

Case story

Ensuring consistent emergency response to convulsions in children

This case story is based on real events and NHS Resolution is sharing the experience of those involved to help prevent a similar occurrence happening to patients and staff. Although the incident may have happened sometime in the past, as you read about it, please ask yourself:

- Could this happen in my organisation?
- Who could I share this with?
- What can we learn from this?

Topic: Sudden Unexpected Death in Epilepsy – Conveying to A&E

Key points:

- There are at least three epilepsy-related deaths a day in the UK. Sudden unexpected death in epilepsy (SUDEP) is less common in young children than in adults, but can still happen.
- All children suffering a first convulsion, whatever the suspected trigger, must be conveyed to A&E; even if the convulsions have stopped by the time the ambulance crew arrive. This is in case the convulsions signify a serious underlying condition requiring treatment.

Charlie's Story

Charlie was a ten year old boy from Wiltshire who tragically died from sudden unexpected death in epilepsy (SUDEP) in October 2011.

Charlie had suffered his first ever epileptic seizure on 7 October, just four days before he died. On that occasion his family called an ambulance, which arrived within 11 minutes. By this time Charlie was conscious and no longer fitting.

Paramedics assessed Charlie. They suggested that Charlie had suffered a febrile convulsion and concluded that there was no need to transfer him to hospital. Febrile convulsions are fits that can happen when a young child has a high temperature. They are not uncommon and are usually harmless, with most children making a complete recovery afterwards.

Charlie's family were still worried and took Charlie to see their GP a few days later. The GP suggested Charlie might be suffering from nocturnal epilepsy and referred him to see a neurologist. Tragically, before the neurologist appointment took place, Charlie had a second seizure and died on 11 October. He was taken to hospital but could not be resuscitated. The post-mortem concluded that the cause of death was SUDEP.

The Claim

Charlie's parents felt strongly that their son should have been taken to hospital by paramedics after his first seizure. Concern was also expressed about this by one of the consultants who tried to save Charlie when he was admitted to hospital. As a result the family made a formal complaint to the ambulance trust.

Lessons learned

The trust carried out an investigation into the care Charlie received, concluding that the ambulance crew who attended Charlie on 7 October had failed to follow the relevant Joint Royal Colleges Ambulance Liaison Committee guidelines at the time regarding the management of convulsions in children. These stated that all children suffering a first febrile convulsion should be transported to A&E, whatever the suspected trigger, and even if the convulsion has stopped by the time paramedics arrive.

SUDEP Action reports there are at least three epilepsy-related deaths a day in the UK. SUDEP is less common in young children than in adults, but can still happen. Children should be conveyed to hospital after a first suspected febrile convulsion just in case the seizure is actually a sign of a serious underlying condition.

The trust's investigation report recommended that:

- The ambulance crew who attended Charlie on 7 October should receive remedial training to ensure their practice would change.
- All clinical staff in the trust should be reminded of the guidelines for managing febrile convulsions in children.
- Information about SUDEP and the management of febrile convulsions should be incorporated into the trust's internal training programme from 2013.

What has changed as a result?

An Ombudsman report in May 2016 found that the trust had not fully implemented the recommended actions, and had not provided additional training on febrile convulsions and SUDEP to clinical staff.

Since then however, the trust has worked with Charlie's family and with the charity SUDEP Action, to develop an appropriate training package. This aims to raise awareness of SUDEP and to help paramedics and other healthcare professionals understand and identify epilepsy risk factors in order to help minimise risks to future patients.

Importantly, the training package includes a video of Charlie's mum and dad explaining what happened and what should have been done differently. Additional classroom learning materials have also been developed by the trust's training team, in association with SUDEP Action. The trust is now rolling out this training to all their paramedics.

Charlie's family and the trust are keen for these materials to have a wider impact and are making the training package available to all UK ambulance services. The video and training package were showcased at the National Education Network for Ambulance Services (NENAS) event in January 2017 and the UK ambulance services have been offered the training pack free of charge except for a donation to SUDEP Action. Six ambulance trusts have already applied for the training pack.

Charlie's parents have also been invited in by paramedic provider universities in the South West of England to speak to undergraduate students.

Charlie's mum Jan says the family just wanted to turn an awful situation into something positive. She hopes that the training will help to save a significant number of lives.

