

Personal tragedies, public crisis

The urgent need for a national response to early death in autism



AUTISTICA
Building brighter futures through autism research

Supported by
Deutsche Bank



Introduction

New research confirms the true scale of the hidden mortality crisis in autism. The inequality in outcomes for autistic people shown by this data is shameful, but we must not forget the real individuals and families behind these statistics. Every death is a personal tragedy and a national outrage. For years, society and the healthcare system have ignored the voices of devastated families who have lost autistic loved ones unnecessarily, and far too young. That ends now. We cannot accept a situation where many autistic people will never see their 40th birthday.

National and local government, research funders and industry, as well as the NHS and service providers, all have a responsibility to step up and tackle this issue. Autistica is totally committed to playing our part, raising at least £10m of new funding through our Autism Lifesavers Fund to find answers and start saving lives.



Jon Spiers,
Chief Executive,
Autistica

About autism

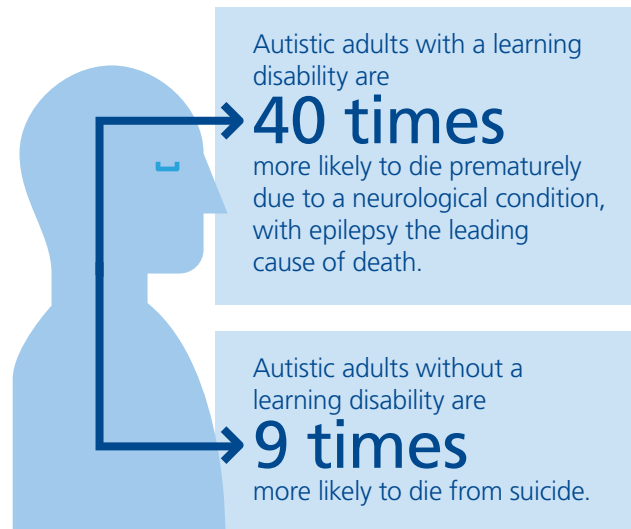
One in a hundred people in the UK has autism, a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. Autism is a spectrum condition, which means that while all people share certain difficulties, 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.

Executive summary

Many families and autistic individuals have raised concerns over early deaths in autistic people. Ground-breaking new research now confirms the true scale of the mortality crisis in autism: **autistic people die on average 16 years earlier than the general population.** For those with autism and learning disabilities, the outlook is even more appalling, with this group dying **more than 30 years before their time.**

Research studies across the world have confirmed that autistic people are at an increased risk of early death. A large study from Sweden in late 2015 made this case stronger than ever by analysing a very large, high quality dataset to compare the general population, autistic people, and people with both autism and a learning disability.

Two findings relative to the general population are particularly striking:



Yet there is still very limited awareness and understanding of the scale of premature mortality for the 700,000 autistic people in the UK and hence very little action to date to reduce it. This hidden crisis demands a national response. Our report lays out the evidence and sets out recommendations for action by national and local government, research funders and industry, as well as the NHS and service providers. These recommendations include calling on:

- **Medical research funders to collaborate to rapidly increase our understanding of premature mortality in autism**
- **The government to establish a National Autism Mortality Review and commit to significantly improved data collection**
- **Service providers to develop clear and specific plans to prevent early death in autism.**

The evidence

Autistic people¹ have been found to have an overall risk of early mortality more than double that of the general population.^{2,3} On average, people on the autism spectrum die substantially earlier than people who are not autistic. A large study from Sweden in late 2015 analysed a very large high quality dataset which allowed for comparisons to be made between the general population, autistic people, and people with both autism and a learning disability. The study found that people with autism died **over 16 years** earlier than non-autistic people. Autistic adults with a learning disability were found to die **more than 30 years** before non-autistic people.³

Autistic people are at increased risk of dying younger from virtually every cause of death. There are specific social, cultural and sensory challenges faced by those with autism which can contribute to premature mortality.³ The Swedish study reported that two leading causes of early death in autism are epilepsy and suicide.³ These major causes of death in autism fit with the strong research evidence that autistic people are at heightened risk of mental health problems such as depression and anxiety,⁴ neurological conditions, especially epilepsy,^{5,6} and other diseases including diabetes and heart disease.⁷

Research findings in related fields such as severe mental illness⁸ and learning disability⁹ have also revealed large mortality gaps, but the scale of the lost years of life in autism appears to be even larger than that seen in other, better-studied areas. The high quality existing work on interventions in these other areas of concern may offer ways to rapidly find answers specific to autism.

