

## Autism and epilepsy A guide to managing epilepsy in autism

People on the autism spectrum are much more likely to have epilepsy than the general population. People who have autism and a learning disability are at particularly high risk and their epilepsy can be difficult to manage.

That's why we've produced this short guide to help autistic people and their families to better understand epilepsy in autism, reduce their risks and know where to go for help.

### What is epilepsy?

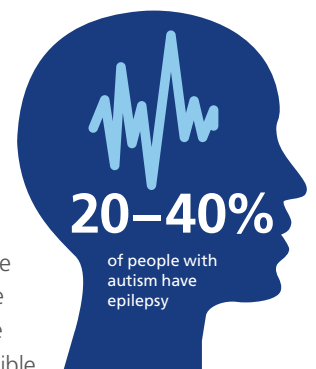
Epilepsy is a condition that affects the brain. When someone has epilepsy, they can have seizures. These are caused by a sudden burst of brain activity which temporarily stops the brain working properly. There are lots of different types of epilepsy and many possible causes. For some people it only lasts for a limited time, but for many the condition lasts a lifetime.

### How is epilepsy different in autism?

Just 1% of the general public has epilepsy. In those with autism, this number rises to 20–40%.

Epilepsy in people with autism often starts much later in life than in the general population – often not until teenage years or even later. People on the autism spectrum may have a different pattern of seizures in the brain. It may be harder to treat their epilepsy with drugs that work in the general population.

Epilepsy is now the leading cause of death in people with autism and a learning disability so it's vital to think carefully about how we keep people safe and well. While a lot is still unknown, there are things we can all do to support people with autism who have epilepsy to manage their condition and stay as healthy as possible.



## Practical tips for managing epilepsy

### Know that it could happen

It's good to make family, friends and carers aware that epilepsy can develop in someone with autism, even if they've never had a seizure before. For some, especially those with learning difficulties or those who speak few or no words, it can sometimes be hard to tell when a seizure is happening.



### Get a personalised plan

Creating a plan with your doctor can help the family and healthcare professionals to work together more effectively to manage seizures. Everyone involved should play an active role in developing and regularly reviewing the plan.



### Regular medication

If medication has been prescribed to control seizures, it's vital that this is taken exactly as instructed. It can take time to find the best medication and dose, so you will need to follow the advice of the doctor to get this right.



### Identify triggers

Not everyone has triggers before a seizure, but some of the common ones are being overtired, missing meals and forgetting to take epilepsy medicines. It can be useful to keep a diary of seizures to help understand potential triggers.



### Avoid heavy drinking

People with epilepsy need to avoid drinking too much. Heavy drinking can cause seizures and may make medication less effective.



### Regular reviews.

It's important to have regular reviews with your GP or epilepsy specialist to make sure the treatment plan is working well. Visiting the doctor may be stressful for those on the autism spectrum, but there are simple things you can do to reduce anxiety. Visit before your appointment so that the journey and environment are more familiar. Ask to book the first or last appointment of the day so you won't have to wait too long and book a double appointment as extra time may be needed. See if there is a quiet area to wait in rather than the busy waiting room. If you make reception staff aware that you or your child has autism, they should do everything they can to help you. You can read more about preparing for a visit to the doctor here:

[autism.org.uk/about/health/doctor](http://autism.org.uk/about/health/doctor)



### Do a safety check

The charity Epilepsy Action suggests that you do a safety check to identify and lower your risks before someone with epilepsy does an activity.

Ask questions like:

- When and where will the activity happen?
- Will there be other people around?
- How far would they be from help?
- What happens if a seizure happens?
- How quickly does the person recover from a seizure?
- Will there be any dangerous tools or equipment involved?
- Will extra equipment or changes to the environment be needed?



Once you have answered your safety check questions, you can help to reduce the risks or even decide not to do the activity if you feel it's not safe enough. You can read more about safety checks here:

[epilepsy.org.uk/info/safety#check](http://epilepsy.org.uk/info/safety#check)

### Where to go for help

The following organisations offer advice and support online or over the phone:

#### The National Autistic Society:

0808 800 4104 [autism.org.uk](http://autism.org.uk)

#### Epilepsy Action:

0808 800 5050 or

[helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk) [epilepsy.org.uk](http://epilepsy.org.uk)

#### Epilepsy Society:

01494 601400 [epilepsysociety.org.uk](http://epilepsysociety.org.uk)

#### SUDEP Action (Sudden unexpected death in epilepsy) :

01235 772850 [sudep.org](http://sudep.org)

You can also take a look at our other information leaflets at:

[autistica.org.uk/autism/useful-information](http://autistica.org.uk/autism/useful-information)

### Get involved in research

To improve our understanding of autism we rely on volunteers to take part in research studies. Taking part in research can be something as simple as completing a survey, or trying a new drug or therapy intervention. How you decide to be involved is up to you. If you, your child or your family would like to take part in research, please visit: [autismspectrum-uk.com](http://autismspectrum-uk.com)

### Support our work

Autistica are working hard to fund vital new studies so we can help everyone affected by autism to live longer, healthier, happier lives. If you would like to support our work, visit [autistica.org.uk/get-involved/](http://autistica.org.uk/get-involved/) or contact us at [info@autistica.org.uk](mailto:info@autistica.org.uk)

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Building brighter futures through autism research

St Saviour's House, 39-41 Union Street, London, SE11 5SD. T: (0)203 857 4340  
[www.autistica.org.uk](http://www.autistica.org.uk) E: [info@autistica.org.uk](mailto:info@autistica.org.uk)  
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# Keep in touch

To receive email updates from Autistica simply complete this form.

