The importance of discussing and managing epilepsy risks with people with a learning disability, autistic people & carers

Background

This report into existing research is part of the My Life with Epilepsy project which is possible thanks to a grant from NHS England and NHS Improvement. The project is managed by SUDEP Action in collaboration with Speakup, Cornwall Partnership NHS Foundation Trust, the University of Plymouth Peninsula Medical School and the University of Sheffield, iHuman research institute, School of Education.

The My Life with Epilepsy project will identify ways to improve epilepsy-mortality risk awareness in people with a learning disability (including autistic people who also have learning disabilities) living with epilepsy. The project will also aim to support carers (both family & paid) to better understand, discuss and reduce epilepsy risks.

This report brings together existing research in this area. This knowledge and evidence will help inform the project. Specifically, this report covers:

- Epilepsy mortality & Sudden Unexpected Death in Epilepsy (SUDEP) risk for people with a learning disability and autistic people living with epilepsy
- Research into providing epilepsy risk-communication to people with a learning disability and autistic people living with epilepsy (and their carers)
- Considerations related to digital inclusion and accessibility for people with a learning disability and autistic people living with epilepsy (and their carers)

How we found our evidence

The initial search looking at the published research on these topics was completed by an Information Specialist and Honorary Clinical Fellow at the University of Plymouth. 3 research databases were used for this search using combinations of 20 keywords including ‘autism’, ‘neurodisability’, ‘SUDEP’ and ‘sudden death’.

Research papers were filtered for relevance and exclusions were made based on the topics of ‘epilepsy mortality and SUDEP risk’, ‘risk communication’ and ‘digital inclusion’. 42 papers fit the search criteria, and 12 additional papers that had not been captured in the initial search were also added by the project team. A final review of these papers was done, considering the context of the My Life with Epilepsy project, resulting in a total of 30 papers being included in this final report.
**Epilepsy risks and SUDEP**

Over half-a-million people in the UK have epilepsy (1) making it the third most prevalent neurological disorder in the UK (2). People with epilepsy are 24 times more likely to die prematurely than the general population (3) and twenty-one people die weekly in the UK; many of whom are young and otherwise healthy.

There is evidence that 50% of all epilepsy deaths are thought to be potentially avoidable (pre-COVID-19) (4). Sudden Unexpected Death in Epilepsy (SUDEP) accounts for a large proportion of epilepsy deaths each year in the UK, with those aged 20-40 being at increased risk.

Research that examined death records to explore epilepsy risk found that in 90% of these deaths there was an increase in seizure frequency 3-6 months before death, half had a record of alcohol misuse and a quarter had been taking drugs to treat depression or anxiety. All of which can lead to worsening seizures and increased mortality risk, but all of which can be better managed if care is patient-centred (5).

These, and other, warning signals could currently be missed if people with epilepsy (or those awaiting diagnosis) are not aware of the importance of risk-management and engaging with epilepsy services to reduce them.

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**Risk in people with a learning disability and autistic people living with epilepsy**

Approximately 22% of people with a learning disability and 12% of autistic people have epilepsy, compared to 0.6% of people in the general population (6). People with a learning disability and epilepsy tend to die at a younger age (7). The 2020 Learning Disabilities Mortality Review (LeDeR) report into deaths in people with learning disabilities showed that epilepsy was the sixth most frequently recorded cause, the most frequent chronic cause, and most frequently associated cause of death (in 2018 and 2019) and the second most frequently reported potentially treatable cause of death (8).

Whilst there are many risks common to people with epilepsy irrespective of whether they have a learning disability or are autistic, learning disability has been linked with higher risk of SUDEP (9, 10). There is potentially greater risk of death in people with a learning disability – an example of these devastating consequences has recently been publicised in the independent review into the death of Clive Treacey (14).
Research has demonstrated the benefits of epilepsy risk communication being patient-centred, personalised and holistic (16, 17, 26, 28). Risk factors linked with a higher risk of SUDEP are well-known, but research has shown that in many cases, many people with a learning disability and autistic people living with epilepsy do not have an epilepsy care plan in place despite it being recognised as best practice (8, 11, 12, 13). Awareness of SUDEP in individuals with a learning disability and epilepsy is also not widespread and evidence of SUDEP discussions with patients and carers (gathered after an epilepsy death has occurred) have also been shown to be lacking (10, 11, 14).

Despite all this, there is evidence of success in having regular, repeated and structured risk discussions around SUDEP in decreasing epilepsy risk (16). The feedback from patients, carers and professionals has been positive in relation to usage of structured guidance on risk discussion (17). Research also shows that self-management interventions can be successful in helping people with a learning disability and autistic people living with epilepsy to be more knowledgeable about their condition and improve how often they have seizures and their quality of life (18). All things we know can lead to reducing the risks linked with premature epilepsy deaths/SUDEP.

Whilst research often emphasises the value in people with epilepsy being encouraged to self-manage their own risk this is not common practice for many people (18). There is no one way to support and encourage people to self-manage their epilepsy, and health professionals will place a different emphasis on this as part of their epilepsy care.

