

Autistica Action Briefing: Other Co-Occurring Conditions

AUTISTICA

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Autistica is the UK's autism research charity. A number of our Action Briefings have focused on specific health problems that autistic people often face. This briefing summarises the most important scientific findings about other co-occurring conditions. It was developed in collaboration with leading researchers and autistic people and families with lived experience of the topic to provide insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, commissioners, services and research funders to act on this information. There is increasing evidence that autistic people are more likely to experience a range of physical and neurological health problems; the services and policies focused on tackling those conditions need to consider ways to address these health inequalities.

www.autistica.org.uk/AutismStrategy

"I struggle with debilitating fatigue and pain that no doctor has been able to explain. Some doctors say it's because I'm autistic. No support has been offered. Because of this, I'm unable to work or leave my house for extended periods of time." ¹

What we know

"I have never slept through the night my entire life. I believe this is associated with autism and my sensory issues, but no-one seems to be able to help." ¹

- Autistic people generally experience poorer health outcomes than the general population² and are **more likely to develop a wide range of conditions** including heart disease, diabetes, stroke, Parkinson's disease, allergies, gastro-intestinal disorders and autoimmune conditions.³
- Difficulties with sleep are common amongst autistic people**, who often experience a longer delay before falling asleep and poorer refreshment on waking up.^{1,4,5,6,7} Sleep disorders are associated with a variety of other health problems.⁸
- Autistic people appear to face **increased rates of obesity**^{3,9,10} and **diabetes**.^{3,11} Reasons for this include difficulties eating a varied diet¹² from issues such as sensory differences,¹³ and barriers to accessing physical activity.^{8,14}
- While autism is not a mental health condition, **mental health conditions are the norm rather than the exception for autistic people**,^{15,16} and suicidality and suicide rates are exceptionally high within the autistic community.^{17,18} Autistica have recently published a series of research and policy recommendations to improve mental health in autistic people.¹⁹
- Many autistic people are prescribed psychotropic medication, such as antipsychotics, for long periods**, even if they haven't been diagnosed with the conditions those drugs are intended to treat.^{20,21,22,23} Giving someone a treatment they don't need is dangerous, and the long-term use of psychotropics is associated with a range of health problems.^{24,25,26,27}

What we need to find out

"The NHS doesn't seem to be able to shed any light on our son's chronic stomach issues." ¹

Autistic people appear to be much more likely to develop a wide range of health conditions.³ However, **more work needs to be done in order to ensure autistic people receive effective healthcare**.²⁸ Key areas for research include:

- Are autistic people at greater risk of cardiovascular events, gut problems, stroke, diabetes, neurological and autoimmune conditions than non-autistic people? Why is this, and how can these risks be reduced?^{29,30}
- What can we learn about the current use of residential facilities by older autistic adults?^{29,30}
- What is the incidence of Parkinson's disease among autistic people and what are the associated risk factors?
- How can researchers and autistic people work in partnership to investigate biological factors affecting the health and wellbeing of autistic people?^{29,30}
- Are hypermobility syndromes more frequent in autistic people and why?³¹
- What are the factors affecting problems with sleep in autistic people? How can we improve sleep in autistic people?^{7,28}
- How effective are existing public health initiatives, such as social prescribing and encouraging healthy diet and exercise, in reaching autistic people? How can these initiatives be improved for autistic people?

What we should do now

- A number of health conditions had only begun to be linked to autistic people when the Autism Act (2009)³² or Think Autism Strategy (2014)³³ were published. The Government recently made reducing early death the primary aim of the Autism Strategy^{34,35} and has launched a review of the Strategy for the future.³⁶

We now know that autistic people are more likely to experience poor outcomes from a range of health conditions. The Department of Health and Social Care should ensure that managing co-occurring conditions becomes a “priority challenge for action”,³⁷ as part of a wider theme on reducing early death.

- The NHS Long Term Plan³⁸ includes detailed commitments about tackling cancer, cardiovascular disease, strokes, diabetes and respiratory disease.

