

Autistica Action Briefing: Epilepsies

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Autistica is the UK's autism research charity. This briefing summarises the most important scientific findings about epilepsies in the autistic community. 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, NICE and public research funders to act on this information. The evidence gaps around autism and epilepsy are putting lives at risk. Through research and policy, we must begin empowering the NHS with better evidenced, personalised diagnostic, monitoring and treatment options.

www.autistica.org.uk/AutismStrategy

"So many of the unexpected and preventable deaths in the news are of people with autism and epilepsy. No-one ever said our son was more likely to die."

What we know

"The hospital were aware I was epileptic but had no care plan for if I was to have a seizure. I was left to eventually write up my OWN care plan, only for them to ignore it." ¹

- **Epilepsy is the leading cause of early death for autistic people with a learning disability.** On average, half of the people in that group do not live to see their 40th birthday.^{2,3}
- **Between 15% and 40% of people with epilepsies are autistic,** compared to just 1% of the general population.^{4,5,6,7,8} Epilepsies are particularly prevalent amongst autistic people with a learning disability.^{9,10}
- Autistic people appear to be **more likely to have epilepsies which resist treatment.**^{9,11} Autistic people with epilepsies face a higher risk of early death than autistic people without epilepsies and non-autistic people with epilepsies.¹²
- **Autistica is funding the first and currently only study in the world on the use and efficacy of anti-seizure medications in autistic people.** Over 1,400 clinical trials have looked at the effectiveness of major anti-epilepsy medications, but we could not find a single well-controlled trial that tested their use in autistic people.¹³
- **Epilepsies can also present differently in autistic people.** For example, for a substantial proportion of autistic people with epilepsy, this develops in adolescence, whereas in the general population seizures more commonly begin in early childhood.^{4,6}

What we need to find out

"I have epilepsy but am very sensitive to medication. It is sometimes a toss-up between staying seizure-free and being able to function at all due to side effects." ¹

Epilepsies are one of the biggest killers of autistic people, particularly those with learning disabilities,^{2,3,12} and existing treatments are often ineffective.^{2,12,13} This is too often accepted as inevitable, but research has the power to prevent tragic premature deaths of autistic people with epilepsies. **Developing personalised treatments to prevent epileptic seizures should be one of the highest priorities of autism science but almost no research is working towards it.**¹⁴ Autistic people, families and researchers at our Autism and Epilepsy Global Summit in 2017¹⁵ identified the following questions as key priorities for research:

- Which autistic people develop epilepsy, when and why?
- Does medication, including anti-psychotics, prescribed at critical developmental stages lead to onset of epilepsy?
- What are the rates of emergency medication use for epilepsy in autistic people?
- Which side effects are more or less common/problematic in autistic people with epilepsy?
- What are the rates of SUDEP (Sudden Unexpected Death in Epilepsy) in autistic people? What are the key risk factors for premature death (including SUDEP) in autism and epilepsy? How can we better educate autistic people, families and caregivers about these risks?
- How do we develop effective care plans for autistic people with epilepsy and ensure they are adhered to?

- What are the factors leading to build-up of anxiety in autistic people with epilepsy and how can these inform management?
- Does sleep differ in autistic people with and without co-occurring epilepsy?
- What, if any, are the genes that drive autism, epilepsy and the co-occurrence of both?
- To what extent are seizures a factor in the increased use of emergency healthcare services by autistic people?^{16,17,18}

What we should do now

- Autistic people with learning disabilities continue to be significantly under-represented in impactful health research.^{19,20,21,22,23} Without a concerted effort to improve the infrastructure for high quality science, we will continue to watch the tragic progression of deaths in NHS care.

The Department of Health and Social Care, NHS England, and public, private and third sector research funders need to collaborate to develop a national strategy for more inclusive autism and learning disability research.

- At present, there is a significant evidence gap for treating epilepsies in autistic people. Autistica is committed to working on this area but tackling premature deaths from epilepsy in autistic people will require a sustained and coordinated programme of research.