“Autistica has identified a stark failure in the delivery of healthcare to people with autism in the UK. There is an immediate need for health services to prioritise high quality risk reduction and for the research community to support the identification of risk, delivery of solutions and provision of novel interventions.”

Professor Michael Kerr, Cardiff University

“The high rates of early death in autism highlighted in this report sadden me but do not shock. I am having a very hard time with my own epilepsy; a seizure at the wrong time in the wrong place could kill me and that terrifies me. It makes me worry for the future of my two girls, both of whom also have autism. The recommendations in this report couldn't come soon enough, and I hope that they activate funders and health services to take action as soon as possible.”

Autistic parent

Epilepsy in autism

Between 20% and 40% of autistic people also have epilepsy and this rate increases steadily with age – in contrast to a one percent prevalence rate in the general population.¹⁰ In the typical population, the risk of epilepsy is greatest in a child's first year, decreasing in risk through childhood, then remaining stable and not increasing again until old age.^{11,12,13} In the majority of autistic people who develop epilepsy, their seizures do not appear until their teenage years, much later than average.^{5,14} This suggests that the underlying triggers of epilepsy may be different in autism.

Autistic adults who also have a learning disability have been found to be almost **40 times** more likely to die from a neurological disorder relative to the general population – with the leading cause being epilepsy.³ Despite the very high prevalence of seizures in autistic people and the high death rate from epilepsy, there has been virtually no research to establish whether treatments used for epilepsy are safe or effective in the autistic population. More research is urgently needed into the relationship between epilepsy and autism and the impact of epilepsy over the lifespan in autistic adults.

Suicide in autism

After heart disease, suicide is now the leading cause of early death in adults with autism and no learning disability. Indeed, the recent Swedish study found that adults with autism and no additional learning disability are over **9 times** more likely (relative to a general population) to commit suicide.³

The recent report from the Mental Health Taskforce identified autistic people as at higher risk of mental health problems.¹⁵ Indeed, research indicates that 70% of autistic individuals have one mental health disorder such as anxiety or depression, and 40% have at least two mental health problems.⁴ When these issues appear alongside autism, mental health difficulties can go undiagnosed and untreated.

Multiple studies suggest that between 30% and 50% of autistic people have considered committing suicide.^{16,17,18} One study found that 14% of autistic children experience suicidal thoughts compared to 0.5% of typically developing children.¹⁹ Another recent study of adults with Asperger syndrome found that two-thirds of participants had lifetime experience of suicidal thoughts and a third of participants had planned or attempted suicide.²⁰

While there are certainly examples of good practice in some locations, the comparative statistics indicate that the majority of mental health and related services are not sufficiently skilled to meet the needs of autistic people with an additional mental health problem, including suicidal thoughts. Numerous personal accounts illustrate how this impacts on the lives of autistic individuals and those who love them.²¹

“As an adult who received an autism diagnosis late in life following a lifelong battle with autism-related mental health issues, I am distressed by these statistics. I hope that this report will bring to light the serious problem of early death, meaning that people with autism can live longer, happier lives.”

Susan, an autistic adult

“Three recent high quality studies have uncovered shockingly high rates of suicidal thoughts, behaviours and completed suicide in autistic adults. Our recent research showed that 66% of autistic adults had contemplated suicide in their lifetime. This was significantly higher than patients with psychosis, a high-risk group in which suicide has been extensively studied.

These results demonstrate an urgent need for more research to prevent suicide in autistic adults – there are no valid assessments or programmes currently available for these individuals. An absolutely imperative first step is to consistently record autism diagnoses in routinely collected government data. This will enable much-needed large-scale research into suicide risk and prevention in autism, and ultimately reduce the tragic health inequalities these individuals experience.”

