



DementiaUK

Helping families face dementia

**Informational
resources about
dementia for Autistic
people, their
supporters and
healthcare
professionals**

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Dementia UK is a registered charity in
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Our team



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What is autism?

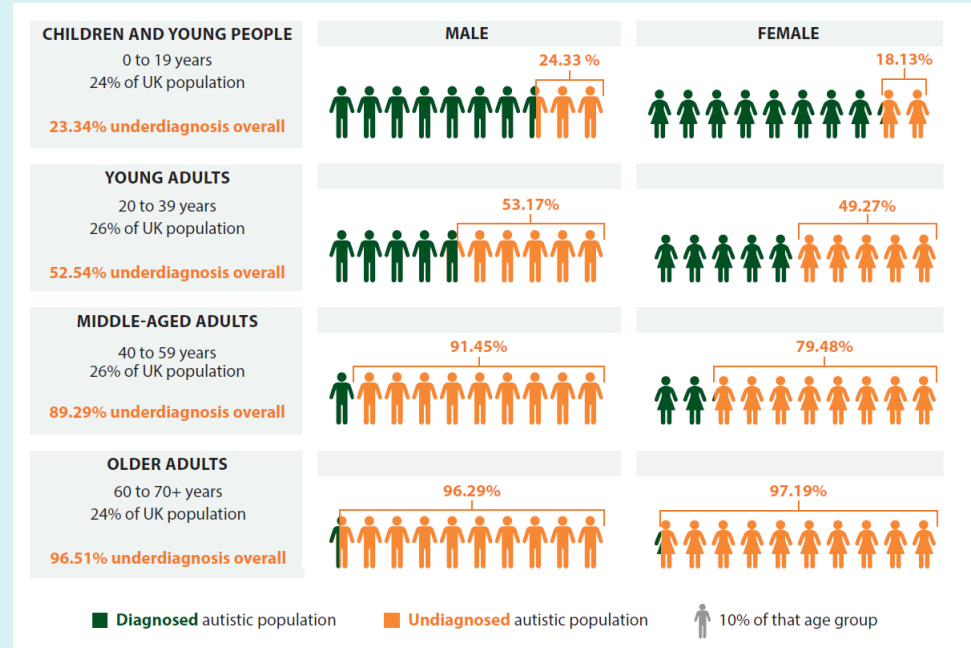
- Autism is a **lifelong neurodevelopmental difference**
- It can affect how a person communicates, processes and interacts with the social world around them
- The differences in communication, attention and sensory processing experienced by autistic people can bring **strengths and challenges** in different contexts. Because autism is a spectrum, there can be huge variation in people's abilities, support needs and experiences.



Prevalence and diagnosis of autism

Stewart and Happé 2025

- **90%** of Autistic adults over 40 are likely not to have a diagnosis of Autism
- Last year almost 200,000 people were awaiting assessment for autism
- In recent years autism **diagnoses in the UK have increased rapidly**, between 1998 and 2018 diagnoses increased by **787%**
- Around 1-2% of the UK population is autistic – that's between **600,000 to 2.1 million**
- While often diagnosed in childhood, early signs can be missed, meaning many people learn they are autistic in adulthood.
- Autism is more commonly diagnosed in males, prevalence rate in males is 2.8%, compared to 0.65% in females.



1.2 million

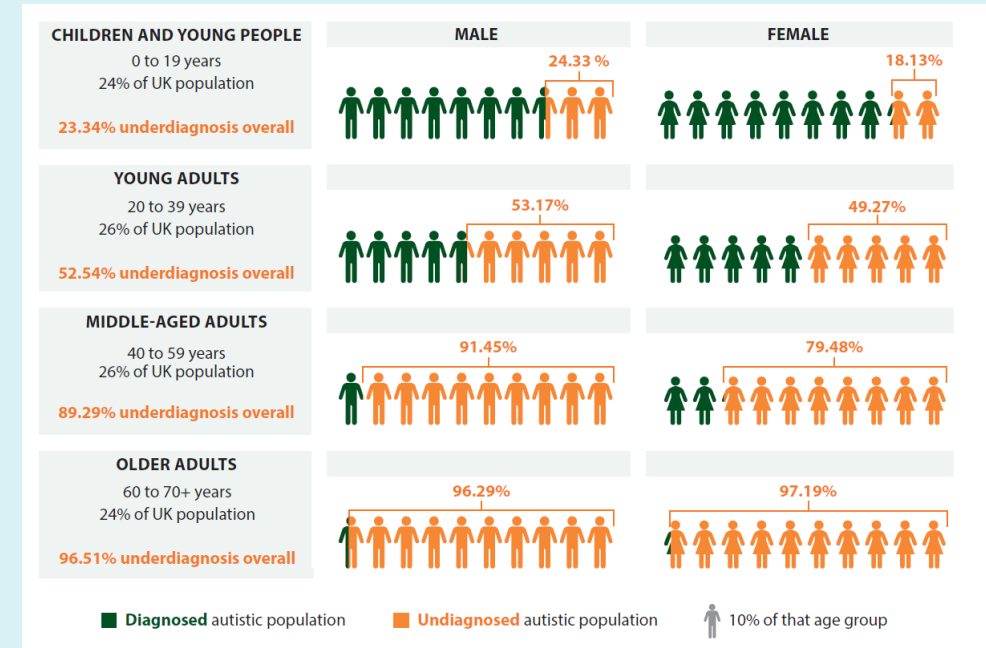
Researchers estimate that there are up to 1.2 million undiagnosed autistic adults in the UK