Send this page in a stamped envelope labelled:

**Autistica**

St Saviour's House  
39-41 Union Street  
London  
SE1 1SD

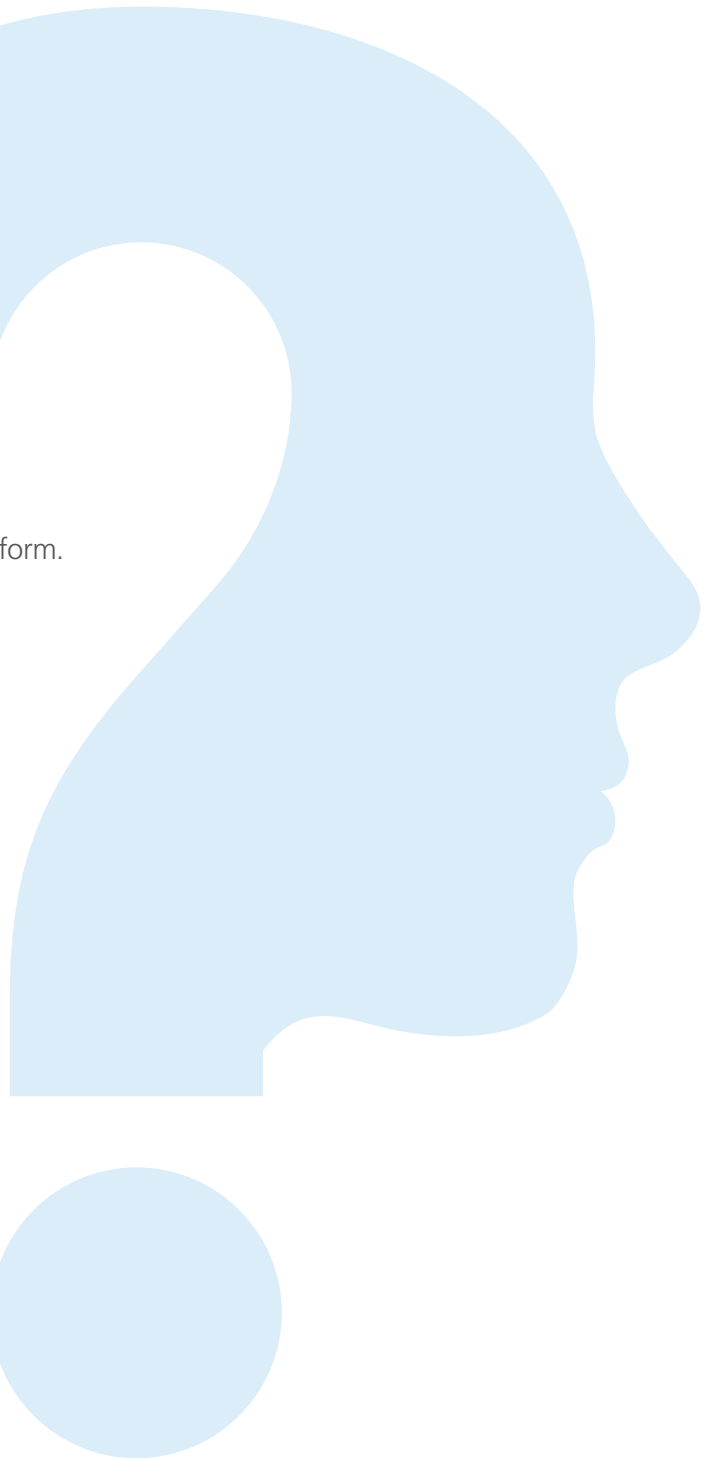
If you're viewing this online, you can sign up to receive information and updates from Autistica [here](#).

Alternatively, phone us on **020 3857 4340**.

**Tell us about your autism connection so that we can personalise the information we send you:**

- I am autistic
- I am a parent
- I am a family member
- I am a professional
- I am a researcher

**Other** \_\_\_\_\_



**Your details**

**Name:**

**Email\*:**

**Address: (optional)**

**Telephone: (optional)**

**Mobile: (optional)**

\*Email is Autistica's standard method of communication. If you wish to receive regular updates from Autistica, you will need to provide an email address.

Your details are always held securely and we will only send you the information that you have opted for, but if you'd rather not hear from us please tick the relevant box:

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