Dr Sarah Cassidy, Coventry University

Other causes of early death in autism

In addition to poorer neurological and mental health, autistic people also experience worse physical health than the general population and are more generally at risk of dying younger from a very broad range of physical health problems. Indeed, multiple studies have found that most autistic adults are at a significantly increased risk of most medical conditions, including cardiovascular disease, diabetes, stroke, circulatory and respiratory conditions.

Why are autistic people dying prematurely?

We simply don't fully understand this. It's likely that both social and biological factors play a role, but the degree to which they contribute to each cause of death has not been established. Findings from genetics and neuroscience have found that the biological underpinnings of autism are related to those of epilepsy, mood disorder and anxiety disorder.^{22, 23}

We do know that autistic people:

- Can have a more restricted diet, limited access to exercise and increased use of medication
- Face social and cultural pressures, including bullying, pressure to conform (which can result in 'masking' serious problems) and social isolation
- Experience depression, anxiety and sensory overload
- Can face significant issues in accessing healthcare.

As we see in the general population, these factors may increase the likelihood of suicide and death from other causes.^{24, 25} Further research is required to more accurately understand the multiple factors which can lead to early death in autism.

Gender differences

The Swedish study found that overall mortality risk was broadly comparable in both autistic males and females. However, the detail is more complex. Overall, autistic men had a higher relative risk of early death from diseases of the nervous and circulatory systems. But autistic women with a learning disability had the highest overall mortality risk of the two genders. Autistic women were also at twice the risk of death from suicide (a finding also supported by UK research²⁰). These findings highlight the need for greater understanding of differences between genders and, where appropriate, targeted interventions.



How can we significantly reduce premature mortality for autistic people?

“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 come at a terrible cost. As a society, we can no longer afford to squander precious human lives and potential in this way.”

Steve Silberman, author of *NeuroTribes: The Legacy of Autism and How to Think Smarter About People Who Think Differently*

Given the significantly increased risk of mortality in autism and the possibly unique causal pathways underpinning the major killers of autistic people, it is critical that we invest now in medical research which can give people with autism the hope of a longer, healthier life.

Globally, there has been very limited research on autism in adults, with the vast bulk of autism science focusing on children and young people. Indeed, Autistica’s *Ageing in Autism* research programme at Newcastle University is one of the first such programmes anywhere in the world. This lack of attention paid to autistic adults is a major reason why data on mortality in people with autism is severely limited. Higher quality data and greater expertise and capacity in adult research among autism researchers are critical.

Autistica’s current research strategy sets out our own commitment to supporting research in both ageing with autism and mental health in autism. But far more research is needed, including the systematic collection and analysis of mortality data, if we are to meaningfully tackle the appalling mortality gap.

There is a precedent in establishing robust research and evidence programmes to tackle health inequalities among specific high-risk groups. The *Confidential Inquiry into premature deaths of people with learning disabilities* highlighted how shortfalls in healthcare provision contributed to deaths – all aspects of care provision were found to be less good for people with learning disabilities.⁹ The Healthcare Quality Improvement Partnership (HQIP) has now established the Learning Disability Mortality Review (LeDeR) on behalf of NHS England. The review will carry out a number of projects, including collating and sharing anonymised information about the deaths of people with learning disabilities so that common themes, learning points and recommendations can be identified and taken forward into policy and practice improvements. A similar approach for autism is a vital first step in quantifying and understanding the scale of the problem and potential solutions.

Autistica’s ambition through this campaign is to:

- Raise awareness of this hidden crisis among policymakers and healthcare providers, sparking national, regional and local responses
- Ensure information and services aimed at treating the conditions with the highest mortality risk are autism-appropriate and can actively reduce premature mortality in autism.

Organisations across research, health and social care should work together to meet two key objectives:

- Rapidly building the research and knowledge base about early death in autism
- Developing evidence-based policies, support, services and treatment to urgently reduce premature mortality.

Therefore, increased investment in research and evidence gathering should focus on:

- **Producing statistics on premature mortality for autistic people in the UK, underpinned by better data collection**
- **Better understanding the link between autism and epilepsy and using the emerging findings to develop better treatments**
- **Increasing our understanding of depression and anxiety in autism, particularly focused on the factors which lead to suicide**
- **Tackling the factors which lead to poorer physical health in autism.**

But our response must go far beyond research. Policies, support, services and treatments should have the ambition of improving quality of life and reducing premature mortality for each person with autism. There are already obligations on government and services to meet the needs of people with autism, but mortality should feature prominently in these obligations. Indeed, local and service-based monitoring and review of early death in autism is a key part of better understanding and tackling this issue.

