Tips for looking after a baby or small child when you have epilepsy

It's not easy looking after babies and small children, as well as looking after yourself. And having epilepsy can add to the challenge.

If you are still having seizures, this information is for you. It is about keeping you, and any child you are caring for, safe. Although some information is specifically for mothers with epilepsy, the tips on keeping a child safe will be just as relevant for fathers or other carers with epilepsy.

Epilepsy Action has information about keeping safe when you have epilepsy. There is also a wealth of general information about baby and child safety on the NHS Choices and mumsnet websites, as well as from midwives and health visitors. If you are no longer having seizures, that information might be all you need.

Looking after yourself: reducing your risk of seizures

It’s easy to lose track of time when you are looking after a baby or small child. But it’s important to look after yourself too, and to try to avoid things that trigger your seizures. Here are some of the seizure triggers that people tell us about:

- Forgetting to take epilepsy medicines
- Not getting enough sleep
- Missing meals
- Getting over tired

Not everyone has triggers for their seizures, but knowing that these are possible triggers, and finding ways around them, could make a difference. These are some suggestions about avoiding these triggers:

- Use an alarm clock, alarm on your mobile phone or a pill reminder to help you remember when to take your epilepsy medicine. The Disabled Living Foundation can give you details of suppliers of pill reminders.
- If possible, share night-time feeds with your partner or a friend, to avoid interruptions to your sleep.
- Try to make meals in advance, so you always have a supply of something ready to eat.
- Try to avoid getting over tired. There are all sorts of ways of doing this, for example, shopping online to save you time and energy. There are lots of discussions about the pros and cons of doing this on mumsnet.
Epilepsy medicines after the baby’s birth
If you are a mum with epilepsy, and your epilepsy medicines were increased while you were pregnant, it's important to have it checked again after your baby is born. You may be taking too much, which could make you unsteady.¹ Or it might affect your vision,² which is a safety risk for you and your baby.

Read Faye’s blog about her experience of taking too much medicine after the birth of her little boy.

This is a recording of a mum with epilepsy talking about looking after her young baby.

Keeping a baby or young child safe
Bathing, changing and dressing
• Top and tail them, rather than bathing, if you are by yourself. This is where you wash the infant with water from a shallow bowl. If the infant can move around, make sure the bowl of water is out of their reach
• Change them on the floor, rather than a changing table or bed • Keep nappies and changing materials on each floor of the house. It’s safer than carrying the baby up and down stairs

This is a recording of a mum with epilepsy talking about looking after her young baby

Feeding a baby
• Whether breast or bottle feeding, sit on the floor, on a thick rug, with your back well supported. It will stop the baby falling onto a hard surface, if you have a seizure
• If your epilepsy medicines make you feel confused, or you have a poor memory, keep a note of when you fed the baby and how much they had • Label food and milk containers with the date and time you prepared it

Feeding a young child
• Strap them into a low chair, rather than a high chair
• If you always fall to the same side during a seizure, make sure they are at the opposite side
• Try to keep a supply of ready-made food for the child, in case you aren’t able to make any after a seizure

Keeping a baby or small child safe during and after your seizures

- If possible, ask somebody else to carry the baby up and down stairs. If it’s not possible, carry them in a car seat – this will help to protect them if you fall during a seizure.
- If you have hard floors, use a pushchair to move the baby around so that they don’t get hurt if you drop them. Try to have a plan for someone else to look after the baby if you need to rest after a seizure. If this isn’t possible, try to make your room as hazard free as possible. There’s lots of information about how to do this on the NHS Choices website.
- If you usually fall asleep after a seizure, ask a friend or relative to phone you or call round at an agreed time, to check that you are ok.
- Don’t leave the keys in the locked door, and don’t use bolts or chains. Make sure they are close by, but not where a small child could get hold of them. Consider giving a spare key to a neighbour or getting a key safe for trusted adults to use. This will make sure people can get in, if you need any help. Key safes are available from various suppliers including Age UK and Cooperative Independent Living.
- Don’t use irons, curling tongs or hair straighteners when you are alone with a child. They stay hot enough to burn a small child even when they have been turned off for some time.

