“Can someone die from epilepsy?”
Witnessing your child or loved one experience their first seizure can be very confronting. People often express fears that they thought their child was dying, not knowing what was happening or what to do.

Like other chronic health conditions it is not unusual for people to question their own mortality and worry about dying especially when diagnosed with conditions such as heart disease or cancer. People diagnosed with a long-term medical condition like asthma or diabetes are usually aware that there is a small risk of dying from their condition.

However, people are less aware that there is also a risk of death from epilepsy. Although many people with epilepsy and their families have concerns about the effects of seizures such as injuries, or drowning, some people may think that seizures cannot be fatal, but in fact, seizures like an asthma attack do carry some risk.

This can be a difficult topic to talk about but it is important to understand the facts so you know the right questions to be asking your doctor.

The risk of dying
Even though the risk of dying from epilepsy is small, like other conditions, a good understanding of the disease and good seizure management and control leads to better quality of life, less seizures and may result in fewer unnecessary deaths.

Community-based studies and reports from specific epilepsy research show that people with epilepsy do have a mortality (death) rate which is two to three times higher than the general population. Although this sounds a lot, the risk of dying, a doubled risk is still very low.

Mortality in epilepsy is sometimes unpredictable but there are some recognised risk factors. For instance, in a 2011 study, Risdale et al found that:

- people with epilepsy and alcohol problems had an almost three times increased risk of death
- people who had not collected their most recent antiepileptic prescription in the past three to six months had nearly double the risk of death
- having “a history of injury” during the previous year increased risk by 40%
- having had treatment for depression increased risk by about 40%.

Causes of death
Seizures are hardly ever fatal. The reasons why people with epilepsy die directly or indirectly related to seizures can be influenced by many things including their age, type of epilepsy and seizures, other health conditions and environment and lifestyle.

Seizure related deaths can happen for a number of reasons. They can be caused by:

1. Accidents and injuries related directly to or as a consequence of a seizure such as a significant head injury, burns, bleeding and drowning.

2 http://www.sudep.org/
3 http://www.springerlink.com/content/92q554nkyn95g7/
4 Premature Mortality in Epilepsy http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2813%2960899-5/fulltext
5 http://www.epilepsyonario.org/client/EO/EOWeb.nsf/web/Mortality-In-Epilepsy-[SUDEP]

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2. Status epilepticus (a prolonged seizure lasting longer than 5 minutes or cluster of seizures where the person doesn’t recover inbetween seizures) or complications from status epilepticus.

3. A stroke or brain tumour, or other problem in the brain which may cause the epilepsy initially can also contribute to an earlier death.

4. Suicide often as a result of severe depression

5. Suffocation from being in the wrong position after a seizure [particularly in bed amongst bedding and pillows], inhaling vomit during or just after a seizure.

6. Severe side effects from antiepileptic medications. Generally these are exceptionally rare and occur during early stages of treatment.

7. SUDEP: Sudden unexpected and unexplained death from a witnessed or unwitnessed seizure, where no other cause for death can be found. These account for up to 17% of deaths in epilepsy.

Sudden Unexpected Death in Epilepsy (SUDEP)
SUDEP is thought to happen when a person with epilepsy who is in their usual state of health dies unexpectedly. The death is not related to an accident and no other cause of death can be found if an autopsy is done.

SUDEP is defined as the sudden unexpected non-traumatic and non-drowning death of people with epilepsy, with or without evidence of a seizure, excluding status epilepticus, and in whom post-mortem examination does not reveal a structural or toxicological cause for death. Research suggests that seizure-provoked heart rhythm changes, breathing difficulties, brain swelling during a seizure or suffocation are possible causes.

The reasons for SUDEP are not yet fully understood. It is a rare condition and is the cause of approximately 10-17% of deaths in people with epilepsy. The risk differs, but is approximately one in three thousand per year for all people with epilepsy but can be as high as one in three hundred for people who have frequent tonic clonic seizures and take high doses of antiepileptic medication.

Risk factors for SUDEP include:

- People with poorly controlled epilepsy who have tonic clonic seizures.
- People who are taking more than two antiepileptic medications
- People who do not take their medications regularly and as prescribed.
- People who stop medication without medical advice.
- People who use illicit drugs and drink alcohol regularly.
- People who have seizures during sleep.
- Younger adults
- People who have an intellectual disability.

Many times, the person is often found to have died in bed and there is sometimes no evidence that a seizure has occurred. However, about a third of people do show evidence of a seizure close to the time of death and in most cases antiepileptic medication blood levels are generally very low.

SUDEP is rare in children.