We very much welcome that *The Government's Mandate to NHS England 2016-17* tasks NHS England with reducing the health gap between people with autism and the population as a whole.²⁶ A specific focus on reducing early death in autism would help health services to work towards this goal.



Recommendations for action

We are calling on a wide range of organisations and bodies to join us in this vital mission. This first report focuses on UK-wide and England-only organisations.

A. Building the research and knowledge base

Autistica will commit at least £10m of funding through our Autism Lifesavers Fund into research on premature mortality over the next five years. Our research will aim to understand:

- The link between autism and epilepsy
- Mental health problems in autism and the factors which lead to suicide and suicidality in autism
- The factors which lead to poorer physical health in autism
- How to improve quality of life and lower the risk of mortality for autistic people
- The crucial perspective and viewpoints of the autism community.

Autism-specific funders, NIHR, MRC, the Wellcome Trust and other charitable funders should collaborate to define, commission and fund new studies into the major causes of mortality in autism: epilepsy and suicide. These studies should include both basic and applied research, including comparative treatment trials, underpinned by comprehensive community engagement.

Mental health research funders should prioritise suicide in autism as a research area.

Research funders of the major diseases which contribute to early death in autism should consider funding specific studies aimed at preventing and treating poor physical health in autism.

NHS England should immediately extend the Learning Disability Mortality Review to include a new National Autism Mortality Review to:

- Establish the mortality risk to autistic people with and without learning disabilities in the UK
- Identify the leading drivers of early death in autism
- Audit the mental health and clinical services responsible for tackling the leading causes of early death in autism to ensure they are autism-appropriate
- Gather local, national and international evidence of best practice in reducing early death in autism
- Make further recommendations to significantly reduce early death in autism.

NHS England, Clinical Commissioning Groups and Health and Wellbeing Boards should collect and analyse standardised mortality data about all autistic people nationally and locally. Autism mortality data should be published in local population profiles and joint strategic needs assessments.



B. Developing policies and providing support, services and treatment which aim to reduce premature mortality

The government should make tackling early death in autism a national priority and ensure national bodies have clear and specific plans to reduce premature mortality among this group.

Members of Parliament should actively support this prioritisation at a national and local level, putting pressure on commissioners and providers in their constituencies.

Local politicians should ensure local bodies have clear and specific plans to reduce premature mortality among people with autism.

The Department of Health should include preventing premature mortality of autistic people as a key outcome in the 2017-18 deliverables in the next refresh of *The Government's Mandate for NHS England*. The Department of Health should also include preventing premature mortality as a key outcome during the 2019 review of the England Adult Autism Strategy. In the intervening period, the DH Autism Programme Board should consider short- and medium-term responses to the evidence base on premature mortality in autism and offer strategic support to other organisations acting on the recommendations in this report.

NHS England and Public Health England in partnership with Clinical Commissioning Groups and Health and Wellbeing Boards should conduct a rapid review to assess health services' current capacity to:

- **Clearly identify autistic people in the National Health Service central registration system and in all healthcare record systems, including any learning disabilities where applicable**
- **Consider autistic people with learning disabilities a high-risk group for deaths from epilepsy and autistic people without learning disabilities a high-risk group for deaths from suicide**
- **Provide autistic people a named healthcare coordinator**
- **Offer patient-held health records to all autistic patients**
- **Address barriers in autistic individuals' access to health care by proactive referral to specialist services**
- **Maximise uptake of an increased range of NHS Health Checks in autistic adults with and without learning disabilities**
- **Conduct local case reviews of early deaths of autistic people.**

These bodies should then set out plans to address any gaps in the above by the end of 2016, including in the development of the Mental Health Taskforce's proposed 'autism mental health pathway'.

These bodies should also ensure all relevant health and care staff access autism training, as stated in the Adult Autism Strategy statutory guidance. Local areas' recent self-assessment returns could help to target specific groups within the local workforce.

