

Parenting with epilepsy

Parenting is a unique and wonderful experience and epilepsy should not be seen as a restriction on becoming a parent if you wish to do so. Becoming a parent is a significant life change and life-long commitment so something most people think through carefully.

If you have epilepsy and are likely to have seizures while caring for your baby, you will need to think ahead about precautions you may need to take. This will depend on the child's age, its nature, and other circumstances in your life.

Here we look at what issues may arise during parenthood if you have epilepsy, and ways you can reduce the chance of having seizures or putting the child at risk.

Avoiding seizure triggers

Something that is likely to 'set off' a seizure in someone with epilepsy is called a seizure trigger. Missed medications, sleep deprivation and stress are all common seizure triggers for people with epilepsy and can increase the chance of seizures. For new parents, sleep deprivation, stress and tiredness are especially common, so it is important to recognise these potential seizure triggers and plan ahead to reduce their impact.

Missing medications

Forgetting to take your medication is easy enough to do on any given day, let alone when you are tired and have other distractions and things to think about. Changes in your normal routine, physical exhaustion and sleep deprivation could easily lead to forgetting and missing medications.

Some practical tips to help you remember include:

- Set reminders on your watch, clock, iPad, smart phone or smart watch
- Placing medications in a safe but visible place
- Using a chart or calendar and tick the day when the medication is taken
- Using a weekly pillbox for this period. They are labelled so you can clearly see if you have taken the day's medication[s].

Getting enough rest and sleep

Caring for a baby or toddler often means broken sleep, and breastfeeding can also leave you feeling a bit drained if you don't look after yourself. It is really important if you need a rest or catch up on sleep that you can. If you are lucky, your baby will allow you some rest time, but this isn't always a guarantee. It is essential you try to avoid getting too run down or sleep deprived, as this only increases the risk of seizures. Try to:

- Take a nap when the baby is having a daytime sleep
- Get someone else to do the last feed of the evening if it is late [express milk if you are breastfeeding or just use formula for this feed time] and go to bed early
- Have a bassinette right next to your bed so that you do not have to go far to settle your baby
- Always accept offers of help or ask for help if or when you need it.
- Try to keep a healthy lifestyle with a good diet and a bit of exercise to keep your strength up.

Co-sleeping is not recommended. The baby or young child of a parent who has epilepsy is safer sleeping in its own cot or bed. There is a chance the child may be injured or smothered if you had a seizure, especially a tonic-clonic seizure, while sleeping.

Stress

Many people with epilepsy commonly report stress as a trigger for their seizures.

Having a baby can change your life in many ways, small and large. It can be a stressful and demanding time, especially while you are learning to adjust and look after your baby. While stress alone can be a trigger for seizures, it can also contribute to sleep deprivation which is another well-known seizure trigger. Anxiety or depression can also create stress and, in turn, cause seizures.

Stress is known to cause worry, depression, frustration and even anger. You cannot avoid all stress, but if you recognise what is causing the stress, you can work to reduce the impact.

Managing stress is very personal and specific to your situation; however, there are some common activities and recommendations:

- Recognise you have needs. Most mothers put their child's needs ahead of their own, but in the long term you need to be healthy to care for your child to the best of your ability, so sometimes you have to put your needs first.
- Do your best to relax. Find time for some activity such as exercise, reading, yoga, tai chi, pilates, a massage, cat naps, or relaxation and controlled breathing techniques. Even if it's just 20mins a day
- Keep to a daily routine
- Avoid or limit contact with people who are negative or sometimes upset you
- Take a break. Forget the housework for a while
- Keep to a good diet
- Do your best to get enough sleep
- Seek help if you feel you need it. Talk to your GP or Neurologist and get support or counselling
- If you think you may have anxiety or depression, talk to your doctor about treatment options
- Go to a mothers group or play groups. These are great ways to talk to other mothers about raising your baby and concerns you may have
- Join a support group or online support community. There are also a number of ways to get help with baby or breastfeeding difficulties. Speak to your Child Health Nurse about these.

Postnatal depression

It is recognised that women with epilepsy are at a higher risk of developing postnatal depression,¹ especially if there is a history of depression in the past. Typically, it develops within four to six weeks after giving birth, but can sometimes take several months to appear. Usually, there is no clear reason for the depression.

If you experience symptoms such as ongoing fatigue, sadness, reduced libido, episodes of crying, irritability, anxiety, and irregular sleeping patterns, then speak to your doctor or child health nurse.

Postnatal depression is common and treatable, so don't suffer in silence. Find out more from <http://cope.org.au/> or panda.org.au

Carrying the baby

If your seizures are not controlled, carrying the baby may be a concern for you. Of course this does not mean you should not carry the baby, just exercise care when doing so.

You may want to consider the following:

- If you get a warning or "aura" of a seizure then you may have time to put the baby in a safe place
- If you have no warning, think about your seizure patterns and when you are more likely to have seizures. Avoid carrying the baby around these times if you have a pattern

¹ <http://www.ncbi.nlm.nih.gov/pubmed/19125843>

Fact Sheet: Parenting

- Breast-feeding and nappy changing by parents who are at risk of having a seizure are best done whilst sitting on the floor or on a low, soft surface where the baby would be safest
- Sometimes it may be safe for you to carry in a baby carrier/ holster which is positioned in front of you
- When pushing the baby in a pram, it is important to always have the safety harness attached to your wrist.

