

E-360

E-newsletter

Edition 4



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PICTURE ME PURPLE Photo Competition

To celebrate Purple Day 2016, Epilepsy Action Australia is hosting a photo competition! Proudly sponsored by [Digital Camera Warehouse](http://www.digitalcamerawarehouse.com), who have kindly donated THREE gift vouchers to be awarded to the 3 photos that receive the most votes over the duration of the competition.

Competition opens on Wednesday 2nd of March, and closes on Sunday the 10th of April, at 5:00pm (AEST). You can enter as many times as you like!

It's easy to enter, simply:

SNAP – take your photo making sure there is something purple in it

UPLOAD – add your picture to our competition website

www.picturemepurple.com

SHARE – tell your friends and family to vote for your photo

VOTE – you can vote for other photos you like too.

Let's get Australia talking about epilepsy! Get snapping (or even if you don't enter please get behind this and cast your vote today)!

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FEATURE STORY: SUDEP - The unexplained consequence of epilepsy

INTRODUCTION

There are many unknown and misunderstood elements to epilepsy. One myth is that epilepsy is a relatively benign condition in which people have seizures and not much more. The reality is that seizures can potentially cause harm directly and indirectly, and occasionally people with epilepsy are at a higher risk of premature death. People with epilepsy may die suddenly and unexpectedly without a known cause. This is one of the most severe consequences of epilepsy.

Here we discuss this phenomenon, *Sudden Unexpected Death In Epilepsy, or SUDEP*, which is not widely known about in the community and often not discussed amongst doctors and their patients.

Rachael, mother of 11 year old Connor found this to be the case. Connor was just 5 years old when he experienced his first seizure, not that they knew it at the time. Over the following days they noticed Connor waking, making unusual movements with his hands and going back to sleep. By the third day Rachael was wondering if this was related to Connor being dragged out of the river, three days earlier, as he seemed to be underwater for longer than usual. As it happened, Rachael was right. During the ensuing period of tests and diagnosis there was no discussion of risk despite that first seizure in the river. Rachael scoured the internet for 'everything epilepsy' and stumbled upon this thing called SUDEP. Although the internet said it was rare, she was reading story after story of families who had experienced the loss of a loved one which made it feel much more common.

"At the time there was no single source clarifying the risk for an individual, no help to put it into perspective as the statistics quoted seemed huge. That had me worried" explains Rachael. "Our solution was to co-sleep as Connor could have an hour long seizure at night but we wouldn't know because they were non-convulsive. We became even more concerned when he started experiencing tonic clonic seizures after his first surgery in 2012."

"Despite Connor becoming seizure free after his last surgery in 2014, we still have that worry at the back of our minds but not to the same degree. We know we have taken all the steps to minimise the risks." continued Rachael "It wasn't until a paediatric neurologist at a seminar stated that about 25 Queenslanders a year die from SUDEP and 5 of those are children that I realised that Connor was not at as great a risk as I previously thought."



"Not once was the topic of SUDEP mentioned by the doctors during the diagnosis nor surgeries, I stumbled across it on the internet."

Oliver's mum, Tanya, first heard of SUDEP through parents on social media about 6 months after he first started having seizures at 3 days old. Tanya would have appreciated hearing about it from the doctors first hand but wonders if they didn't want to burden them with too much information on top of the tough time they were already going through.

“When is the best time to raise it?” Tanya continues “We did our own research and have always been really vigilant with medications, monitoring his seizure triggers especially when he is unwell with a fever and using a video monitor. Oliver has averaged one seizure a year for the last three years, compared to the 80-90 seizures he had each year in the beginning, he is relatively well controlled however we remain ever vigilant.” Both Tanya and Rachael agree that parents need to know as much as they can about epilepsy and the facts about SUDEP.

SUDEP EXPLAINED

SUDEP is the most common condition-related cause of death in chronic epilepsy.⁽¹⁾

SUDEP is generally defined as the *sudden, unexpected, witnessed or unwitnessed, non-traumatic, and non-drowning death in patients with epilepsy with or without evidence for a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a structural or toxicologic cause for death* (Nashef, 1997).⁽¹⁾

Thankfully the SUDEP risk is still quite low, but does vary from person to person. SUDEP is not linked with all seizure types so you may not need to consider this risk. The risk may be greater for a small number of people, which is why it’s important to talk to your doctor about your own risk.

SUDEP and death in epilepsy need ongoing open discussion, and information needs to be freely available so people know what it means for them and ways they may be able to reduce their risk.