All providers of care and support for autistic people should:

- **Include reducing early death in their outcome measures and monitor this over the long term to track service performance**
- **Develop individualised risk plans to reduce early mortality**
- **Ensure that autistic people are adequately supported to access healthcare in a timely manner, including screening services**
- **Screen autistic individuals for suicidal ideation, so that suicidal crises can be prevented**
- **Include developing individuals' own resilience to prevent suicide in care and support plans**
- **Ensure all health professionals have a meaningful level of adult autism training.**

The Care Quality Commission and Monitor should regularly assess providers' efforts to reduce premature mortality among autistic people.

Suicide reduction organisations should ensure their staff are trained in autism-appropriate communication techniques and building resilience in people with autism. Services should ensure front-line workers are aware of the high lifetime risk of suicidal ideation and suicide plans or attempts, especially in individuals receiving a late diagnosis of autism.

The pharmaceutical and technology industries should examine the commercial viability of developing personalised treatments for epilepsy in autism, with NICE and regulators supporting the rapid adoption of innovative therapies, including through the Early Access to Medicines programme if applicable.

Conclusion

Research clearly shows that autistic people are dying prematurely, often decades before their non-autistic peers. Across every major cause of death, mortality risk is increased in autism, but early deaths due to epilepsy and suicide are particularly, and unacceptably, high. We cannot and should not accept that many people on the autism spectrum will die 30 years before the typical population.

This crisis requires a national response. Failure to act would be tacit acceptance of the stark inequality in outcomes for autistic people. We are urgently calling for a combined effort from national and local government, research funders, the NHS, service providers and industry to start saving lives now.

Autistica will share this report nationally and internationally, maximising discussion with the autism community, galvanising responses from a broad range of relevant stakeholder organisations and pushing for concerted action.

Early death in autism should be reduced across the UK. Health and social care are devolved to the Welsh Government, Scottish Government and Northern Ireland Executive. We would like to hold initial meetings with these three administrations and relevant bodies to discuss how these research findings can inform policy and practice. We then plan to re-present research findings and recommendations within a Welsh, Scottish and Northern Irish context.

- ¹ Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., Pellicano, E. (2015). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*.
- ² Schendel, D.E. et al. (2016). Association of Psychiatric and Neurologic Comorbidity with mortality among persons with autism spectrum disorder in a Danish population. *JAMA Pediatrics*.
- ³ Hirvikoski, T. et al. (2015). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 207(5).
- ⁴ 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*. Vol 47, 8. P.921.
- ⁵ Bolton, P.F. et al. (2011). Epilepsy in autism: features and correlates. *British Journal of Psychiatry*, 198, 289-294.
- ⁶ Woolfenden, S. et al. (2012). A systematic review of two outcomes in autism spectrum disorder – epilepsy and mortality. *Developmental Medicine and Child Neurology*.
- ⁷ Croen, L.A. et al. (2015). The health status of adults on the autism spectrum. *Autism*. 19 (7) 814-823.
- ⁸ Rethink Mental Illness (2013). *Lethal Discrimination*.
- ⁹ Heslop, P. et al. (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report.
- ¹⁰ Tuchman, R., Rapin, I. (2002). *Lancet Neurol*, 1, 352-358.
- ¹¹ Ellenberg, J.H., Hirtz, D.G., Nelson, K.B. (1984). Age at onset of seizures in young children. *Ann Neurol* 15: 127-134.
- ¹² Hauser, W.A. (1994). The prevalence and incidence of convulsive disorders in children. *Epilepsia* 35 Suppl 2: S1-6.
- ¹³ Hauser, W.A., Annegers, J.F., Kurland, L.T. (1993). Incidence of epilepsy and unprovoked seizures in Rochester, Minnesota: 1935-1984. *Epilepsia* 34: 453-468.
- ¹⁴ Viscidi, E.W. et al. (2013). Clinical Characteristics of Children with Autism Spectrum Disorder and Co-Occurring Epilepsy. *PLoS ONE* 8(7): e67797.
- ¹⁵ The Independent Mental Health Taskforce to the NHS in England (2016). *The five year forward view for mental health*.
- ¹⁶ Balfe, M., Tantam, D. (2010). A descriptive social and health profile of a community sample of adults and adolescents with Asperger syndrome. *BMC Research Notes*, 3: 300.
- ¹⁷ Raja, M. (2014). Suicide risk in adults with Asperger's syndrome. *Lancet Psychiatry*. 1(2), 99-101.
- ¹⁸ Segers, M., Rawana, J. (2014). What do we know about suicidality in autism spectrum disorders? A systematic review. *Autism Research*, 5;7(4):507-21.
- ¹⁹ Mayes, S.D. et al. (2013). Suicide ideation and attempts in children with autism. *Research in Autism Spectrum Disorders*.
- ²⁰ Cassidy, S. et al. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study.
- ²¹ Wallace, S. et al. (2013). One in a hundred. Putting families at the heart of autism research.
- ²² Cross-Disorder Group of the Psychiatric Genomics Consortium (2013). Identification of risk loci with shared effects on five major psychiatric disorders: a genome-wide analysis. *The Lancet*, February 28, 2013.
- ²³ Amiet, C. et al. (2013). Epilepsy in Simplex Autism Pedigrees in Much Lower Than the Rate in Multiplex Autism Pedigrees. *Biological Psychiatry*, 74, e3-e4.
- ²⁴ Hawton, K. et al. (2012). Self-harm and suicide in adolescents. *Lancet* 379 (9834): 2373-82.
- ²⁵ Qin, P. et al. (2003). Suicide risk in relation to socioeconomic, demographic, psychiatric, and familial factors: a national register-based study of all suicides in Denmark, 1981-1997. *Am J Psychiatry* 160 (4): 765-72.
- ²⁶ Department of Health (2016). *The Government's mandate to NHS England 2016-17*.