Bathing

If you have poorly controlled seizures it is best not to bathe the baby alone. If you can, ask someone else to be with you. If you are the only person who can possibly bathe the baby, then some things to consider are:

- Avoid doing it when seizures are more likely to occur for you. For example, if you are more likely to have seizures in the morning, then bathe the baby in the afternoon, or if you have had very little sleep and feeling exhausted, don't bathe the baby at this time
- You can always wash the baby without immersing it in a bath. Use a cloth and some soapy water to wash the baby whilst lying on a towel
- You can place the baby in a safety designed bath seat (in the bath) and use a hand held shower hose and leave the plug out. These seats are plastic and relatively cheap. An example is the Buddy Bath seat which can be purchased at a number of retailers. [See picture].



Breastfeeding

For most women with epilepsy, breast feeding is encouraged as breast milk offers many benefits to the baby and mother, including protection against infection (immunity). Whilst in the womb your baby has already been exposed to your medications so breastfeeding is considered safe unless you have been advised not to do so by your Neurologist or Obstetrician. Usually the medication exposure in utero is much higher than the exposure from breastmilk. However, as always, the benefits of breastfeeding must be weighed against the risks when a mother is taking any medication.

Because a small number of antiepileptic medications have higher quantities found in breast milk, it is important to speak to your doctor if your baby is suffering from fussy feeding habits, sleepiness and irritability. Be aware that most babies have some irritability and wind pains so don't assume that these are medication effects. If you take two antiepileptic medications, or barbiturates (sedatives), your baby may show signs of drowsiness. If you suddenly stop taking medication or a barbiturate whilst you are breastfeeding, your baby may show signs of medication withdrawal such as increased irritability, difficulty sleeping, or sweating so it is advised to only withdraw from medications very slowly and follow your Neurologist or Obstetrician's instructions.

For more information on individual medications, the effects during pregnancy and breastfeeding and services [click here](#).

Toddlers and children

As the baby becomes a toddler, other possible risks confront a parent whose seizures are not fully controlled. For example, walking or playing near a busy street with an impulsive, active 2-year-old could be potentially dangerous if the parent had a seizure and the child wandered off alone, ran out onto the road, or the child may escape out of the house. Although events such as this are uncommon, it is worth considering ways of reducing this type of risk. Things such as:

- Consider wearing a medical ID bracelet so others can identify that you may be having a seizure.
- There are plenty of non-medical ID bracelets available that you can also attach to your child, with your details and phone number on it
- Wear a wrist strap and attach it to your child so they can't wander
- When your child is in the pram, always keep them strapped in
- Keep the pram strap attached to your wrist

- Keep the outside house doors locked when you are home
- Use child safety gates or playpens
- When the child is old enough, explain to them about your epilepsy, seizures and what to do, plus teach them to use the phone and possibly have important numbers on speed dial
- Having an alarm or alert system in place, so someone close to you will be aware when you have a seizure especially if you have tonic-clonic seizures.



Teach your child to use the phone and have important numbers on speed dial.

Explaining to the children

When you feel your child is able to understand, it is important to tell to them about your epilepsy. Children often understand more than you give them credit for, and they may already be aware of the seizures and possibly frightened by them. Explaining to them what a seizure is, why you take medication, and why they should not worry is important. As the child grows, they need to be told more about epilepsy and what to do.

Here are some ways to communicate with your child about epilepsy. When you decide to tell your children about your epilepsy is your decision.

Some of this explanation may not be suited to your type of seizures. This is just a guide.

Our brain controls our body and sends messages to every part of our bodies, telling them how to work and what to do. The messages are carried by millions of tiny electrical signals.

A seizure is when there are lots and lots of these signals firing all at once in the brain, mixing up the messages being sent to the body. It doesn't hurt, but it causes my body to feel different or do things that I can't control. Things like making me shake, or go stiff, or feel strange or do or say unusual things or maybe not being able to speak for a short time or just look like I'm daydreaming.

There are lots of different kinds of seizure. Sometimes they happen when I'm awake and sometimes they happen when I'm asleep.

The seizures only happen sometimes. Someone who has seizures has epilepsy. Epilepsy is when you have had more than one seizure, and will probably have more if you don't treat them. Some people call seizures fits or convulsions. My seizures look like.....

In between seizures I am OK and can do everyday things.

Taking medication every day can make seizures go away or have less of them for most people.

We don't always know why someone has epilepsy. Sometimes it can happen when:

- You've had a bad accident that injures your head and brain
- You've had a stroke or bleed in the brain
- You've had an illness that made the signals in your brain work in a different way
- You might be born with an abnormality in the brain that causes seizures
- Some other people in your family may have epilepsy

Fact Sheet: Parenting

You can't catch epilepsy from somebody else and they can't catch it from you.

It is not hard to look after someone who is having a seizure. Most seizures are quick and stop on their own in less than 2 minutes. So...

- If I fall to the ground put something soft under my head
- Stay with me until I'm back to normal. I might be a bit sleepy afterwards
- If you can, afterwards lie me on my side
- Call an ambulance or another adult if you are worried

DON'T do things like:

- Try to put anything in my mouth
- Try to stop the seizure or move me unless I am in danger of getting hurt

For any further information about parenting with epilepsy or safety products please call us on 1300 EPILEPSY or visit our website <https://www.epilepsy.org.au/how-we-can-help/epilepsy-products>

© Epilepsy Action Australia

This information is given to provide accurate, general information about epilepsy. Medical information and knowledge changes rapidly and you should consult your doctor for more detailed information. This is not medical advice and you should not make any medication or treatment changes without consulting your doctor.

