My Life With Epilepsy

Background Report
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This report tells us about the ‘My Life with Epilepsy’ project.

The project aims to tell people about the risks of death from epilepsy in people with a learning disability and autistic people.

This report looks at research and what we already know about this area. This will help to make the project better.

The report will look at three main things:

1. Deaths and SUDEP risks. SUDEP means – Sudden Unexpected Death in Epilepsy.

2. Providing information on epilepsy risks for the people with epilepsy and their carers.

3. Technology and Accessibility for people with a learning disability and autistic people.
How we found our evidence and information

We found information from 30 published research papers and studies.

Epilepsy Risk and SUDEP

Half a million people in the UK have epilepsy.

People with epilepsy are more likely to die earlier than people without epilepsy.

21 people die each week because of epilepsy. SUDEP, (Sudden Unexpected Death in Epilepsy) is thought to cause a large number of these deaths.

People aged between 20–40 years old are at a bigger risk.
Half of deaths linked to epilepsy may have been stopped if people knew more about safety risks and did things to reduce them.

We know there are some things that make the risk of an early death more likely:

- In nearly all cases, the person had more seizures (fits) in the 6 months before their death and their seizures (fits) had got worse
- Half of people had a history of drinking too much alcohol
- A quarter, (25%), of people had been taking medication for anxiety or depression
These are not all the risks people with epilepsy need to know about. But they are things that can lead to more seizures (fits) and a bigger chance of an early death.

Together we could lower this number if people with learning disabilities and autistic people are given better care which, is person centred.

These risks may not be known unless people with epilepsy and or supporters and carers know about them.

Risk in people with a learning disability and/or autistic people living with epilepsy

More people with a learning disability and autism have epilepsy than people in the general population.
People with a learning disability and epilepsy are more likely to die younger than those without.

The LeDeR report in 2020 showed epilepsy was the sixth most likely cause of death for people with learning disabilities.

**Telling people about the risks**

Research tells us that there is lots we can do to make the support for people with epilepsy better.

An epilepsy care plan can help. This tells people what to do in an emergency, so everyone knows what they can do to help keep people as safe as possible.

People with learning disabilities and autistic people need to know more about epilepsy and what SUDEP is, including what might make a person more at risk.
Talking about the risks of epilepsy helps to lower the number of people dying early.

People with learning disabilities and autistic people should be supported to make their own plans about epilepsy care and how to live more safely.

Research tells us that people who have cared for or known someone who has died often did not know enough about the risks of epilepsy.

How technology can help:

There is lots of technology and support to help people with epilepsy make their quality of life better.
Technology can come in different forms like smart phones, phone apps, video calling (like Zoom) and tablets.

People should be supported and helped to access this technology, so people have more access to support and importantly to help them lower their epilepsy risks so people can live safely.

**Why is this important?**

The research we have seen tells us about risk and what we can do.

Risks for people with epilepsy are higher. There are things we can do to make the risk less, but we need the right knowledge and support to do this.

People who have a learning disability or who may be autistic have a high risk with epilepsy.
People with learning disabilities and autistic people need clear plans in place so people can live good lives.

To do this we need to make sure people can:

• Access information in a way that works.
• Make sure care is person centred.
• Support people to learn how to lower the risks. Each person is different so people need information and skills to help themselves.

What do our experts by experience have to say?

The My Life with Epilepsy project can help people with a learning disability and autistic people living with epilepsy to understand their condition and find new ways to manage it.

We need to make sure information is clear and accessible and works for the person.