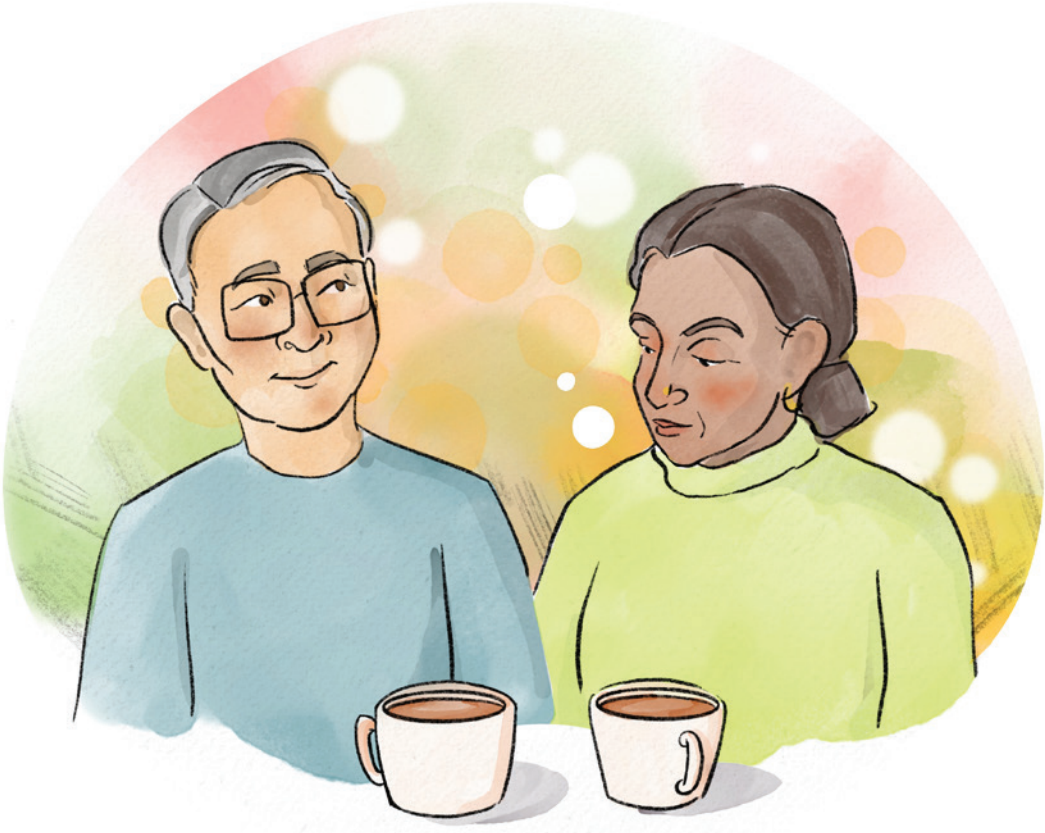
DementiaUK
Helping families face dementia

Understanding autism and dementia

A guide for professionals supporting autistic adults



Introduction

Autism and dementia are different conditions, but some people experience both together.

This guide is for healthcare and social care professionals who support autistic adults, including professionals working in legal, forensic, criminal justice and service organisations, and policy makers.

The guide explains how dementia may present in autistic people, signs to be aware of, and where to get more information and guidance. It aims to promote autism-informed, rights-based and person-centred care by increasing professionals' understanding of how autism and dementia may interact, and what good support looks like across services.

Terminology and language

In this information resource, we use identity-first language, such as 'autistic people/person', reflecting the preference of many autistic people and recommendations from organisations including Autistica and the National Autistic Society. We recognise that individual preferences will vary and some people may prefer person-first language such as 'people with autism'.

TIP Ask the person which terminology they prefer and use it consistently.

What is autism?

Autism is a lifelong condition, and autistic people often experience and interact with the world differently. This can include differences in:

- **Communication:** some autistic people use few or no words, while others prefer written or other non-verbal communication.



