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## Epilepsy and autism

### What is epilepsy?

Epilepsy is due to an imbalance in brain chemistry, which means that the messages that travel between nerve cells or neurons becomes scrambled. Because of this, the activity of neurons is disturbed and results in a seizure or loss of consciousness. Many types of seizure can occur and epilepsy can affect anyone at any age.

### Is there a link between autism and epilepsy?

The relationship of autism to epilepsy has been an area of scientific interest for decades. The first studies on the subject in the 1960s helped to show that autism is a condition of the brain. We now know that autistic people are more likely to develop epilepsy than those who are neurotypical. We also know that people with epilepsy are more likely to be autistic than those without epilepsy.

### Does epilepsy cause autism?

There is no evidence that seizures or epilepsy (that is, recurrent seizures) cause autism. Several research studies have shown that the relationship between autism and epilepsy is not one of cause and effect.

### Who is most at risk of developing epilepsy?

Different studies have shown that intellectual disability (ID) is the major risk factor for autistic people developing epilepsy. The risk for epilepsy in autistic children without an ID is 8%, increasing to 20% in those with an ID. The risk can be as high as 40% in those with severe intellectual disability. Among autistic children who have IQs above 70, approximately 4% develop epilepsy.

As children with autism reach the teenage years, the risk of developing seizures increases, and continues to increase into young adulthood. Other factors such as gender, regression of language and social function don't increase the likelihood of an autistic child developing epilepsy.

### **How does diagnosis work?**

The way that a neurologist (or paediatrician) diagnoses seizures or epilepsy is the same whether or not the person is autistic. However, there are some characteristics associated with autism which can be confused with signs of seizures, such as staring or repetitive movements. If an autistic person stares without responding or does short, rhythmic movements which are unusual, it could be worth seeing a specialist to check whether they are having seizures. Even a slight concern should always be checked out.

Before [making a diagnosis of epilepsy](#), a neurologist will find out the cause of the seizures by doing some tests. This may include:

- an electroencephalogram (EEG) during sleep
- an MRI
- genetic testing.

### **Supporting people with autism and epilepsy with seizures**

Many of the aspects of supporting autistic people with epilepsy are similar to supporting someone who has epilepsy and is neurotypical. For example, [first aid for seizures](#). However, being autistic can make it harder to explain individual experiences and sensations to others – which can mean it's harder to get the right help at the right time.

For example, a person with epilepsy may have odd sensations before a seizure happens, such as a strange taste in the mouth or blurred vision. Often these signs may not be obvious from the outside, and if a person is autistic they may have difficulty communicating what they are experiencing.

There is also a risk the signs of an imminent seizure might be misinterpreted as sensory issues relating to someone's autism and not their epilepsy. It's therefore especially important to be alert to any small changes in behaviour which might mean something's not quite right. This might be:

- Fidgeting
- picking fingers,
- slapping lips
- becoming unusually clingy.

Getting to know the individual is key to understanding their particular triggers and signs.

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## Helping with communication

Some autistic children or adults will be able to tell you about the feelings they are experiencing, but for those who use alternative communication it's important to have a methodology in place that they are comfortable using to tell you how they are feeling.

For example, symbols or pictograms of the body can be helpful when trying to work out what hurts or feels strange. [Social stories](#) may be helpful, or having a particular [sign or symbol in PECs or Makaton](#) to indicate something hurts or doesn't feel right.

## Keeping everyone informed

Sharing information about how a person's epilepsy affects them with key people across the different settings in their life (at home, school, work or in services they use), is vital and should be done as a matter of course.

This includes general information about their epilepsy, such as the normal length of their seizures and recovery, as well as specific information such as how best to communicate with them about triggers. It's important that autistic people with epilepsy aren't made to feel different because they have epilepsy, and that they are included in everything they are able and want to take part in.

## References

[Jeste, S. S. and R. Tuchman \(2015\). "Autism Spectrum Disorder and Epilepsy: Two Sides of the Same Coin?" J Child Neurol 30\(14\): 1963-1971](#)

[Tuchman, R. \(2015\). "Autism and Cognition within Epilepsy: Social Matters." Epilepsy Curr 15\(4\): 202-205](#)

[Tuchman, R., et al. \(2013\). "NINDS epilepsy and autism spectrum disorders workshop report." Neurology 81\(18\): 1630-1636](#)

## Further information

[Epilepsy Society](#)

[Epilepsy Action UK](#)

[Autistica: autism and epilepsy leaflet](#)

[Research Autism: epilepsy](#)