WHY DOES SUDEP HAPPEN? ⁽²⁾

While it is still debated, the mechanisms leading to SUDEP seem to be usually triggered by a generalised tonic-clonic seizure (GTCS), however there are exceptions particularly of cardiac cause.⁽³⁾ What is clear is having an understanding of how SUDEP happens is an important first step in reducing the risk.

There is no exact known cause of SUDEP, and it is unlikely there is a single cause, but progress is being made to understand what may contribute to it happening. When someone dies of SUDEP, often, but not always, there is evidence of a seizure, particularly a GTCS happening prior to death.

Because the brain controls almost everything that happens in our body, including the heart and the lungs, it has a flow on effect when these seizures happen. During seizures, a change in breathing or heart rhythm is often seen. Normally, this is not a problem, but if more serious changes occur, for example, a major drop in oxygen levels in the blood, then this might be a trigger for SUDEP.

Studies examining the causes of SUDEP have focused on three main areas of involvement – the brain, the lungs and the heart. So briefly, what may contribute to SUDEP is:

- a. Electrical shutdown of the brain: When a seizure happens, the brainwaves (EEG) are firing rapidly, at a much faster rate, so after the seizure it can be quite common to see a flattening of the brain waves - known as EEG suppression. This pattern has been identified

1) <http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2010.02952.x/full>

2) <http://www.epilepsy.com/learn/impact/mortality/sudep/how-sudep-occurs>

(during previous EEG monitoring) in the EEG recordings of people who have died of SUDEP. Once the brain shuts down, breathing then stops followed by heart failure.

- b. Breathing difficulties: Problems with breathing are commonly associated with seizures. Difficulties can occur during or after a seizure. Air exchange during a GTCS is considerably reduced and might be responsible for low oxygen levels.⁽³⁾ Breathing difficulties cause low oxygen levels and high carbon dioxide levels in the blood. These abnormalities can contribute to changes in heart rhythms and blood pressure. If severe enough, they can affect brain function, leading to sleepiness, seizures, coma and death. Breathing difficulties can also be aggravated if the person is lying in a position that compromises breathing even further such as lying face down, or the head it nestled amongst pillows.
- c. Cardiac changes: Some seizures are known to affect heart rhythms. Seizures often cause an increase in heart rate and less often, the heart rate can slow down too much during or after a seizure. Irregular heart rhythms or even periods without a heart beat can also occur. Another possibility is that there is a genetic link between seizures and heart rhythm abnormalities. Genetic conditions are well known to cause sudden unexpected death in young people. A cardiac condition called *long QT syndrome* is an inherited condition that affects the heart and can cause sudden death. Similar gene mutations can also affect the electrical activity of brain cells, so studies are looking at whether these disorders could make people more likely to have seizures and sudden death.

SUDEP has often been compared to Sudden Infant Death Syndrome (SIDS). In both situations, the deaths occur more frequently in sleep and a cause of death is not found on autopsy. Scientists have found that some infants who died of SIDS had an abnormality of the brainstem, a part of the brain that is critical for the control of breathing and heart function. This suggests that there may also be a brainstem link with SUDEP.

The risk of SUDEP varies widely within the epilepsy population and some people are at much higher risk than others. In the general population of people with epilepsy the risk is 1:1000⁽⁴⁾ but:

- people with absence or myoclonic seizures are not known to have increased risk for SUDEP,
- the risk increases if you have frequent GTCS. The risk varies between 1:50 to 1:300.

SUDEP risk factors must be applied to the specifics of a person's situation and discussed within the context of their epilepsy.

There are several risk factors for SUDEP identified over a number of studies. These include demographic characteristics (gender, age), seizure type and characteristics, antiepileptic drugs (AEDs), and other diseases or conditions.

Some risks are avoidable and some are not.

3) <http://www.ncbi.nlm.nih.gov/pubmed/23646967>

4) <https://www.sudep.org/what-sudep-1>

Some factors can put people at a higher risk of SUDEP. These include^{(5) (6)} :

Demographics

- Being male is associated with a slight increased risk for SUDEP
- The risk appears to be lower among children than adults.
- People with onset after age 60 are 60% less likely to have SUDEP

Epilepsy Factors

Greatest risks are found amongst people with severe chronic epilepsy. Duration of epilepsy for more than 15 years is associated with a 1.95-fold increased risk of SUDEP.

Increasing number of GTCS per year is associated with an increased risk for SUDEP compared with people without GTCS.