Autistic people may also focus on concrete details and literal interpretations, finding abstract or figurative speech more difficult to understand

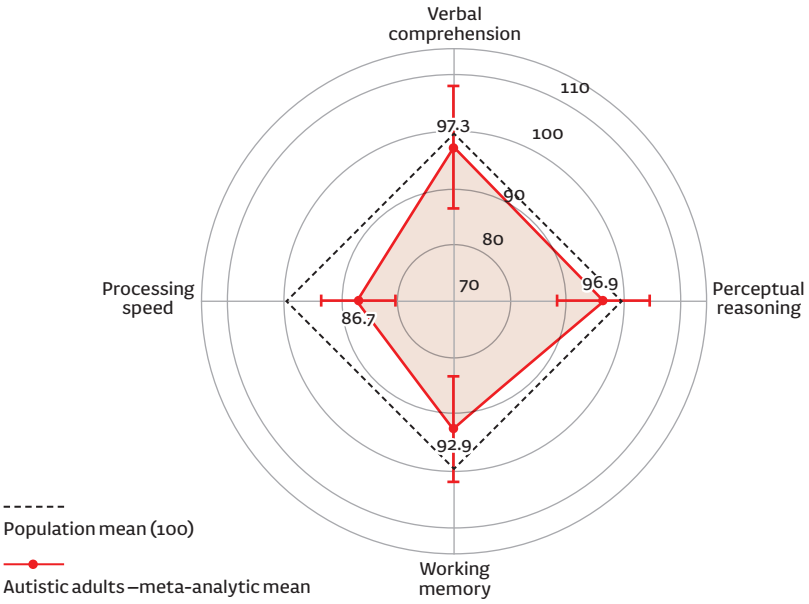
- **Relationships:** some autistic people may find social interaction, social rules and social roles difficult or exhausting
- **Routine and predictability:** some autistic people find changes difficult to manage
- **Sensory processing and experiences:** sights, sounds, textures, temperature and other sensory input might be experienced either very intensely or less strongly by autistic people compared to non-autistic people

How autistic people experience these characteristics can vary considerably. Autistic people may have different cognitive abilities, and some might have a learning difficulty or intellectual disability.

Some autistic people have a 'spiky' cognitive profile. This means they have an uneven distribution of cognitive strengths and limitations, with the differences between abilities being markedly greater than in the general population. Abilities and support needs can also be affected by environmental stressors and changes in physical and mental health, and at different life stages.

Pooled WAIS-IV index scores across autistic-adult samples

Group-level standard scores (population mean = 100; SD = 15)



Depiction of spiky cognitive profiles in autistic adults: adapted from Wilson (2024) – a systematic review and meta-analysis that pooled Wechsler Adult Intelligence Scale (WAIS-IV) index scores from 437 autistic adults identified through searches of large literature databases.

While our understanding of autism has changed greatly over the past several decades, many autistic people reach later life without an autism diagnosis. This is particularly true for women and others whose autistic traits are less well recognised or understood, better masked, or have been attributed to other conditions.

Autistic people may also experience other physical and mental health differences, and other forms of neurodivergence such as attention deficit hyperactivity disorder (ADHD) and dyspraxia, alongside autism.

Because autism is lifelong, it is important to plan for the future to effectively support autistic people in older age, improve quality of life and empower them to thrive.

What is dementia?

Dementia is an umbrella term for more than 200 neurodegenerative conditions that cause progressive change in cognitive function and cannot be reversed. Common types of dementia include Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia and mixed dementia (two or more forms that occur together).

Depending on the type of dementia and the individual, the signs and symptoms include changes in:

- memory
- thinking
- decision-making
- communication
- mood
- behaviour
- the ability to manage everyday activities

While dementia is more common in older adults, younger people can also be affected. Where symptoms develop before the age of 65, it is known as 'young onset dementia'. In very rare cases, dementia can also affect children.

