

Autistica Action Briefing: Eating Disorders

AUTISTICA

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Autistica is the UK's autism research charity. This briefing summarises the most important scientific findings about eating disorders in the autistic community. It was developed in collaboration with leading researchers and autistic people with experience of eating problems as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, NICE, commissioners, services and public research funders to act on this information. The evidence about eating disorders in the autistic community has moved on; services and policies aimed to tackle them must now do so as well.

www.autistica.org.uk/AutismStrategy

"I'm just so heavy with my peers and friends dying... I can think of 3 friends I suspect will die this year and that is just people I know. I know of others just allowed to exist at weights that absolutely will mean they die in 5-10 years and this is just accepted because they have ASD"

What we know

"I almost died from anorexia at university. Had I been diagnosed with ASD prior to/during anorexia I would have recovered more quickly. The support I received did not help me at all."¹

- Approximately **1 in 5 women with anorexia** in eating disorder services are autistic.^{2,3,4}
- Anorexia has the **highest mortality rate of any mental illness**. Other eating disorders also significantly increase people's risk of dying early.⁵
- **Autistic people with anorexia face worse outcomes** than their non-autistic peers, with reduced levels of recovery and more persistent difficulties with their wider mental health, social skills and employment.^{6,7,8}
- **Anorexia assessments and treatments will need to be significantly adapted** for some autistic patients. Factors typically associated with anorexia, like the thin ideal or fat-phobia, may be less common or significant for autistic people who develop eating disorders, according to preliminary evidence and accounts from lived experience.^{9,10,11,12}

What we need to find out

"There appears to be no service to address my son's serious binge eating and no one with an understanding of the low mood, sensory and reward issues surrounding it."¹

Research is beginning to explore **how anorexia and other eating disorders can differ for autistic people**.^{13,14,15} It is important for autistic and non-autistic people that more studies identify whether participants are autistic, so they don't make misleading conclusions about the effectiveness of eating disorder treatments for everyone. However, to make lasting improvements to care, we need to understand more about:

- How common other eating disorders like bulimia,¹⁶ binge eating and Avoidant/Restrictive Food Intake Disorder (ARFID)¹⁷ are amongst autistic people? At present, much of what we know about autism and eating disorders focuses on anorexia.
- What early signs could indicate risk of eating disorders in autistic people, especially young people?
- How should eating disorder assessments be adapted for autistic people to identify what is causing or exacerbating their difficulty eating?¹⁰
- What adaptations would make eating disorder treatments more effective amongst autistic people and whether new interventions would be effective?¹¹
- How can inpatient eating disorder services be made more appropriate and supportive for autistic people?

"Staff in eating disorder units don't have enough understanding of autism or sensory issues it can cause. They seemed constantly frustrated with me. I felt like a nuisance."¹

What we should do now

- We know a lot more about eating disorders and autism now than we did when the Autism Act (2009)¹⁸ or Think Autism Strategy (2014)¹⁹ were published. The Government recently made reducing early death the primary aim of the Autism Strategy,^{20,21} and have now launched a review of the Strategy for the future.²²

The Department of Health and Social Care should ensure that tackling eating disorders become a “priority challenge for action”,²³ as part of a wider theme on reducing morbidity and early death.

- A significant number of the people health professionals in eating disorder services will see are autistic. Despite this, the current NICE guidelines on eating disorders do not reference autism or prepare clinicians for any of the adaptations that may be required when assessing and treating autistic patients.²⁴

NICE should prioritise a review of NG69 to ensure it reflects the latest evidence on autism and eating disorders.²⁵

- The NHS Long Term Plan highlights that “‘research-active’ hospitals have lower mortality rates” and prioritises action to reduce preventable deaths amongst autistic people.²⁶ Disturbingly few clinical innovations for autistic people have been tested in NHS eating disorder services, even though they represent one of the groups at highest risks of dying early.

NHS England and the National Institute for Health Research should support all eating disorder services to become actively involved in clinical research to improve outcomes for autistic and non-autistic people. Research funders should prioritise further research into eating disorders in autism, informed by the priorities and input of autistic people and their supporters.

- Eating disorder services are a setting where undiagnosed autistic people, particularly women and girls, can often present in crisis for the first time. Identifying whether patients have autistic traits could help services build a more holistic picture of those people’s needs;¹⁰ especially for those who repeatedly present to services or whose eating disorders appear to be severe and enduring (SEED).

NHS England should consider auditing all identified autistic people with eating disorders in inpatient settings to establish whether there were missed opportunities to intervene earlier, had autism been considered.

- The Long Term Plan committed to developing and testing support packages for children diagnosed with neurodevelopmental conditions.²⁶ Families of autistic people should be supported with new, evidence-based information on eating disorders and autism.

NHS England, research funders and charities should work together to ensure support packages include evidence-based advice on preventing and managing eating difficulties across the lifespan, including at points of transition.