Epilepsies with an unknown cause (Idiopathic/cryptogenic) and idiopathic generalised epilepsies (IGE) are associated with a lower risk for SUDEP.

Having a history of night time seizures was associated with an increased SUDEP risk however having someone sleeping in the same room reduced the risk by more than 50%. Special precautions such as listening devices were associated with a further risk reduction.

Antiepileptic drug (AED) therapy

It was once previously thought that AED polytherapy was associated with a statistically significant increased risk for SUDEP. This may be the case when GTCS are poorly controlled. This has recently been challenged and recent studies have reported that none of the AEDs tested were found to increase SUDEP risk as monotherapy or as polytherapy when GTCS frequency was taken into account—meaning that number of GTCS increases SUDEP risk, not AEDs.⁽⁷⁾

Taking one AED (monotherapy) was protective for SUDEP however non-adherence to the prescribed treatment is considered to be a significant risk factor for SUDEP.

Therefore, perhaps the most important known risk factor is the occurrence and frequency of GTCS.

Therefore one way to help prevent SUDEP is to reduce the frequency and risk of GTCS with education and optimal medical management. If GTCS occur during sleep, then using appropriate safety precautions are also recommended⁽³⁾.

Although more knowledge is needed on risk factors, all risks are in the end individual. You could be in a high risk group but may have options to reduce that risk such as epilepsy surgery. You may be considered low risk but your treatment or life-style choices may expose you to greater risk, such as poor adherence to medication or excessive drinking of alcohol. Making conscious



5) <http://www.sudepglobalconversation.com/#!tomson/c1975>

6) <http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2010.02952.x/full>

7) <http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2011.03354.x/full>

choices about the risks that can be controlled, those that cannot be controlled, and those you choose to ignore should be done as an informed choice. This is where the conversation with a health professional can be enormously helpful in considering risk factors.

REDUCING THE RISK

Managing seizures

The most important step you can take to avoid SUDEP is to minimise the number of seizures you have. Working to have as few seizures as possible, particularly reducing the number of GTCS, is the most important way to lessen the risk of SUDEP. For people with poorly controlled seizures, particularly GTCS, have regular reviews with the neurologist so the most appropriate and effective AED treatment is used.

Improving your knowledge about your epilepsy and treatment, helps with understanding the importance of ⁽³⁾:

- taking your medication as prescribed, and not to make changes without consulting your specialist
- avoiding seizure triggers and lifestyle choices that can exacerbate seizures
- reacting appropriately and managing GTCS, seizure clusters, missed medications and any other situations such as diarrhoea or other medication reactions, that could lower your AED concentrations,
- and being active with your seizure management.

It may also be worth considering other epilepsy treatments, such as surgery, when AEDs are not working to control seizures effectively.

Other ways to manage SUDEP risk factors ⁽⁸⁾

Be informed. Understand as much as you can about the type of epilepsy you have, what triggers your seizures and how best to manage it. Ask questions until you believe you are comfortable with the information you are receiving and understand it. Risk factors need to be discussed and understood within the context of your specific situation.

Try to arrange a meeting with your specialist, GP or an epilepsy nurse. Acknowledge fear and concerns you may have related to having seizures, talk about them with your healthcare providers, your family and friends, and make a clear plan for how you are going to deal with them. Understand that life will always have ups and downs.

Knowledge, support, and understanding the SUDEP risk factors and what they mean for you, and ultimately believing in your ability to manage epilepsy overall will go a long way toward enjoying a fulfilling life.

Safety factors

Putting in place some safety measures, particularly if you have seizures during sleep, is a good idea.

Think about using a pillow such as a lattice pillow or anti-suffocation pillow.

8) <http://www.sudepglobalconversation.com/#!/sierzant/cwac>

In situations that are relevant, night time monitors can help alert other people in the house that a seizure is happening. They can then respond quickly to reduce the changes of breathing difficulties. It is likely that early assistance after a GTCS may help prevent a fatality. There are many products available, but often a baby monitor can do the job for most people.

Confide in people close to you. Tell them that you have epilepsy and explain what they should do if you have a seizure.

If your neurologist has recognised that you have significantly reduced oxygen levels after a seizure, or you have had previous episodes of breathing difficulties, then providing oxygen immediately after a seizure may be warranted.

FUTURE OUTLOOK

Considering the highly successful use pacemakers and implantable defibrillators over decades in the prevention of sudden cardiac death, there may be hope one day that comparable systems for preventing SUDEP are developed.