Shared characteristics of autism and dementia

Autism and dementia are distinct conditions, but can share certain characteristics such as:

- **behavioural differences** with social interaction and communication
- **psychological/emotional experiences**, such as anxiety and depression
- **cognitive challenges** with executive function, social cognition and language processing

This overlap can make it harder to identify dementia in an autistic person. The key question is not what characteristics are present, but what has changed in the person's usual way of functioning.

Diagnosis and assessment

Diagnosing dementia in an autistic person

Diagnosing dementia in an autistic person can be complex because of the overlap in characteristics between the two conditions. When new symptoms or changes are assumed to be part of a person's autism rather than investigated as possible signs of dementia or another health condition, this is known as 'diagnostic overshadowing'. Professionals should look for new or progressive changes in the person's usual communication, behaviour, abilities and everyday functioning, rather than focusing simply on whether particular characteristics are present.



Changes in behaviour, communication, cognition and daily functioning do not necessarily indicate dementia. They may instead be signs of depression, anxiety, autistic burnout, sleep difficulties, physical illness or pain, medication side effects, delirium or changes in hearing or vision.

Autistic people may experience or communicate pain, distress and illness differently, so withdrawal, increased sensory sensitivity, reduced communication or loss of skills should be explored carefully.

Because autism presents differently in every person, changes may be more obvious in some people than others. 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. They may be able to mask dementia symptoms as well.

However, masking can be tiring and can take a toll on a person's wellbeing, resulting in poorer mental and physical health, which may present similarly to dementia. Dementia itself may also make masking more difficult, with previously hidden autistic traits becoming more apparent.

In someone with lifelong challenges in the characteristics mentioned, subtle changes can be difficult for healthcare professionals to identify. Standard cognitive screening tools may not accurately capture an autistic person's abilities. Most cognitive tests are not designed with neurodivergent people in mind. Throughout the diagnostic process, assessment should consider the individual's cognitive profile, communication needs and usual functioning.

Types of dementia: why awareness matters

Dementia can present in different ways depending on the type and the individual and does not always begin with memory problems. While Alzheimer's disease is the most recognised form, other types, such as frontotemporal dementia, may initially affect language, social understanding or behaviour, rather than memory.

In an autistic person, these changes can be easily misinterpreted unless clinicians understand the person's usual communication style and characteristics. Being autism-informed is essential to avoid diagnostic overshadowing and ensure appropriate support.

Certain health or genetic conditions may be associated with an increased likelihood of developing dementia. However, in many cases, dementia is not inevitable, and assumptions should not be made on the basis of another diagnosis or a person's age.

What matters most is recognising changes in a person's usual pattern of functioning. Regular input from those who know the person well is key to identifying when additional assessment or support may be needed.

TIP Record and regularly review a person's communication style, abilities and behaviour profile to support early identification of cognitive change.

Understanding baseline variation and monitoring change

Whenever possible, services should record information about a person's cognitive, communication and daily functioning abilities. This then provides a baseline against which future changes can be compared.

Autistic people who also have a learning disability may be eligible for an annual health check through their GP, which can provide an opportunity to identify any early signs of dementia.

Where routine reviews are not available, concerns about any new or worsening changes over time should be recorded and shared with the person's GP. Information from the person and, with their consent, people who know them well can be particularly valuable.

TIP Encourage the autistic person to bring someone who knows them well to health appointments. They can provide advocacy and a collateral history by describing any changes they have noticed, and when.

Understanding sensory preferences

Autistic people may experience certain sensory information differently. Some people may be hyper-sensitive to sensory input (for

example feeling uncomfortable around loud noises or bright lights), while others may be hypo-sensitive (for example not feeling the cold or dressing inappropriately for the weather). Some people may also be sensory-seeking and actively engage with some sensory stimuli (for example having a strong preference for certain fabrics).

Understanding the individual's sensory needs and preferences can considerably support their ability to engage with healthcare services and allow for their specific needs to be met.

