for the person makes it easier to spot when something is wrong.

Involve people who know the person well: family, friends and long-term carers and supporters can help explain preferences, routines and behaviours. Trusted people and familiar faces are especially important as dementia progresses.

Create a personal profile document such as a [life story](#): this outlines the person's likes, routines and sensory needs and will help health and social care professionals understand them better.

Looking after yourself as a carer

If you are caring for someone with dementia and/or autism, it is important to take care of your own wellbeing. There are many sources of support, including groups and networks for carers and counselling services.

You might be able to get financial help, such as Carer's Allowance. It is also a good idea to request a [carer's assessment](#) from your local council to identify what support might help, for example a break from your caring responsibilities.

You can contact Dementia UK's Admiral Nurses – specialist nurses who support people with dementia and their families and carers – for advice at any stage, from pre-diagnosis to [grief and bereavement support](#). [Find out how we can help](#).

Tip: sharing experiences with others can build understanding, learning and support.

Staying safe and supported as an autistic person with dementia

Living with autism and dementia can bring additional challenges, for example with managing daily life and health conditions or becoming isolated. As an autistic person, it is important that your support network continues to respect who you are. This includes supporting your communication style, preferences and sensory needs.

Support could come from:

- trusted people such as family members or advocates
- services that understand both autism and dementia
- safe, comfortable places to live that meet sensory and social needs

If you have concerns about your own safety, or the safety of someone you care for, there are laws and protections in place to help. This is known as 'safeguarding'. You can speak to a GP or social worker for advice or contact the Safeguarding Team via the local council's Adult Social Services.

Tip: ask for a care needs assessment from the local council. This should consider any support needs relating to autism and dementia, including communication preferences, support with routines and sensory adaptations.

Staying connected

Whether you have autism and dementia or are supporting someone close to you, staying connected with people who understand your experiences is important. Support groups, peer networks and online communities can help you feel heard, included and supported. They provide opportunities to share experiences, advice and encouragement with people who understand your situation. You can often find local listings on noticeboards at your library, GP surgery, community centre or places of worship.

Planning ahead with confidence

Planning ahead can help make sure that a person's views and preferences – for example, their wishes around future care – are understood and recorded. This means any decisions can be taken in the person's best interests if their support needs change over time. It reduces future stress and makes any changes easier to navigate.

Planning for the future with dementia is sometimes known as 'advance care planning' and includes thinking about preferences for care and support, medical treatment and financial decisions. Read more about [advance care planning](#).

Decision-making and legal rights

Everyone has the right to make decisions about their own life. The law (Mental Capacity Act 2005) protects a person's right to make their own choices, as long as they have the [mental capacity](#) to do so. This means being able to understand the decision, make an informed choice and communicate that decision to others. Sometimes people may need help to understand information or communicate their choices. Autistic people and those with dementia may express their preferences in different ways, so adjustments like extra time, clear explanations or visual information may be needed as part of any decision-making process.

Tip: to make sure decisions are made in the person's best interests if they become unable to make them themselves, it is important to set up a [lasting power of attorney](#) (LPA). This is a legal process that enables a trusted person/people to make decisions about someone's health, care and finances if they lose mental capacity.

Managing finances and accessing financial support

Managing money can feel complicated but knowing what support is available can help you feel more in control, whether you are living with dementia yourself or supporting an autistic person with dementia. You might want to find out more about:

- **Attendance Allowance, Personal Independence Payment (PIP) or disability benefits:** financial support with the additional costs of having a long-term disability or health condition like dementia
- **Council support:** local councils may offer grants or help with adaptations at home to make life safer and easier
- **Carer's Allowance:** a benefit for people who care for someone for 35 hours a week or more, depending on their own financial position
- **Other financial support:** this could include help with Council Tax, housing benefits or social care funding

You can ask your local  **Citizens Advice** for guidance on benefits, eligibility and how to apply.

Read our information on  **financial and legal support.**

Tip: applying early for benefits or financial support can make a big difference. Getting help from someone you trust can make the process easier and less stressful.

Living well at home and in the community

A safe and comfortable living environment can play a big role in helping people feel supported and maintain their independence as far as possible. For autistic people and those with dementia, this might include providing quiet spaces, ensuring clear communication from support workers or carers, and maintaining routines that make daily life more predictable.

Living options might include:

- staying at home with the right support if possible
- housing that suits the person's routine and preferences, such as supported living or autism-friendly housing providers
- a residential care home, in the later stages of dementia

Tip: it can be helpful to start thinking about the types of support or care you might prefer in the future, and to understand what options are available. You can talk to your GP, support worker or an Admiral Nurse if you'd like help exploring these.

Where to find more help and information

Whether you are an autistic person living with dementia or are supporting someone, you can find lots of advice and information through [Dementia UK](#), [Autistica](#), other charities and support groups. Some organisations offer helplines, groups and online communities where you can connect with people who have similar experiences.

The local council's Adult Social Care Team can help with arranging care needs assessments, support for daily living and access to community services, and help coordinate care packages tailored to individual needs.

Support from Dementia UK

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](#)

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](#)

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](#)

Dementia UK resources

- [Advance care planning \(including template\)](#)
- [Financial and legal sources of support](#)
- [Getting a diagnosis of dementia](#)
- [Getting the best out of health appointments](#)
- [Lasting power of attorney](#)
Includes information on equivalent powers of attorney in Scotland, Wales and Northern Ireland
- [Learning disabilities and dementia](#)
- [Looking after yourself as a carer](#)
- [Mental capacity and decision-making](#)
- [Types of dementia](#)
- [What is young onset dementia?](#)

Support from Autistica

➤ **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 and longer lives.

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

➤ **Molehill Mountain:** a mobile app to help autistic people understand and self-manage anxiety

Other resources

- [Carer's Allowance](#)
- [Care needs assessment](#)
- [Citizens Advice](#)
Free, confidential advice on money, benefits, housing, legal rights and more
- [Find local authority Adult Social Care Services](#)
- [Find your local council](#)
- [Making a Will](#)
- [NHS health passport](#)
- [Patient Liaison and Advice Service \(PALS\)](#)
Free, confidential advice, support and information on NHS health matters
- [Personal Independence Payment \(PIP\)](#)
- [VoiceAbility](#)
Advocacy around health, care and wellbeing