About Autistica

Autistica is the UK's leading autism research charity. We work to transform the lives of children and adults with autism through funding, stimulating and leveraging investment in ground-breaking research. We receive no direct funding from government, but work in partnership with statutory and other funders to build autism research capacity in the UK and ensure that resources are deployed where they can bring greatest benefit. We work with scientists, health services and individuals and families across the UK, so together we can understand autism better, improve diagnosis and develop the best ways to support people, so that everyone with autism can fulfil their potential.

Autistica is very grateful to all those who helped shape the report and recommendations, including Prof Patrick Bolton (King's College London), Dr Sarah Cassidy (Coventry University), Susan Dunne, Dr Michael Fitzpatrick, Alison Hardy, Dr Pauline Heslop (University of Bristol), Prof Michael Kerr (Cardiff University), Sarah Lambert (National Autistic Society), Jennifer Leavesley, Cos Michael, Dr Damian Milton (London South Bank University/National Autistic Society), Joshua Muggleton, Prof Eric Taylor (King's College London) Tim Nicholls (National Autistic Society) and Robyn Steward and members of Deutsche Bank's Government and Regulatory Affairs Department.

This Report has been approved by our Science Advisory Group.

Authors

Dr James Cusack
Simon Shaw
Jon Spiers
Rebecca Sterry

If you are affected by the issues highlighted in this report, these organisations offer advice and support:

Samaritans helpline:

116 123 (freephone) or jo@samaritans.org
www.samaritans.org

Mind helpline:

0300 123 3393 or info@mind.org.uk or text 86463
www.mind.org.uk

The National Autistic Society:

0808 800 4104
www.autism.org.uk

SUDEP (Sudden unexpected death in epilepsy) Action:

01235 772850
www.sudep.org

Epilepsy Action:

0808 800 5050 or helpline@epilepsy.org.uk
www.epilepsy.org.uk

Epilepsy Society:

01494 601400
www.epilepsysociety.org.uk

Cruse Bereavement Care:

0844 477 9400
www.cruse.org.uk



Find out more and support us at www.autistica.org.uk

Registered with the Charity Commission in England No. 1107350 Company No. 5184164

St Saviour's House, 39-41 Union St, London SE1 1SD, United Kingdom.

T: +44 (0)203 857 4340 E: info@autistica.org.uk

Autistica is Deutsche Bank's charity partner for 2016-17.

Pro bono design support very gratefully received from **bigdog**, part of **the mission**.™