Accessible, autism-informed care

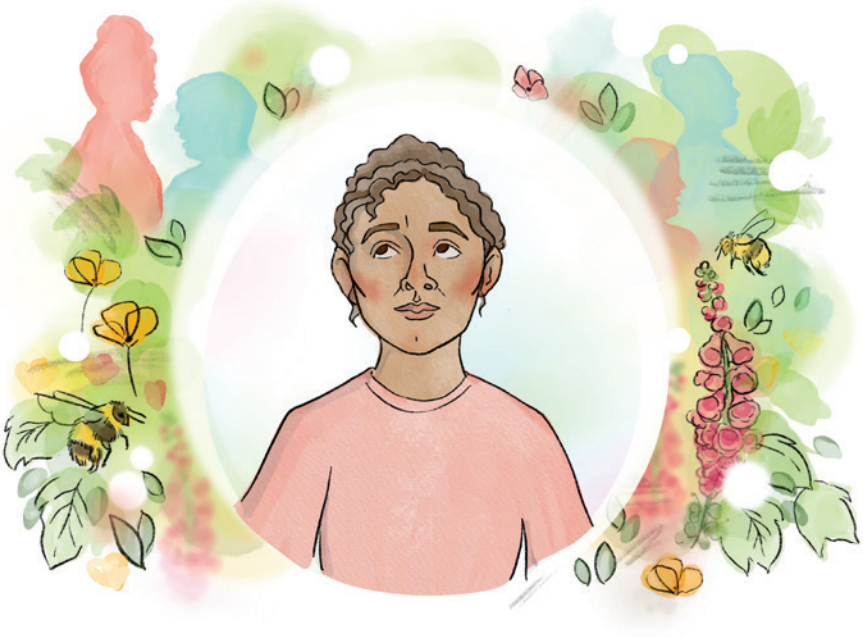
Making dementia services accessible

Dementia services should make reasonable adjustments based on individual needs. A person-centred approach to each autistic individual can greatly increase their likelihood of engaging with dementia healthcare services and thus receiving a timely diagnosis and the necessary support.

The NHS Health Passport is a useful resource that gives autistic people the opportunity to communicate their needs to healthcare staff ahead of their appointment. It allows autistic people to state what adjustments they require and what communication needs they have, so that they can be supported and accommodated as is their right under the Equality Act 2010, the Autism Act 2009 (England legislation), and the amended Autism Act Northern Ireland (2022).

Communication across services

Dementia services and autism services typically operate distinctly. Within them, staff may have expertise in one area or the other, but rarely both. Good communication between services, either in the form of knowledge sharing or direct training, could greatly improve the experiences of autistic people during the dementia diagnosis



process and encourage well-timed and appropriate referrals between services.

TIP Do not assume that another service has recorded, communicated or acted on an important change. Record concerns clearly and confirm who is responsible for follow up.

Access to social care and reasonable adjustments

Older autistic adults may have long-standing or emerging support needs. Under the Care Act 2014 (England), all adults have a right to a care needs assessment, which must consider autism-related needs including sensory regulation, communication, anxiety and routines.

The Social Care (Self-Directed Support) (Scotland) Act 2013 places duty on local authorities to offer people eligible for community care a range of choices on how they receive their support, meaning collaboration is key.

In Wales, the Social Services and Well-being (Wales) Act 2014 requires local authorities to assess adults who appear to have care and support needs. Assessments must consider the person's individual needs and desired outcomes, including autism-related needs where relevant, with their involvement central to planning support.

In Northern Ireland, the Health and Personal Social Services (Northern Ireland) Order 1972 and Disabled Persons (Northern Ireland) Act 1989 underpin assessment and support through local Health and Social Care Trusts. The Carers and Direct Payments Act (Northern Ireland) 2002 also enables eligible people to arrange their own support through direct payments, supporting choice and control.

Care planning should be person-centred and include appropriate reasonable adjustments, such as accessible communication, predictable routines, low-sensory environments or advocacy where required. Family members or other supporters should be involved if the person wants this and provides consent.