All clinical priority teams within NHS England should consider the health inequalities facing autistic people and people with learning disabilities in their ongoing work.

- The Long Term Plan committed to piloting specific health checks for autistic people and, if successful, to extending these more widely.³⁸ Autistica and the National Autistic Society have recruited a Policy Officer to tackle the practical and policy changes in delivering health checks.

NHS England should work closely with Autistica and National Autistic Society policy teams to deliver this commitment using an evidence-based approach with the involvement of autistic people and their families.

- The NHS also recently announced that the STOMP-STAMP programme to stop the overmedication of autistic people and people with learning disabilities would be expanded.³⁸ Anonymised NHS data is vital for ensuring that programmes like STOMP-STAMP can be delivered and monitored effectively. Public Health England recently found that there wasn't enough data available to analyse how many autistic adults are at risk of overmedication.²⁷

NHS England, NHS Digital and local health services need to prioritise improving the consistency and quality of NHS records concerning autistic people's healthcare, particularly within primary care.

- The NHS Long Term Plan highlights that “‘research-active’ hospitals have lower mortality rates” and prioritises action to reduce preventable deaths amongst autistic people.³⁸ Few clinical innovations in different specialisms are focusing on testing the effectiveness of interventions for autistic people despite the high rates of health inequalities.

The National Institute for Health Research, NHS England, and public, private and third sector research funders need to collaborate and support more healthcare professionals to become involved in impactful autism research.