Many of those bereaved by epilepsy were not aware that epilepsy could be a fatal condition and were not themselves aware of the risks associated with epilepsy (29, 30). This can lead to complex, traumatic grief reactions potentially impacting on them for many, many years, sometimes never to be resolved. This is particularly so if it is felt that epilepsy mortality / SUDEP risks were not communicated well or at all with their loved one. Many bereaved after the death want lessons to be learnt by those responsible for their loved one's epilepsy and care, in the hope of preventing future deaths, and to save others from the pain and devastation they have and continue to experience (29, 30).

"Devastated... not knowing that you can die from epilepsy and that there were things that could have been done to help prevent her death. I feel I could have done something if I had known the seriousness of the condition"

Bereaved Parent [The Epilepsy Deaths Register, www.epilepsdeathsregister.org]
The role of digital technology to better support people with epilepsy has the potential to help improve quality of life and how health services are able to better support their epilepsy patients. (20, 21). Existing digital tools, such as apps and devices are currently unable to prove they can prevent SUDEP / epilepsy deaths (22, 23, 24). However, they can play a role in supporting people with epilepsy to increase their knowledge and take steps to reduce their epilepsy risks (25, 26).

The literature review revealed a lack of academic papers on the use of digital solutions for self-management of epilepsy risks by people with a learning disability and/or autistic people. Nevertheless, it is recognised that devices such as smart phones and tablets are regularly used by people with a learning disability, autistic people and carers. They could have potential for encouraging participation in improving epilepsy risk awareness (27).

Tools like the EpSMon app are validated and well evidenced to communicate risk. EpSMon is recognised as best practice in the NHS RightCare Epilepsy Toolkit for management of risk (13, 26). However, the app has not been specifically designed for people with a learning disability and/or autistic people living with epilepsy or for their carers. This could mean that some people aren't able to use the app at all, or it is not easy/helpful to do so.

This is both a challenge and an opportunity as during this project one can learn more about how to improve the app to make it more inclusive and accessible for people with a learning disability and/or autistic people living with epilepsy and carers.

Why is this important?

Risk is part of all our lives. Yet we have seen in the research covered in this report that the risks, and our choices we make to reduce these are starker and with greater consequences for people with epilepsy.

People with a learning disability and autistic people face a greater challenge when they have epilepsy. These are influenced by an often more complex and severe epilepsy, their lives occurring in often more complex and challenging social networks and settings; and a need for information that must be tailored to the individual. Their epilepsy management also must happen in the context of the challenges (emotional, physical and social), so often faced by these individuals.

This combination of needs is often summarised by terms like 'complexity'. Such complexity leads sadly all too often to failure in care delivery, leaving individuals with unnecessary restrictions, unnecessary risks and left feeling unempowered. This can sometimes lead to a reduction of the quality of life for people with a learning disability & autistic people with epilepsy, and for some it can lead to premature and avoidable death.

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The personal stories shared with SUDEP Action from bereaved families about loved ones who have died shows the urgency to make change happen now for people with a learning disability and autistic people living with epilepsy.

The My Life with Epilepsy project recognises that addressing this issue is vital and solutions must have personal choice at their heart, supported by the highest level of support in terms of communication of risk and skilled management of the epilepsy. It recognises that adapting knowledge to meet complexity can provide clarity and simple solutions which can make a positive difference to lives. Such an approach will lead to immediate change in the lives of those with a learning disability and autistic people who also have epilepsy.

"We miss Ben beyond belief, losing him tore our lives apart. I would love for you to use Ben's story if it would help, to prevent anyone else having to live with the pain we do. This new project is a fantastic idea, and only wish our GPs, and neurologist, had made us aware of the risk of SUDEP."

Ben's Parents (Ben had autism and epilepsy, he died due to SUDEP aged 27)

Thank you to the SUDEP Action supporters who are supporting this project by sharing their loved one's story with us. Click on the photos below to read their stories:

Ben  Jenny  Clive  Karen
Richard  Georgie  Stephen

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A final word from our experts by experience:

"People with learning disabilities and/or autism are at high risk of premature mortality from epilepsy. It is extremely important that people with learning disabilities and/or autism (or their carers) have access to information about epilepsy and know their own person-centred risk factors, identify changes to them, as well as knowing who to contact if they feel that they are at risk.

If the information is not given well, it can affect every part of a person's life as they may feel unsafe and be scared of what could happen to them if they are on their own, this could lead to people losing their independence and no longer taking part in activities they used to enjoy. This could also lead to a person becoming isolated from friends and could cause them to feel low, however different types of epilepsy can affect different people in different ways and therefore in some cases people may not be as heavily affected as others.

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. The project could also help people without epilepsy to understand epilepsy, and how it can affect people's lives and how to help a person with epilepsy if they are having a seizure. It can give carers of people with epilepsy more information on how to help the person they care for and give them more first aid training on seizures."

"The My Life with Epilepsy work is important as it helps people who have epilepsy, or friends and family with epilepsy, understand how to live their lives to the full. People have lost their lives to epilepsy and with this work, we can help people live healthy lives with the condition."

Jodie Bradley, Speakup - an expert by experience

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References

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