Advances in research mean that we are getting closer to identifying the critical risk factors for SUDEP. However, it is difficult to set up clinical trials to assess the how effective intervening (during a seizure) would be, so this is a major hindrance for the development and implementation of unique strategies. Moving forward requires collaborative efforts to identify people at high risk of SUDEP and to allow carrying out feasible and informative clinical trials.

The successful public campaigns that resulted in marked reduction of the incidence of SIDS can serve as an inspiration for the application of simple interventions as well as innovative methods to assess their effectiveness.

CONCLUSION

Prevention of SUDEP remains a major clinical challenge for the epilepsy community, but with efforts to reduce seizures, be better informed and improve safety, the risk can be lowered. With what we currently know, the most obvious action is to aim for better control of convulsive seizures, GTCS, optimised use of AEDs, as well as early referral of suitable people for surgery.

WHERE TO FIND HELP

SUDEP information <https://www.sudep.org/what-sudep-1>

SUDEP information from professionals <http://www.sudepglobalconversation.com/>

SIDS and KIDS for counselling after loss of a child <http://www.sidsandkids.org/>

SUDEP stories <http://www.sudepglobalconversation.com/#!/family-stories/c1ele>

SUDEP poster "Dare to say SUDEP"

<http://www.epilepsy.com/learn/impact/mortality/sudep/dareto-say-sudep-infographic>

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IN THE NEWS THE LATEST ON EPILEPSY

Modified Atkins diet for children with poorly controlled seizures.

The ketogenic diet is a treatment option for children with drug-resistant epilepsy. For many reasons, it is difficult to maintain over a long period of time, hence the Modified Atkins diet has been proposed as a more feasible option. This study compares the two diets and concludes the Modified Atkins Diet is a reasonable choice before attempting the Ketogenic Diet, in children over 2 years.

See more http://www.practiceupdate.com/c/34818/1/7/?elsca1=emc_news_expert-insight&elsca2=email&elsca3=practiceupdate_neuro&elsca4=neurology&elsca5=newsletter&rid=MTM1NzAyODc4MzM2S0&lid=10332481

Also see the Atkins for Seizures website for more information, recipes and forums <http://www.atkinsforseizures.com/>



Seizures after Stroke

Seizures are common in the years following a stroke, with nearly one in six survivors requiring hospital care after a seizure, which is almost double the rate of people who have seizures after a traumatic brain injury. For more visit

<http://thehealthcast.com/heart-cardiovascular/stroke-survivors-develop-seizures-study-confirms/>

False Brain Training Claims

Lumos Labs, the company behind the popular brain-training web site *Lumosity*, has agreed to refund subscribers after making deceptive and "unfounded" claims about its products. For more visit

http://www.medicinenet.com/script/main/art.asp?articlekey=192951&ecd=mnl_day_010816

Kara hopes to raise awareness with clothing line

Kara Sampson hopes she's found a way to make a profit and a difference. Everything from her clothing and merchandise line, The Kendall Connection, includes eight words that have always inspired Sampson: "Be kind. Be true. Be strong. Be you." Products can be bought from her site <http://shopkendallcollection.com/> with also has a Facebook page.

Can brain training techniques help people improve their seizure control?

It's commonly known that mental stress can increase seizures and presumed relaxation techniques can reduce the risk of seizures. Studies undertaken at the Brighton and Sussex Medical School have found that training people with epilepsy to increase their levels of alertness, actually helped them to calm their brain and reduce the incidence of seizures. For more visit

<https://www.bsms.ac.uk/about/news/2015/05-12-could-brain-training-techniques-help-epilepsy-patients-control-their-seizures.aspx>



Q&As

OUR SERVICE PROVIDERS ANSWER YOUR QUESTIONS

Q: After recent seizures, I have noticed my child has weakness on one side of his body, slight facial drooping and slurred words for about an hour or so. We first thought this may be a stroke, but when it improved, thought it might just be part of the seizure.

A: What you are describing is possibly *Todd's Paresis* also called *Todd's Paralysis*. However because these symptoms can also be signs of a stroke, you need to follow this up with your doctor. Todd's Paresis mostly causes paralysis of one side of the body after a seizure which can last for hours, sometimes up to 48 hours. It may affect speech and vision and has been reported (rarely) to cause sensory changes. There is usually a full recovery, although on rare occasions permanent deficits can occur, but they are uncommon. The exact cause is unknown.

If your child is having regular seizures, it may be worth having some monitoring with video EEG to catch one of these events. Even going in for a simple EEG when he/she is experiencing these symptoms may be helpful.