1 Autistica (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters, conducted in October 2018. 2 Rydzewska E, et al. (2019) General health of adults with autism spectrum disorders – A whole country population cross-sectional study. *Research in Autism Spectrum Disorders* 60, 59-66. <[scencedirect.com/science/article/pii/S1750946719300133](https://doi.org/10.1016/j.rasd.2018.10.012)> 3 Croen L, et al. (2015) The health status of adults on the autism spectrum. *Autism* 19(7), 814-123. <[ncbi.nlm.nih.gov/pubmed/25911091](https://doi.org/10.1177/1063426914562285)> 4 Baker E & Richdale A (2015). Sleep Patterns in Adults with a Diagnosis of High-Functioning Autism Spectrum Disorder. *Sleep* 23(11), 1765-1774. <[academic.oup.com/sleep/article/38/11/1765/2662285](https://doi.org/10.1093/sleep/23/11/1765)> 5 Baker E & Richdale A (2017) Examining the Behavioural Sleep-Wake Rhythm in Adults with Autism Spectrum Disorder and No Comorbid Intellectual Disability. *J Autism Dev Disord* 47(4), 1207-1222. <[ncbi.nlm.nih.gov/pubmed/28160224](https://doi.org/10.1007/s10803-016-2762-0)> 6 Ballester P, et al. (2018) Sleep problems in adults with autism spectrum disorder and intellectual disability. *Autism Research* 12(1). <[onlinelibrary.wiley.com/doi/full/10.1002/aur.2000](https://doi.org/10.1002/aur.2000)> 7 Cohen S, et al. (2014) The relationship between sleep and behaviour in autism spectrum disorder (ASD): a review. *J Neurodev Disord* 6(1), 44. <[ncbi.nlm.nih.gov/pmc/articles/PMC4271434](https://doi.org/10.1007/s12246-014-0271-4)> 8 Grandner M (2018) Sleep, Health, and Society. *Sleep Med Clin* 12(1), 1-22. <[ncbi.nlm.nih.gov/pmc/articles/PMC6203594](https://doi.org/10.1016/j.smcl.2017.11.001)> 9 McCoy S, et al. (2016) Comparison of Obesity, Physical Activity, and Sedentary Behaviors Between Adolescents With Autism Spectrum Disorders and Without. *Journal of Autism and Developmental Disorders* 46(7), 2317-2326. <[link.springer.com/article/10.1007/s10803-016-2762-0](https://doi.org/10.1007/s10803-016-2762-0)> 10 Broder-Fingert S, et al. (2014). Prevalence of Overweight and Obesity in a Large Clinical Sample of Children With Autism. *Academic Pediatrics* 14(4), 408-414. <[ncbi.nlm.nih.gov/pubmed/24976353](https://doi.org/10.1016/j.acped.2014.03.003)> 11 Chen M, et al. (2016) Risk of Developing Type 2 Diabetes in Adolescents and Young Adults With Autism Spectrum Disorder: A Nationwide Longitudinal Study. *Diabetes Care*. <[care.diabetesjournals.org/content/diacare/early/2016/03/19/dc15-1807.full.pdf](https://doi.org/10.2337/141111)> 12 Mari-Bauset S, et al. (2014) Food Selectivity in Autism Spectrum Disorders: A Systematic Review. *Journal of Child Neurology* 29(11), 1554-1561. <[dadun.unav.edu/bitstream/10171/34300/1/ZazpeFoodautism.pdf](https://doi.org/10.1177/088526551454422)> 13 Cermak S, et al. (2010) Food selectivity and sensory sensitivity in children with autism spectrum disorders. *J Am Diet Assoc* 110(2), 238-246. <[ncbi.nlm.nih.gov/pmc/articles/PMC3601920](https://doi.org/10.1016/j.jada.2009.11.001)> 14 Blagrove A & Colombo-Dougovito A. (2019) Experiences Participating in Community Physical Activity by Families with a Child on the Autism Spectrum: a Phenomenological Inquiry. *Advances in Neurodevelopmental Disorders*. <[link.springer.com/article/10.1007/978-1-4939-9094-0_15](https://doi.org/10.1007/978-1-4939-9094-0_15)> 15 Lever A & Geurts H (2016) Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders* 46(6), 1916-1930. <[ncbi.nlm.nih.gov/pubmed/26861713](https://doi.org/10.1007/s11467-016-0611-3)> 16 Simonoff E, et al. (2008) Psychiatric disorders in children with ASD: prevalence, comorbidity and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry* 47(8), 921. <[ncbi.nlm.nih.gov/pubmed/18645422](https://doi.org/10.1111/j.1469-7610.2008.01962.x)> 17 Hirvikoski T, et al. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 207(5), 232-8. <[ncbi.nlm.nih.gov/pubmed/26541693](https://doi.org/10.1111/bjp.12693)> 18 Autistica (2016). Personal tragedies, public crisis: The urgent need for a national response to early death in Autism. <[autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf](https://www.autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf)> 19 Autistica (2019). Recommendations for changes to the Autism Strategy. <[autistica.org.uk/AutismStrategy](https://www.autistica.org.uk/AutismStrategy)> 20 Houghton R, et al. (2018) Psychiatric Comorbidities and Psychotropic Medication Use in Autism: A Matched Cohort Study with ADHD and General Population Comparator Groups in the United Kingdom. *Autism Res*. 