To drive progress, NIHR and UKRI should collaborate with third sector funders to establish a virtual research network on autism and epilepsy and ensure impactful research is being supported across all those organisations' funding streams.

- The impact of epilepsies in the autistic community was barely known when the Autism Act (2009)²⁴ and Think Autism Strategy (2014)²⁵ were published. The Government recently made reducing early death the primary aim of the Autism Strategy^{26,27} and have launched a review of the Strategy for the future.²⁸

The Department of Health and Social Care should ensure that preventing death from epileptic seizures becomes a "priority challenge for action",²⁹ as part of a wider theme on reducing morbidity and early death.

- The current NICE guidelines on epilepsies³⁰ do not mention autism, even though up to 4 in 10 people with epilepsies are autistic and there is evidence indicating clinical differences in how their conditions present.

NICE are currently reviewing their epilepsies guidelines for children and adults. They should take this opportunity to ensure those guidelines alert health professionals to the different clinical requirements that an autistic person with epilepsy may have.

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 Hirvikoski T, et al. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, 207(5), 232-8. <[ncbi.nlm.nih.gov/pubmed/26541693](https://doi.org/10.1192/bjp.2016.207.5.232)>
3 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)>
4 Bolton PF, et al. (2011). Epilepsy in autism: features and correlates. *British Journal of Psychiatry*, 198, 289-294. <[ncbi.nlm.nih.gov/pmc/articles/PMC3065774](https://doi.org/10.1192/bjp.2010.200.5.289)>
5 Woolfenden S, et al. (2012). A systematic review of two outcomes in autism spectrum disorder – epilepsy and mortality. *Developmental Medicine and Child Neurology*. <[onlinelibrary.wiley.com/doi/full/10.1111/j.1469-8749.2012.04223.x](https://doi.org/10.1111/j.1469-8749.2012.04223.x)>
6 Viscidi EW, et al. (2013). Clinical Characteristics of Children with Autism Spectrum Disorder and Co-Occurring Epilepsy. *PLoS ONE* 8(7): e67797. <[journals.plos.org/plosone/article?id=10.1371/journal.pone.0067797](https://doi.org/10.1371/journal.pone.0067797)>
7 Tuchman R & Rapin I (2002). Epilepsy in autism. *Lancet Neurol*, 1(6), 352-358. <[ncbi.nlm.nih.gov/pubmed/12849396](https://doi.org/10.1016/S1473-2101(02)00000-0)>
8 Croen LA, et al. (2015). The health status of adults on the autism spectrum. *Autism*. 19 (7) 814-823. <[ncbi.nlm.nih.gov/pubmed/25911091](https://doi.org/10.1177/1063426915581109)>
9 Royal College of Psychiatrists (2017). College Report CR206: Prescribing anti-epileptic drugs for people with epilepsy and intellectual disability.
10 Robertson J, et al. (2015) Prevalence of epilepsy among people with intellectual disabilities: A systematic review. *Seizure – Eur J Epilep* 29, 46-62. <[ncbi.nlm.nih.gov/pubmed/26076844](https://doi.org/10.1111/epi.12668)>
11 Sansa G, et al. (2011) Medically refractory epilepsy in autism. *Epilepsia* 52(6). <[onlinelibrary.wiley.com/doi/full/10.1111/j.1528-1167.2011.03069.x](https://doi.org/10.1111/j.1528-1167.2011.03069.x)>
12 Pickett J, et al. (2011) Mortality in Individuals With Autism, With and Without Epilepsy. *Journal of Child Neurology* 26(8), 932-929. <[ncbi.nlm.nih.gov/pubmed/21471551](https://doi.org/10.1177/0885066611411551)>
13 Heax (Unpublished). Autism and Comorbid Epilepsy: Translation Ready Report, October 2017