Dementia and autism research

Stewart and Happé 2025

Research

- Just **0.4%** of Autism research focuses on older adults
- Research in the US found that Autistic people are **2.6x more likely** to develop dementia, specifically young onset dementia
- It is not yet known how generalisable this is to all autistic people



Autism and Dementia: A Summative Report from the 2nd International Summit on Intellectual Disabilities and Dementia

M. P. Janicki^{1,14} · P. McCallion² · N. Jokinen³ · F. K. Larsen⁴ · D. Mughal⁵ · V. Palanisamy⁶ · F. Santos⁷ · K. Service⁸ · A. Shih⁹ · S. Shoostari¹⁰ · A. Thakur¹¹ · G. Tiziano¹² · K. Watchman¹³

Research Letter | Neurology

Prevalence of Dementia Among US Adults With Autism Spectrum Disorder

Giacomo Vivanti, PhD; Wei-Lin Lee, MAS; Jonas Ventimiglia, MAS; Sha Tao, MPH; Kristen Lyall, ScD; Lindsay L. Shea, DrPH

Autism and Dementia

- Autistic traits can be mistaken for early signs of dementia
- Dementia can be overlooked or misinterpreted as autistic traits
- Masking of traits can mean dementia is missed
- Both conditions can affect executive function
- No specific tests available to diagnose dementia in autistic people

Information and resources

SEARCH RESULTS

Nothing Found

Sorry but we could not find anything which resembles you search criteria. Try again.



Support and Care for People with Dementia

December 30, 2024 | Autism World



Diagnosis Assessments Dementia

December 30, 2024 | Autism World



Signs and Symptoms of Dementia

December 27, 2024 | Autism World



Causes and Risk Factors of Neurological Conditions

December 30, 2024 | Autism World



Dementia Autism Challenges

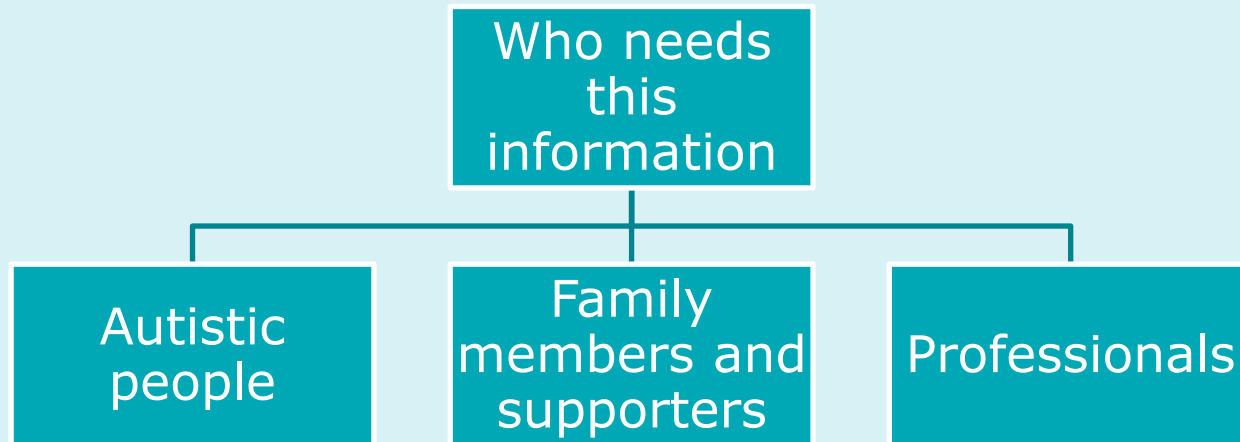
December 27, 2024 | Autism World



Understanding Dementia

December 27, 2024 | Autism World

Our project



Our research cohort	N
Autistic person	6
Person with dementia	1
Family carer of someone with dementia or Autism	2
Family member of someone with dementia or Autism	4
Professional who works with Autistic people or people with dementia	3
Autism researcher	2