11(12), 1690-1700. <[ncbi.nlm.nih.gov/pubmed/30380202](https://doi.org/10.1002/aur.2000)> 21 Park S, et al. (2016) Antipsychotic Use Trends in Youth With Autism Spectrum Disorder and/or Intellectual Disability: A Meta-Analysis. *J Am Acad Child Adolesc Psychiatry* 55(6), 456-468. <[https://www.ncbi.nlm.nih.gov/pubmed/27238064](https://doi.org/10.1093/aag/aaq064)> 22 Esbensen A, et al. (2009) A Longitudinal Investigation of Psychotropic and Non-Psychotropic Medication Use Among Adolescents and Adults with Autism Spectrum Disorders. *J Autism Dev Disord* 39(9), 1339-1349. <[ncbi.nlm.nih.gov/pmc/articles/PMC2829244](https://doi.org/10.1007/s10803-009-0003-3)> 23 Public Health England (2015). Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England <[bit.ly/2Fdkh9](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/429492/2Fdkh9)> 24 Dimensions & Books Beyond Words (2018). My GP and Me: Making primary care fair <[dimensions-uk.org/get-involved/campaigns/make-gps-accessible-mygpandme/report/](https://www.dimensions-uk.org/get-involved/campaigns/make-gps-accessible-mygpandme/report/)> 25 NHS England (2018). Stopping over medication of people with a learning disability, autism or both. <[england.nhs.uk/learning-disabilities/improving-health/stomp/](https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/)> 26 Canitano R & Scandurra V (2008) Risperidone in the treatment of behavioral disorders associated with autism in children and adolescents. *Neuropsychiatr Dis Treat* 4(4), 723-730. <[ncbi.nlm.nih.gov/pmc/articles/PMC2536539](https://doi.org/10.1080/14737170802356539)> 27 Public Health England (2019) Psychotropic drugs and people with learning disabilities or autism. <[gov.uk/government/publications/psychotropic-drugs-and-people-with-learning-disabilities-or-autism](https://www.gov.uk/government/publications/psychotropic-drugs-and-people-with-learning-disabilities-or-autism)> 28 Murphy C, et al. (2016) Autism spectrum disorder in adults: diagnosis, management, and health services development. *Neuropsychiatr Dis Treat* 12, 1669-1686. <[ncbi.nlm.nih.gov/pmc/articles/PMC4940003](https://doi.org/10.1080/14737170802356539)> 29 Autistica (2017). Global Summit on Autism throughout the Lifespan: Physical Health & Wellbeing. <[autistica.org.uk/downloads/files/Ageing-Summit-Report.pdf](https://www.autistica.org.uk/downloads/files/Ageing-Summit-Report.pdf)> 30 Warner G, et al. (2018) Workshop Report: Establishing Priority Research Areas to Improve the Physical Health and Well-Being of Autistic Adults and Older People. *Autism in Adulthood* 1(1). <[liebertpub.com/doi/10.1089/aut.2018.0003](https://doi.org/10.1089/aut.2018.0003)> 31 Cederlöf M, et al. (2016) Nationwide population-based cohort study of psychiatric disorders in individuals with Ehlers-Danlos syndrome or hypermobility syndrome and their siblings. *BMC Psychiatry* 16:207. <[ncbi.nlm.nih.gov/pmc/articles/PMC4932739](https://doi.org/10.1186/s12874-016-0273-9)> 32 HM Government (2009). Autism Act 2009. <[legislation.gov.uk/ukpga/2009/15/pdfs/ukpga_20090015_en.pdf](https://www.legislation.gov.uk/ukpga/2009/15/pdfs/ukpga_20090015_en.pdf)> 33 DHSC (2015). 'Think Autism': an update to the government adult autism strategy. <[bit.ly/1eef55P](https://www.thinkautism.org.uk/2015/05/20/think-autism/)> 34 DHSC (2018). Think Autism strategy: governance refresh 2018. <[gov.uk/government/publications/think-autism-strategy-governance-refresh-2018](https://www.gov.uk/government/publications/think-autism-strategy-governance-refresh-2018)> 35 Autistica (2018). Government to make early death top priority for autism policy. <[autistica.org.uk/news/government-make-early-death-the-top-priority-for-autism-policy](https://www.autistica.org.uk/news/government-make-early-death-the-top-priority-for-autism-policy)> 36 Hansard (2019). Minister of State for Care, responding to Health and Social Care Oral Questions on 15th Jan 2019. <[bit.ly/2RPPoolZ](https://www.parliament.uk/business/committees/committees-a-z/commons-secondary/health-and-social-care/oral-questions/2019-01-15/)> 37 DHSC (2015). Think autism: updating the 2010 adult autism strategy. <[bit.ly/2O2YUCc](https://www.thinkautism.org.uk/2015/05/20/think-autism/)> 38 NHS (2019). The NHS Long Term Plan. <[longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf](https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf)>