It appears that the risk of SUDEP is closely related to seizure frequency, being 40 times higher in people whose seizures are not controlled.
Reducing the risk of mortality

What can people with epilepsy do to reduce their risk of dying during a seizure? Some suggestions include:

- **Maintain good seizure control** by taking antiepileptic medication as close to the prescribed schedule as possible. Be aware that there is an increased chance of seizures with medication changes or withdrawal.
- **Identify and avoid seizure triggers** where possible.
- **Avoid high risk activities** if seizures are not controlled (e.g., swimming, scuba diving, rock climbing).
- **Do not drive if seizures are not controlled** or if feeling overtired or poorly.
- **Adopt a healthy lifestyle** as good health is a positive way to increase resistance to any health challenge.
- **Avoid heavy alcohol use** and illicit drugs.
- **Get enough sleep** to avoid fatigue.
- **Be aware of safety issues** to minimise the risk of injury during a seizure. See our Safety Factsheet.
- **Don’t change medication brands** without discussing with your doctor.
- **Never stop your medication suddenly**.

For people attending to a seizure:

- Monitoring breathing during and after a seizure.
- Stimulating (such as calling their name or touching their shoulder) someone after a seizure is believed to reduce the chances of apnoea (stopping breathing).
- Encourage the person with epilepsy to take their medications as prescribed.

Today’s challenge is to develop and assess interventions that may reduce or prevent many deaths. This is where good communication amongst health professionals, good continuing care for people with epilepsy and even electronic health records can have a place. These strategies can help identify people at high risk and possibly prompt monitoring, better management or a review of their health current status.

Talking about it

Death is never an easy topic to raise or discuss. Most people feel uncomfortable with it. Doctors may or may not discuss SUDEP and other mortality issues with their patients. Some doctors choose to avoid the subject so not to raise alarm. Many are willing to discuss it, but lack the time during a consultation. If you have concerns, it is essential that you discuss it with your doctor to assess your situation and individual risk.

Education

Educating people with epilepsy, their families, and the community at large, will enhance a better understanding of epilepsy, managing seizures and understand the possible complications of seizures and epilepsy. Education about death in epilepsy can play a role in prevention if people know the risks and how to lessen them.

Training

Caregivers can be trained in how to manage seizures, particularly tonic-clonic seizures, including positioning the person during and after seizures. It is advisable for caregivers to know how to resuscitate someone should the need arise.

Impact on families

One of the most common responses heard from parents and families after the sudden death of a loved one is “no one told me you could die from this”.
The response to not being told is overwhelmingly negative. Commonly people feel anger, resentment, disempowerment and guilt.

- Maybe I could have done more?
- I would have kept a closer eye on him/her had I known.
- I didn’t think it was that serious.
- How dare the medical profession keep this information from me, what right do they have deciding what I should know?
- We would have done things much differently if we knew this was a possibility.

Families often feel guilt about what they feel they could have done; anger, especially if they had not been told; feelings that they were not given the opportunity to have taken more care but in most situations there is nothing they could have done anyway. These are all valid responses and indeed there is a greater trend towards telling people and their families about this risk even though the risk isn’t high.

Whilst people may not have been able to prevent someone from dying, the justified anger surrounds the lack of control they have about being able to make choices. Some would argue that they would have made different choices based on the information had they been informed.

Certainly trying to reduce the risk factors is likely to reduce sudden death, however, despite all the precautions one takes it can still happen. Like SIDS and other unexplained deaths, these continue to occur even though we do not know why.

**Conclusion**

It is important to remember that seizures themselves are rarely fatal. There is a low risk of death from either an accident during or after a seizure or from SUDEP. However good seizure control, prevention, prediction, detection and response to seizures are all important in reducing the likelihood of a tragic death.

The person with epilepsy needs to be aware of the risks and take sensible precautions, but not let the risks prevail over taking part in life. Being informed gives people the option to make informed choices.

Speak with your neurologist about any concerns or questions you have, call Epilepsy Action Australia, join a support group and become an expert on your epilepsy. This allows YOU to be in control.

**For help:**

- Sids and Kids – offer bereavement counselling for any families who have lost a child. Not limited to families who have lost a child to SIDS. Website http://www.sidsandkids.org/ and go to your local region, or call 24 hour phone line 1300 308 307.
- There are many bereavement support services in Australia. Here is a link to some of them https://goodgrief.org.au/links
- Lifeline 24 hour phone line 13 11 14 if you need to talk to someone immediately.

**Further information:**

- Epilepsy Foundation USA. How serious are seizures? http://www.epilepsy.com/learn/epilepsy-101/how-serious-are-seizures

**References:** Mortality in Epilepsy http://www.ncbi.nlm.nih.gov/pmc/articles/PMC320680/

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