Teaching a small child about seizures and first aid

It’s important that a very young child doesn’t feel responsible for you during a seizure – they just need to know how to contact another adult.

As soon as the child is old enough, teach them how to use a phone. They can use this to get help if you are unwell or you have a seizure. Many phones have a speed dial facility, which will make it easy for a young child to use.

As soon as you think they will understand, talk to the child about what happens to you during a seizure. You can use Epilepsy Action’s story about a parent with epilepsy to do this.

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Keeping a small child safe when you are outside

Prams and pushchairs
No particular type of pram or pushchair is recommended if you are at risk of having seizures. But here are some suggestions for choosing and using one:

• Choose a pram with a lot of padding, if there’s a risk you might push it over during a seizure – it could protect the baby if you fall. Alternatively, use a portable car seat/pram combination • Buy a safety brake that automatically comes on when the handle is released for the pram or pushchair. Epilepsy Action has details of companies that provide safety brakes
• If you become confused during a seizure, tie a label with some emergency contact numbers to the handle of the pram or pushchair

Child carriers and baby slings
The child might not be safe if you had a seizure while carrying them in a child carrier or baby sling. Before deciding whether or not to use one, you might want to answer these questions:

• Do your seizures cause you to fall? If so, would this hurt the child if they are in a sling or carrier at the time? • Do you have an aura or warning before a seizure? If so, would that give you enough time to make the child safe?

Child reins, harnesses and wrist straps
These can keep a young child, who can walk, close to you when you’re out and about. But, if your seizures cause any loss of awareness or cause you to fall, you need to consider the following:

• If you just hold one end of the reins or harness, it would be easy to drop it, giving your child chance to run away • If you use a wrist strap, your child would still be attached to you, and could be injured during your seizure

Keeping a child safe in open spaces
• Try to let someone know where you are going, and what time you expect to be back
• Don’t go near unguarded water such as ponds, streams, swimming pools, or rivers if you are alone with a child • Try to avoid other dangers such as steep steps, roads or railway lines
• Give the child an identity card with a contact number on, to show an adult
• Go with another adult if you think it would be safer

Baby changing facilities
• Rather than using a changing table in public toilets, consider carrying a changing mat with you, to use on the floor

Getting home after a seizure
If you would find it difficult to get home after a seizure, consider you and your child carrying contact details of a trusted adult who could be contacted in an emergency. You could do this on your mobile phone, which your child could dial, if old enough. Or Epilepsy Action has cards you could use for this.

Getting help from other people
If you are a parent with epilepsy who is still having seizures, you may need some help to look after your children. To see if you would qualify, have a look at the help for disabled parents section of the NHS Choices website.

Claiming benefits to help care for a child
Depending on your needs and circumstances, you may be able to claim benefits to help you care for your child. The Turn2us website has lots of information that might help you find out.

This information has been checked by a person with knowledge of epilepsy and has a baby.

About this information
This information is written by Epilepsy Action’s advice and information team, with guidance and input from people living with epilepsy, and medical experts. If there is anything you would like to say about the information, please contact us.

Epilepsy Action makes every effort to ensure the accuracy of information but cannot be held liable for any actions taken based on this information.

Date: April 2016
Due for review: April 2019

Code: F059.04

Your support
We hope you have found this information helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this.

- Visit www.epilepsy.org.uk/donate
- Text ACT NOW to 70700 (This will cost you £5 plus your usual cost of sending a text. Epilepsy Action will receive £5.)
- Send a cheque payable to Epilepsy Action to the address below.

Did you know you can also become a member of Epilepsy Action from as little as £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.

**Epilepsy Action Helpline**
Freephone 0808 800 5050, text 0753 741 0044, email helpline@epilepsy.org.uk, tweet @epilepsyadvice

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