What they told us



Awareness, training and understanding



Challenges accessing and navigating services and support

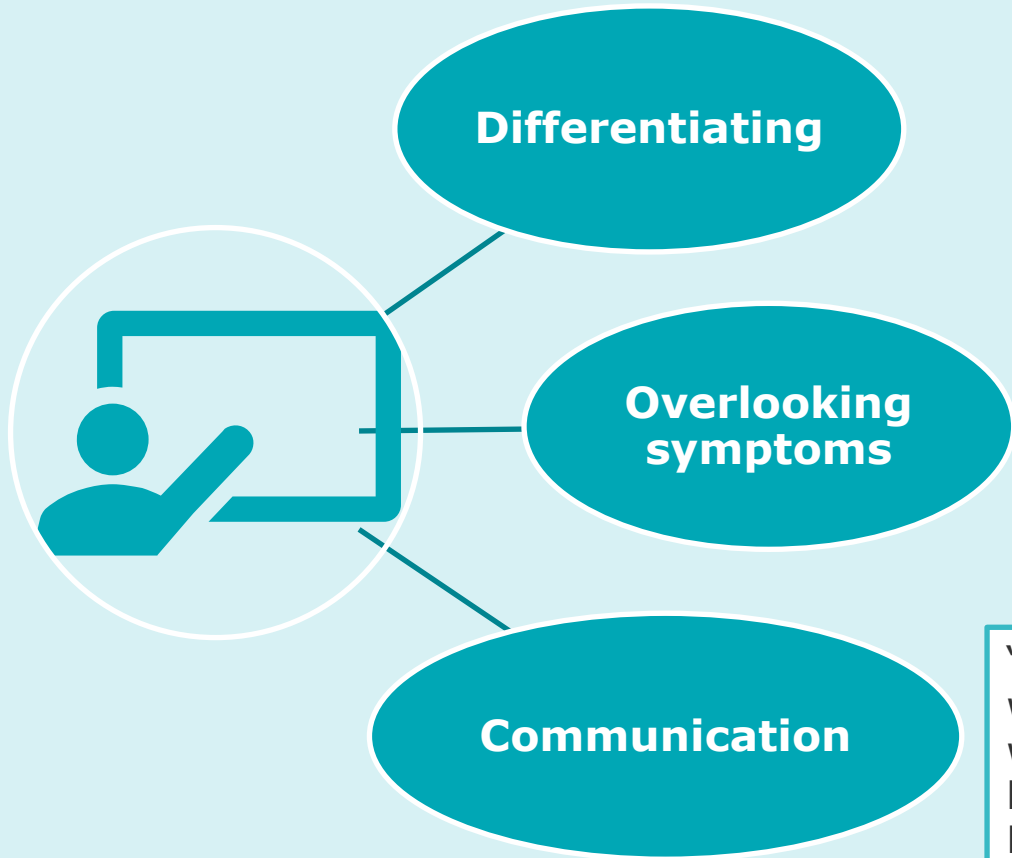


Misunderstandings and assumptions



Practical support and resources

Awareness, training and understanding



"Some of the first signs may be difficulties with social interaction... something that autistic people struggle with all the time but are also signs of dementia. Separating them out is difficult."

— *S4 autistic person with a parent with dementia*

"It's about awareness of these different conditions and trying to increase education, but also communication between different services."

— *P2 Autism researcher*

"You have groups of professionals who work with autistic people... and people with dementia, and often there is very little understanding of the other. Because it's just not something that come on people's radar."