Health inequalities and the role of professionals

Autistic people are more likely to experience health inequalities, including delayed diagnosis, barriers in access to care and unmet needs. These disparities can widen in older age.

Barriers may include inaccessible appointment systems, unsuitable sensory environments, poor support for communication differences, lack of reasonable adjustments and limited professional understanding of autism. New symptoms may also be incorrectly attributed to autism, a learning disability, mental health difficulties or ageing. This diagnostic overshadowing can result in missed or delayed diagnoses.

Professionals can help address this by proactively offering reasonable adjustments, building trust and working together across autism and dementia services.

TIP Being autism-informed can help reduce barriers to care and is a key part of reducing inequality.

Supporting autistic people to live well with dementia

Legal rights and capacity: what professionals need to know

Autistic people with dementia retain the same legal rights as other adults and are protected under several UK laws that affirm their right to make decisions and access support in ways that meet their needs.

People with dementia often lose the mental capacity to make decisions as their condition progresses. Under the Mental Capacity Act 2005, capacity must be presumed unless proven otherwise in relation to the specific decision being made, and account for how information is presented. This is especially important for autistic individuals who may communicate non-verbally or process information differently.

Please note that this legislation applies to England and Wales only, and the Adults with Incapacity (Scotland) Act 2000 can be consulted for a Scottish context. In Northern Ireland, the Mental Capacity Act (Northern Ireland) 2016 is only partially in force; many decisions about care and treatment remain governed by common law.

Healthcare professionals should:

- seek to use clear, concrete and sensory-considerate formats to present information

- allow time for reflection
- support decision-making with any required materials
- involve independent advocates where needed

TIP If a person is assessed as lacking capacity, decisions made on their behalf must reflect their best interests, incorporating their known wishes, beliefs and values. This includes aspects related to neurodivergent or autistic identity.

Safeguarding older autistic adults

Older autistic adults may be more vulnerable to safeguarding risks including exploitation, neglect or abuse. Social isolation, communication differences and inaccessible support can heighten this risk and make it harder to identify or report concerns.

It is important to recognise that distress or withdrawal may signal safeguarding issues and to apply adult safeguarding processes in an accessible way that is neurodiversity-informed.

TIP Evidence-based and person-centred autism understanding should be embedded into safeguarding training. In this way, safeguarding guidelines and responses can encompass the early recognition of risk and inform more appropriate responses and support.

Planning for the future: supporting autonomy and advance decision-making

Advance care planning can help autistic adults express and record their preferences about future health, care and financial decisions while they have capacity to do so.

Tools such as lasting power of attorney (LPA) (England and Wales), power of attorney (PoA) (Scotland) and enduring power of attorney (EPA) (Northern Ireland) should be introduced early, ensuring the person has time and support to understand their options.

The use of NHS Health Passports and advance statements should also be encouraged to record wishes, while supporting individuals and families to prepare by focusing on control and empowerment, not crisis.

TIP Frame future planning around choice and control, rather than crisis.

Housing and living environments

Safe, accessible and predictable environments can be particularly important for an autistic person living with dementia. Changes to living arrangements should consider the individual's preferences and sensitivities, including sensory and social needs and routines.

It is important that professionals know that local authorities have a duty to assess housing needs and that housing adaptation grants or supported accommodation schemes may be necessary. All changes to living environments should be planned carefully to reduce distress.

TIP Autistic people should be supported to make housing decisions that take into account their current and future needs.

Financial considerations and advocacy in later life

Dementia may affect a person's ability to manage finances, benefits or financial decisions. This makes it crucial for professionals to have the knowledge to signpost to welfare rights advisors or advocacy services, as well information on claiming

benefits such as Carer's Allowance, Personal Independence Payment (PIP) and Pension Credit.

Within this, professionals should identify whether the individual has capacity to manage their finances, and if not, involve appropriate safeguards (for example appointeeship or LPA).

