

# AUTISTICA

Building brighter futures through autism research

## PRESS RELEASE

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### New report sheds light on ‘shocking’ rates of early death in autism

A major report<sup>1</sup> from the leading autism research charity Autistica brings together for the first time research studies that show people on the autism spectrum are dying decades younger than the non-autistic population. The charity is calling for a national response to this hidden crisis, including massive investment in research and an NHS England review of premature death in autism.

The report includes recently published data from the Karolinska Institute in Sweden showing that, on average, people with autism die 18 years younger than the general population. Those with autism and intellectual disability die 30 years before their non-autistic peers, with epilepsy the leading cause of death. Autistic adults with no intellectual disability die an average of 12 years earlier than the typical population, driven in large part by suicide<sup>2</sup>.

Although autistic people are at an increased risk of dying early from virtually every cause of death, autistic adults with learning difficulties are 40 times more likely than the typical population to die prematurely from a neurological condition, particularly epilepsy. Autistic adults without a learning disability are 9 times more likely to die from suicide compared to the general public, with autistic women at the greatest risk.

These Swedish figures are taken from a very large epidemiological research study and confirm previous findings from smaller studies of autism mortality risk across the globe. Virtually no research has been done to determine how to optimally treat epilepsy and suicidal tendencies in autistic populations.

Ahead of World Autism Awareness Day on 2 April, Autistica’s report, “Personal tragedies, public crisis”, puts forward detailed recommendations for action and calls on the Government to ensure national, regional and local care providers have clear and specific plans to reduce premature mortality in this group<sup>2</sup>.

Autistica aims to raise £10 million to kickstart research to tackle early death in autism, but stress that given the scale of the problem, the response needs to go far beyond the charity sector. Jon Spiers, Autistica’s Chief Executive, said:

“This new research confirms the true scale of the hidden mortality crisis in autism. The inequality in outcomes for autistic people shown in this data is shameful. We cannot accept a situation where many autistic people will never see their 40<sup>th</sup> birthday. Everyone involved in supporting people on the autism spectrum from the Government right down to local care providers has a responsibility to step up and start saving lives as soon as possible.”

Gill, mother to Ellie, a 19-year-old with autism who recently began having seizures, said:

“Seeing your child suffer a seizure is shocking and painful enough. To know that as someone with autism they are also more likely to die early from epilepsy is a double blow. We need proper answers and we need them now. We cannot simply stand by and watch people with autism die because of a lack of research and specialised care.”

Steve Silberman, award-winning author of the recent bestseller *Neurotribes* documenting the history of autism, is backing the campaign:

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“The shocking levels of premature death and suicide among people on the autism spectrum should be a wake-up call to governments and service providers worldwide: dramatic proof that bullying, lack of support, inadequate health care across the lifespan, insufficient allocation of resources to create options for housing and employment, and a failure to aggressively pursue research into better treatments for chronic anxiety and seizures comes at a terrible cost. As a society, we can no longer afford to squander precious human lives and potential in this way.”

## NOTES TO EDITOR:

### Autism

One in a hundred people in the UK has autism, a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. Autism is a spectrum condition, which means that while all people share certain difficulties, their autism will affect them in different ways. Some autistic people are able to live independent lives but many have learning disabilities or co-occurring healthcare conditions often requiring a lifetime of specialist support, as well as the health issues we all face as part of the normal ageing process.

[Autistica](#) both funds and campaigns for medical research to understand the causes of autism, improve diagnosis, and develop new treatments and interventions. All the research that Autistica carries out is guided by families, to ensure that it makes a real difference to the lives of those living with autism. Since being founded in 2004, Autistica has raised over £9 million in support of autism research.

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Case studies can be provided on request.

### References

<sup>1</sup> Cusack, J., Shaw, S., Spiers, J., Sterry, R. (2016). Personal tragedies, public crisis: The urgent need for a national response to early death in autism.

<sup>2</sup> Hirvikoski, T. et al. (2015). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 207(5).