

# SUDEP awareness

Family's experiences and potential risk minimising in relation to SUDEP. Collated for the UK Paediatric Epilepsy Programme Board, 2022 by the Expert by Experience representative.

## Bad Experiences

I agree our son had epilepsy for 10 years he passed away in his sleep due to SUDEP we were never told of this we did the brain surgery the VNS and was told he will be fine . Passed away at 17 . Then the neurologist said wow I was hoping he'd live until 30 . Makes me mad . Why lie to you ....

I agree, I wish I would have known before my 15-year-old son passed away from SUDEP. Doctor's need to be held accountable for not giving all the information.

We read this time and time again. Years go by, and still, people are none the wiser. It will be 3 years on 16 June since my lovely J passed away, like most others in his bed alone. The first we heard of SUDEP was when the coroner spoke to us. Same story different, wonderful young person.

My son had Epilepsy for four years before he died from SUDEP at 19 years old. No doctor told him or us about his risk or how to lower his risk. I am so gutted by this. Maybe it could have been different if we had information.

Our neurologist NEVER said a word...EVER

My son's diagnosis was very badly handled they wouldn't commit to anything for months and months, so nothing was mentioned about SUDEP I was given some leaflets about epilepsy and told to go online to get information thankfully I found Epilepsy Action and useful reliable information. My son's seizures are nearly 100% nocturnal so his consultant should have talked to us about this.

It was my good friend who messaged me the night before I was scheduled to call coroner's office...told me to google death from Epilepsy. What an eye opener...She's forever 24

There's a theme here. It seems that the first time anyone hears about what SUDEP is or its potential it's often after a family has lost a loved one. Whilst epilepsy is incurable, for many (but not all) it can be controllable. It is estimated that one third of all sufferers aren't getting the right drugs (usually because the doctors haven't worked out the right combination of drugs or that it's difficult to diagnose the exact type of epilepsy).

Hi, no. I wasn't aware at all of the SUDEP. It's a bit scary though.

My daughter suffered for years with massive tonic clinic seizures day and night- she would stop breathing. As well as all other types of seizures. She got so bad - 100's a day until she was in constant seizure/ encephalopathy- the neurologist felt the next step was an induced coma. I never heard about SUDEP from an NHS professional. I still haven't. She's 10. I believe she was having seizures from birth. (Although the NHS care was excellent). Thankfully we have found therapy and lifestyle which mean she is now seizure free.

## Concerning Risks

I was aware but not through medical profession through my own research. It always worried me & affected my sleep would worry about my daughter & it happening. I did bring it up with her neurologist, but he dismissed it said she had just the same chance of it happening as someone without seizures 🙄

Absolutely you should be aware of it. My daughter 36 years old just died in October and the medical examiner said it was SUDEP. She had Epilepsy since she was 14. She was on medication and only had a breakthrough seizure if she was not compliant with her medication and that only happened when she was a teenager. The second breakthrough seizure was after she had our granddaughter and was prescribed an antibiotic for an infection she contracted, and the medication did not interact correctly with her seizure medication. We cannot understand why she had a seizure that killed her. She was alone. Idk so heart wrenching.

We had to raise it with our sons' medical team. One nurse during an inpatient admission asked if he had any equipment at home whilst he was sleeping but that was it. He has always had nocturnal seizures.

I only came to understand death was possible with prolonged seizures, but it wasn't given a name – she used to have night terrors prior to her epilepsy diagnosis & I still worry about seizures in her sleep as we've had a few in bed, recently - I only came to understand SUDEP through Daisy Garland

We need to talk about SUDEP and work out how to prescribe the right drugs.

I honestly couldn't tell you much about what information was given to us at the time of diagnosis, probably not the right time to discuss. Especially when it's a catastrophic form of epilepsy.

Hope that it never changes awareness and education is the only way forward

I have been on a few 1st aid courses and 'bought' it up...also more in-depth epilepsy training. As it seems it's skipped over!

I tell everyone about it, been into hospitals and schools, talk to parents, written stories, spoken at length to my MP, and work hard to help keep young people safe from it.

We were never told, I found out when looking up about epilepsy

We offer our SUDEP info to all that want it...but professionals should be doing that.

## Rare occasions being told by specialist

We were told by our consultant after scans of the heart.

We have always had it discussed it's becoming part of policy now that it should always be spoken about, however more so when children are teens as it can be challenging to have the conversation in front of a child as it may not be an age-appropriate conversation for the child to be aware of

We was made aware at initial diagnosis at 5 months old. My son's neurology consultant came and sat with me on the ward and discussed at length numerous things. Which immediately prompted me to reach out to The Daisy Garland for a SATs monitor. This was 6 and a half years ago.

They made us aware of SUDEP as soon as she was diagnosed - we had a whole separate appointment about it as the epilepsy nurse thought it was so important to be informed.

I asked about it having read about it, at least 2 years into diagnosis. I was quite taken aback when they explained it was a risk as her seizures were always nocturnal. I find it tends to be me who raises it rather than staff.

The day I had an official diagnosis I was also told about SUDEP. I was aware already as a boy at my son's school had died. Horrendous 😞

We discussed it a few days after diagnosis at home by the epilepsy nurse. I felt this was appropriate and allowed us to take on the diagnosis talk 1st and process it.

It was one of the 1st things the doctor told me about when we got my daughters EEG results. She told us "The EEG has come back abnormal, and I need to make you aware with this result and the type of seizures there's a higher risk of SUDEP". I think it depends on the doctor.

Hi, it was highlighted by my son's consultant immediately. I am registered with SUDEP Action and as a community Pharmacist I have the SUDEP checklist available to try and do my bit to help parents understand the individual risks to their children. Hope this helps.

When my daughter was diagnosed at 6 months it was discussed with me by her Epilepsy Nurse Specialist.

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There were many other testimonials which I have kept anonymous and had input from SUDEP Action and The Daisy Garland.

My interaction with SUDEP Action gave an insight and the tools they have available to health care professionals, that it's a constant fight and needed support whether for grieving or worry. Indicating that the conversation maybe hard but needs addressing to help minimize risk and stress, making it mandatory not just guidelines.

To go forward I feel that not on the first appointment but a second either with a specialist or epilepsy nurse go through the risks and give patient and parents the information.

I also have a document of all testimonials collected along with the tools available from SUDEP Action.

On Monday of this week, we provided funding for a further 61 SATs/epilepsy monitors under our 'Reducing the Risk of SUDEP' programme. We are regularly told by families that our monitors are saving the lives of vulnerable children who are at high risk of SUDEP. To date, we have provided funds for 700+ monitors. Monitors that are not available on the NHS for home use, despite the devastating consequences of SUDEP, which we know of only too well from our own first-hand experience.

## Links

### SUDEP Action

- [SUDEP and Seizure action checklist](#)
- [Epilepsy Self-Monitoring](#)
- [Short guide for healthcare professionals](#)
- [Parents' Guide](#)
- [SUDEP: what you need to know for parents](#)
- [Epilepsy Safety Devices](#)

### RCGP

- [SUDEP Action/RCGP training for professionals](#)

### Journal article

[Decreasing the risk of sudden unexpected death in epilepsy: structured communication of risk factors for premature mortality in people with epilepsy](#)

### Daisy Garland

- <http://www.thedaisygarland.org.uk/>

**Thank you to the Expert by Experience for collating these views and the parents/carers/families who shared their experiences.**