14 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/10.1177/1744501916669003)>
15 Autistica (2017). Global Summit: Autism & Epilepsy. <[autistica.org.uk/downloads/files/Epilepsy-Summit-Report.pdf](https://www.autistica.org.uk/downloads/files/Epilepsy-Summit-Report.pdf)>
16 Zerbo O, et al. (2018) Healthcare Service Utilization and Cost Among Adults with Autism Spectrum Disorders in a U.S. Integrated Healthcare System. *Autism in Adulthood*. <doi.org/10.1089/aut.2018.0004>
17 Vohra R, et al. (2016) Emergency Department Use Among Adults with Autism Spectrum Disorders (ASD). *Journal of Autism and Developmental Disorders* 46(4), 1441-1454. <[ncbi.nlm.nih.gov/pmc/articles/PMC4845033](https://doi.org/10.1007/s10803-016-3844-y)>
18 Hand B, et al. (2018) Ambulatory Care Sensitive Admissions in Individuals With Autism Spectrum Disorder, Intellectual Disability, and Population Controls. *Autism Research*. <[onlinelibrary.wiley.com/doi/abs/10.1002/aur.2050](https://doi.org/10.1002/aur.2050)>
19 Autistica (2019). A review of the autism research funding landscape in the United Kingdom. <[autistica.org.uk/downloads/files/Autistica-Scoping-Report.pdf](https://www.autistica.org.uk/downloads/files/Autistica-Scoping-Report.pdf)>
20 Russell G, et al. (2019) Selection bias on intellectual ability in autism research: a cross-sectional review and meta-analysis. *Molecular Autism* 10:9. <[ncbi.nlm.nih.gov/pmc/articles/PMC6397505](https://doi.org/10.1186/s13023-019-0090-9)>
21 Stedman A, et al. (2018) Are Children Severely Affected By Autism Spectrum Disorder Underrepresented in Treatment Studies? An Analysis of the Literature. *J Autism Dev Disord*. <[link.springer.com/article/10.1007/s10803-018-3844-y](https://doi.org/10.1007/s10803-018-3844-y)>
22 Tager-Flusberg H & Kasari C. (2013) Minimally Verbal School-Aged Children with Autism Spectrum Disorder: The Neglected End of the Spectrum. *Autism Research* 6(6), 468-478. <[onlinelibrary.wiley.com/doi/full/10.1002/aur.1329](https://doi.org/10.1002/aur.1329)>
23 Shankar R, et al. (2018) Under representation of people with epilepsy and intellectual disability in research. *PLoS ONE* 13(6): e0198261. <[ncbi.nlm.nih.gov/pmc/articles/PMC6013187](https://doi.org/10.1371/journal.pone.0198261)>
24 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)>
25 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](https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy)>
26 DHSC (2015). Think autism: updating the 2010 adult autism strategy. <[webarchive.nationalarchives.gov.uk/20150601164549/http://autismstrategy.dh.gov.uk/15-priority-challenges](https://www.webarchive.nationalarchives.gov.uk/20150601164549/http://autismstrategy.dh.gov.uk/15-priority-challenges)>
27 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)>
28 Hansard (2019). Minister of State for Care, responding to Health and Social Care Oral Questions on 15th Jan 2019. <[bit.ly/2RPPoLZ](https://www.parliament.uk/business/committees/committees-a-z/commons-secondary/health-and-social-care/oral-questions/2019-01-15/)>
29 DHSC (2015). Think autism: updating the 2010 adult autism strategy. <[webarchive.nationalarchives.gov.uk/20150601164549/http://autismstrategy.dh.gov.uk/15-priority-challenges](https://www.webarchive.nationalarchives.gov.uk/20150601164549/http://autismstrategy.dh.gov.uk/15-priority-challenges)>
30 NICE (2012). Clinical guideline [CG137] Epilepsies: diagnosis and management. <[nice.org.uk/guidance/cg137](https://www.nice.org.uk/guidance/cg137)>