For more information go to:

<http://www.ninds.nih.gov/disorders/toddsparalysis/toddsparalysis.htm>



Q: My grandfather has diabetes and epilepsy, and sometimes he has funny turns. How can I tell if they are a seizure or a low blood sugar event?

A: There are many different seizure types, but focal (dyscognitive) seizure can present as a "funny turn" so to speak. These seizures are often very subtle, sometimes unusual, and may go unnoticed or be confused with other events. They vary from person to person but typically can begin with a vacant stare, loss of expression or a vague, confused appearance. Awareness is altered, and the person may or may not respond. If they do respond, it is usually inappropriate. They can have unusual and repetitive behaviours such as chewing, fidgeting, walking around or mumbling. They can last from 30 seconds to three minutes and resolve on their own. Afterwards the person is often confused for a short period and may not remember much about the seizure.

Low blood sugar (hypoglycaemic) attacks are easy to recognise in spite of some variability between people. Symptoms can include: nervousness or irritability, the skin becoming cold and clammy to touch, sweating, hunger and nausea, shakiness, rapid heart beat confusion, and difficulty speaking.

It is important to clarify which is occurring as a hypoglycaemic attack needs quick management. Speak to your grandfather to see if he can inform you about what episode is a seizure and what is a hypoglycaemic attack. If your grandfather has an episode, offer him something sweet or sugary like a drink orange juice. If this resolves the problem it is most likely a hypoglycaemic attack. Whereas if it is a seizure, it is likely to continue to run its course and there is a good chance he won't respond or even take or drink the juice.

Q: I have nocturnal seizures and went to see my GP the other day, who has subsequently suspended my driver's license. I haven't had any daytime seizures so I don't know why this has happened?

A: I'm sorry to hear that you have had your license suspended. There are two lines of thought, either the GP was correct in temporarily suspending your licence based on the information you have told him, and clinical assessment of you until further investigations have been done. The other line of thought is that if it truly is nocturnal seizures and they never occur during the day the GP may be unaware of the current guidelines for assessing fitness to drive.

The roads and traffic authority *Assessing Fitness to Drive* booklet explains:

Sleep-only seizures: Some seizures occur only during sleep and hence are not a hazard to driving. In people who have never had a seizure while awake but who have an established pattern of seizures exclusively during sleep, the risk of subsequent seizures while awake is sufficiently low to allow private driving, despite continuing seizures while asleep. In people with an established pattern of sleep-only seizures but a history of previous seizures while awake, the risk of further seizures while awake is higher. Therefore, a longer period of sleep-only seizures is required before driving by this group than in those who have never had a seizure while awake. This applies only to private vehicle drivers. The full booklet can be viewed at: <http://www.austroads.com.au/drivers-vehicles/assessing-fitness-to-drive>.

Epilepsy Action also has a *Nocturnal Seizures Factsheet*. If you are unsure, speak to your GP and follow this up with your treating neurologist.

Q: I have a 9 year old daughter who has a benign or "mild" type of epilepsy. Her seizures aren't under control and she is really upset about it, even talking about killing herself, which is very distressing given her age. We don't know what to do.

A: Firstly, seek the support of your regular GP or paediatrician immediately. It is important to take seriously any talk about wanting to die or hurt herself. Whether such talk represents a clear intention of suicide or is a way of expressing feelings of depression, it indicates a high level of distress that needs attention. Most hospitals will provide services or referrals to the closest children's hospital for specialist support.

Depression is quite common in people with epilepsy, and in children and adolescents with epilepsy it occurs in about 23-33% which is very high. Understanding the underlying reasons for the low mood or depression may take time, but it is probably caused by a combination of things which may include difficulties at school, the effects of the seizures or the medication, fear of having seizures or just feeling different.



At home, be supportive, spend time with and listen to your daughter. Encourage her to be involved in interests and activities still, and try and discuss and work around negative thoughts. Keep it as positive as you can. Remind her that it will not always be like this.

This information may help:

<https://www.kidsmatter.edu.au/families/mental-health-difficulties/depression/depression-how-depression-affects-children>

There are links here about getting help as well.

Lifeline is 13 11 14 if you also need to speak to someone or

Headspace is a good resource and help for your daughter www.headspace.org.au

WIN!

Free entry to win this fabulous outdoor living setting, comprising a top of the range BBQ and Mimosa outdoor furniture setting for four valued at \$2,900, simply visit our website (www.epilepsy.org.au) and click on the homepage banner to enter!



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