- *P2 Autism researcher*

Challenges accessing and navigating services and support

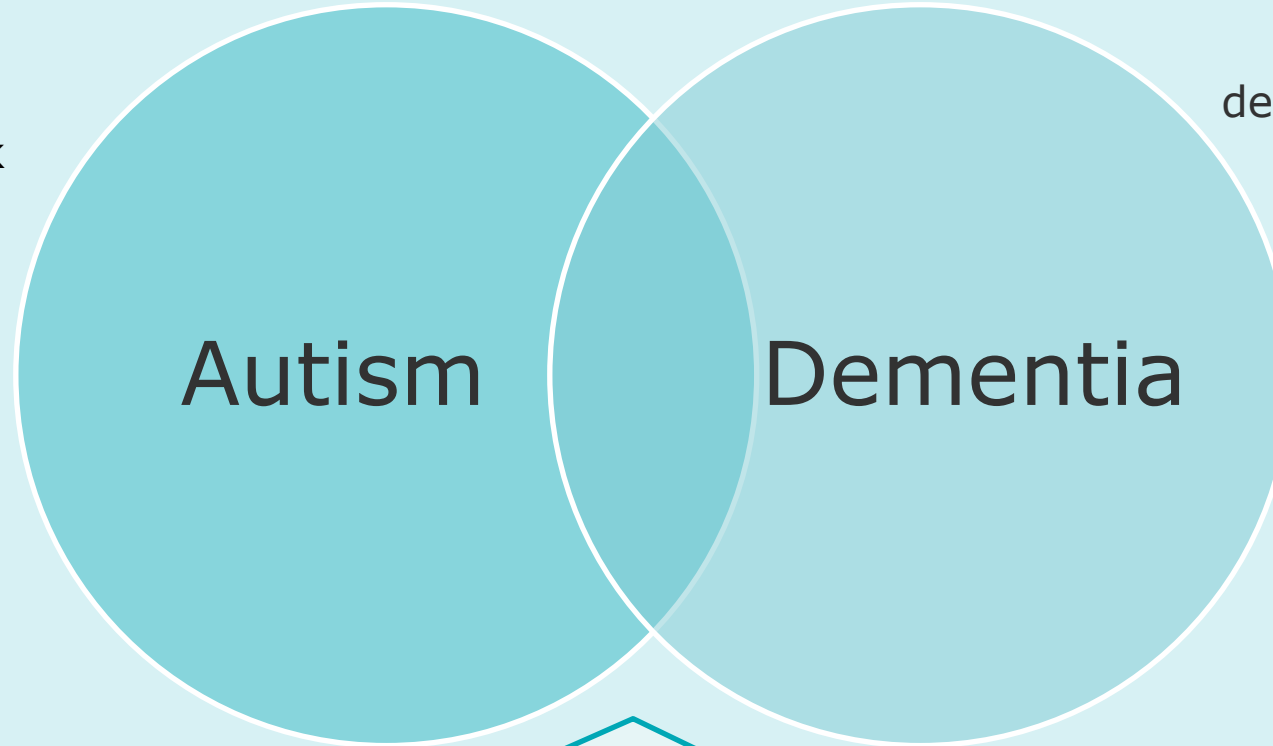
"You're pigeonholed into one or the other, and I think this will straddle service provision structures. At the moment it's really hard sometimes to access the right service."
— S2 Care worker with autistic adults

My experience of getting diagnosed at 46 is like, here you go, you're Autistic. Good luck with that. Good luck with the comorbid conditions and the increased risk of mental health conditions."
— S3 autistic person and dementia carer

Misunderstandings and assumptions

“People are perceived as being less intelligent than they are, if they have autism people think they have a lower understanding. Assume that if you’re non-verbal you’re stupid.”

- IJ family member



“They usually think about the cognitive symptoms of dementia, and they often don’t or aren’t very aware of the behavioural difficulties...”

- P2 autism researcher

“Expecting dementia to show up the same in people with autism and typical people, it doesn’t.”

- IO autistic person and family member

Practical support and resources

“Utilising what is already available with the NHS Autism Passport... it gives an autistic person the opportunity to put down on paper everything that is important to them within an environment.”
- *S5 Autistic person*

“People very often just won’t even claim because they can’t put themselves through that process.”
- *P1 family member*



““It would be really good if it could just be mentioned on the leaflet that if you are Autistic, that under the Equalities Act, people do need to accommodate you and you only have to make them aware of what you need to be accommodated.”
- *S5 Autistic person*



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'.



Long Version



Short Version



Image designed by
www.alicehaskell.com
in co-production with
Autistic people & families

Thank you

Any questions? Please email me:
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The resources for Autism and Dementia will be available for free on dementiauk.org and www.autistica.org.uk