TIP Advocacy plays a crucial role in helping older autistic adults access entitlements and make informed financial decisions.

Further information and autism training resources

The following organisations, tools and guidance may be helpful for professionals, autistic people and their families.

The list also contains resources for professionals, such as further reading, clinical tools and training.

Further reading

What is autism?

Stewart, GR and Happé, F 2025. Aging across the autism spectrum. Annual Review Developmental Psychology. 7:461-484.
doi.org/10.1146/annurev-devpsych-111323-090813

Wilson, AC (2024). Cognitive profile in autism and ADHD: a meta-analysis of performance on the WAIS-IV and WISC-V. Archives of Clinical Neuropsychology: the official journal of the National Academy of Neuropsychologists, 39(4), 498-515.
doi.org/10.1093/arclin/acad073

Types of dementia
Dening, T and Sandilyan, MB (2015). Dementia: definitions and types. Nursing Standard (Royal College of Nursing (Great Britain): 1987), 29(37), 37-42. **doi.org/10.7748/ns.29.37.37.e9405**

Understanding sensory preferences
Patil, O and Kaple, M (2023). Sensory processing differences in individuals with autism spectrum disorder: a narrative review of underlying mechanisms and sensory-based interventions. Cureus, 15(10), e48020. **doi.org/10.7759/cureus.48020**

National organisations and support

Dementia UK
The specialist dementia nursing charity. Our nurses, known as Admiral Nurses, provide support, advice and information to people living with dementia, their families, and professionals supporting those affected by dementia.
dementiauk.org
Free Helpline: **0800 888 6678**
Online and telephone virtual clinic appointments:
dementiauk.org/book

Autistica
Research- and evidence-based resources, toolkits and policy guidance to improve services and outcomes for autistic people, helping them live happier, healthier, longer lives.
autistica.org.uk

Citizens Advice
Information on legal rights, money management and financial support, benefits and housing.
citizensadvice.org.uk

National Autistic Society
Advice and guidance for autistic people, their families and healthcare professionals.
autism.org.uk

Clinical and practical tools

Annual health checks
Available to autistic adults with a learning disability. Keep up to date with NHS England plans to extend access to all autistic adults.
england.nhs.uk/learning-disabilities/health

Communication Passport
A person-centred tool that shares how someone prefers to communicate and be supported.
communicationpassports.org.uk

NHS Health Passport
A document that communicates key information about a person's healthcare needs, communication preferences and reasonable adjustments.
england.nhs.uk/health-and-care-passport-plain-english

Planning and rights

Autism and Neurodiversity Toolkit (Skills for Care)
Practical guidance for staff and service leaders.
skillsforcare.org.uk

Employers' Guide to Neurodiversity (Autistica)
Evidence-based guidance for employers to support reasonable adjustments in the workplace for autistic people.
autistica.org.uk/get-involved/employers/employers-guide

The Equality Act 2010
A legal requirement to make reasonable adjustments to avoid discrimination.
legislation.gov.uk/equality-act-2010

Disability Discrimination Act 1995 (Northern Ireland)
An act that makes it unlawful to discriminate against disabled people in Northern Ireland.
legislation.gov.uk/ukpga/1995/50/contents

Lasting power of attorney (LPA) (England and Wales)
A legal framework enabling individuals to appoint someone to make decisions on their behalf, if needed.
gov.uk/power-of-attorney

Enduring power of attorney (EPA) (Northern Ireland)
A similar framework to LPA in England and Wales, applicable in Northern Ireland and covering financial issues only.
nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney

Power of attorney (PoA) (Scotland)
An equivalent legal framework to LPA in England and Wales, applicable in Scotland.
mygov.scot/power-of-attorney

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

Contact our Helpline:
0800 888 6678 or **helpline@dementiauk.org**

Book a virtual appointment:
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**
- Scan **the QR code**

Thank you.

Dementia UK
Helping families face dementia

King's College London

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