1 Autistica (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters. October 2018.

2 Mandy W & Tchanturia K (2015) Do women with eating disorders who have social and flexibility difficulties really have autism? A case series. *Molecular Autism* 6:6. <molecularautism.biomedcentral.com/articles/10.1186/2040-2392-6-6>

3 Westwood H, et al. (2017) Clinical evaluation of autistic symptoms in women with anorexia nervosa. *Molecular Autism* 8:12. <ncbi.nlm.nih.gov/pubmed/28331571>

4 Koch S, et al. (2015). Autism spectrum disorder in individuals with anorexia nervosa and in their first- and second-degree relatives: Danish nationwide register-based cohort-study. *Br J Psychiatry* 206(5), 401-7 <ncbi.nlm.nih.gov/pubmed/25657359>

5 Arcelus J, et al. (2011) Mortality Rates in Patients With Anorexia Nervosa and Other Eating Disorders: A Meta-analysis of 36 Studies. *Arch Gen Psychiatry* 68(7), 724-731.

6 Nielsen S, et al. (2015) Effects of autism spectrum disorders on outcome in teenage-onset anorexia nervosa evaluated by the Morgan-Russell outcome assessment schedule: a controlled community-based study. *Molecular Autism* 6:14 <ncbi.nlm.nih.gov/pubmed/25774282>

7 Wentz E, et al (2009). Adolescent-onset anorexia nervosa: 18-year outcome. *The British Journal of Psychiatry: The Journal of Mental Science*, 194(2), 168–174. <ncbi.nlm.nih.gov/pubmed/19182181>

8 Tchanturia K, et al. (2017). Characteristics of Autism Spectrum Disorder in Anorexia Nervosa: A Naturalistic Study in An Inpatient Treatment Programme. *Autism*. <ncbi.nlm.nih.gov/pubmed/29105513>

9 Spectrum News (2016). The invisible link between autism and anorexia. <spectrumnews.org/features/deep-dive/the-invisible-link-between-autism-and-anorexia/>

10 Tchanturia K, et al. (2013). Exploring autistic traits in anorexia: a clinical study. *Mol Autism* 4(1), 44. <ncbi.nlm.nih.gov/pubmed/24220604>

11 Tchanturia K, et al (2016). How anorexia nervosa patients with high and low autistic traits respond to group CRT. *BMC Psychiatry*, 16(1), 334. <ncbi.nlm.nih.gov/pmc/articles/PMC5041290/>

12 Westwood H & Tchanturia K (2017). Autism Spectrum Disorder in Anorexia Nervosa: An Updated Literature Review. *Curr Psychiatry Rep*. 19(7), 41. <ncbi.nlm.nih.gov/pubmed/28540593>

13 Autistica (2018). Our research: Treating anorexia in autistic women. <autistica.org.uk/our-research/research-projects/treating-anorexia-in-autistic-women>

14 Medical Research Foundation (2018). The Triple A study (Adolescents with Anorexia and Autism): A search for biomarkers. <medicalresearchfoundation.org.uk/projects/the-triple-a-study-adolescents-with-anorexia-and-autism-a-search-for-biomarkers>

15 Tchanturia K (2019). Developing Innovative clinical pathway for women with Autism spectrum features and Eating Disorders (DIAED). <bit.ly/2RVli4y>

16 Mansour S, et al (2016). Emotions mediate the relationship between autistic traits and disordered eating: A new autistic-emotional model for eating pathology. *Psychiatry Research*, 245, 119-126. <ncbi.nlm.nih.gov/pubmed/27541347>

17 Nicely T, et al. (2014). Prevalence and characteristics of avoidant/restrictive food intake disorder in a cohort of young patients in day treatment for eating disorders. *J Eat Disord*. 2(1), 21. <ncbi.nlm.nih.gov/pubmed/25165558>

18 HM Government (2009). Autism Act 2009. <legislation.gov.uk/ukpga/2009/15/pdfs/ukpga_20090015_en.pdf>

19 DHSC (2015). ‘Think Autism’: an update to the government adult autism strategy. <gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

20 DHSC (2018). Think Autism strategy: governance refresh 2018. <gov.uk/government/publications/think-autism-strategy-governance-refresh-2018>

21 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>

22 Hansard (2019). Minister of State for Care, responding to Health and Social Care Oral Questions on 15th Jan 2019. <bit.ly/2RPPolZ>

23 DHSC (2015). Think autism: updating the 2010 adult autism strategy. <bit.ly/2MHInCs>

24 Kinnaird E, et al. (2017). Clinicians’ views on working with anorexia nervosa and autism spectrum disorder comorbidity: a qualitative study. *BMC Psychiatry* 17: 292. <ncbi.nlm.nih.gov/pmc/articles/PMC553805>

25 NICE guideline [NG69] Eating disorders: recognition and treatment. <nice.org.uk/guidance/ng69>

26 NHS (2019). The NHS Long Term Plan. Available: <longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>