"Sudden unexpected death in epilepsy is one of the top ten causes of early death. The condition kills more people in the UK than cot deaths. Healthcare professionals need to know more about it and the differences of seizures and convulsions. This training will help make sure our son didn't die in vain."

Conclusion

Charlie's death was desperately sad and affected all those involved. By working together with Charlie's family and SUDEP Action, the trust as an organisation has learnt from this experience. All paramedics employed by the trust are now aware that any child suffering a first convulsion must be conveyed to A&E, they also have a greater awareness of SUDEP and what risk factors to watch out for.

Sharing the training package with other ambulance trusts will also ensure that lessons from Charlie's death have a much bigger impact, reaching thousands of frontline NHS staff across the UK.

***Any profits the trust makes by sharing the training videos will be given to SUDEP Action.**

For more information about the charity, please visit www.sudep.org

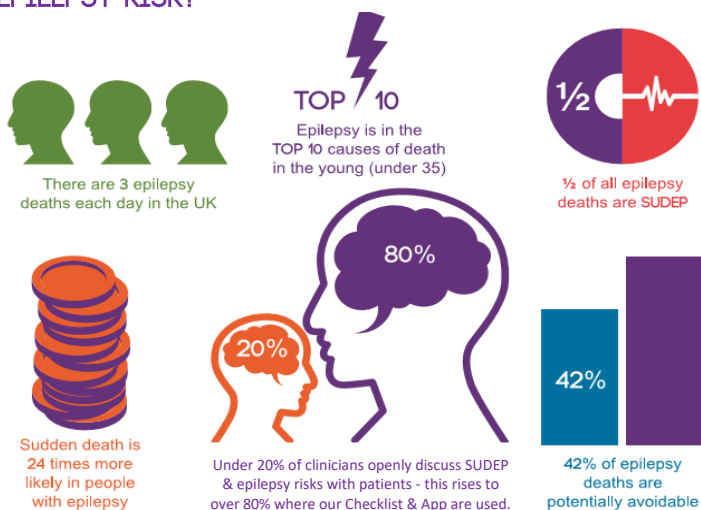
(Published April 2017)

The following material is being shared at the request of Charlie's family

Sudden Unexpected Death in Epilepsy (SUDEP) is when a person with epilepsy dies suddenly and prematurely and no other cause of death is found.

It is not a condition or disease, but rather a category to aid research and monitoring of deaths. Not everyone with epilepsy is at risk of SUDEP, and it is important that people with epilepsy discuss their individual risks and concerns with their health professionals.

WHY IS IT IMPORTANT TO KNOW ABOUT SUDEP AND EPILEPSY RISK?



The best way to lower risks of SUDEP is by achieving seizure freedom.



SUDEP ACTION is dedicated to raising awareness of epilepsy risks and tackling epilepsy deaths, including Sudden Unexpected Death in Epilepsy. They are the only UK charity specialised in supporting and involving people bereaved by epilepsy.

For over 20 years **SUDEP ACTION** provide free tools and services to support clinicians, people living with epilepsy and bereaved families.

PATIENT RISK FACTORS INCLUDE

- Having generalised tonic clonic seizures (sometimes called Grand-Mal or convulsive).
- Not taking medication regularly and as prescribed.
- Having seizures at night or when asleep.
- Having had epilepsy for a long time (often starting in childhood).

OTHER RISKS INCLUDE

- Lifestyle changes eg: increased stress and pregnancy,
- Substance or alcohol abuse.

People don't have to have frequent seizures to be at risk of SUDEP. Even people with controlled seizures should still take medication as prescribed, and have a regular medical review.

HOW CLINICIANS AND CARE PROVIDERS CAN HELP:

1. See the NICE Guidelines for suspected & diagnosed epilepsy care pathways & management recommendations.
2. Provide people with epilepsy with information about epilepsy risks, including SUDEP.
3. Promote the use of the **SUDEP & Seizure Safety Checklist** to clinicians to support their epilepsy annual reviews.
4. Encourage patient self-management of epilepsy and risk levels in between appointments with the **EpSMon app**.
5. Develop your own knowledge using our e-learning, leaflets, website and e-news.
6. Offer condolences to bereaved families and signpost them to The **Epilepsy Death's Register**.
7. Signpost people with epilepsy and bereaved families to **SUDEP Action**.

