

Looking after a baby or young child when you have epilepsy - a guide for parents and carers

It's not easy looking after babies and young children, as well as looking after yourself. And having epilepsy can add to the challenge. This information has suggestions to help keep you and any child you care for safe. On this page we talk about 'parents', but the information should be just as useful for any carer or guardian.

Being a parent with uncontrolled seizures

Being a parent with uncontrolled seizures can come with some concerns. Here are things some parents with epilepsy have identified:

- Worry around your child's safety
- The insecurity brought on by unpredictable seizures
- The feelings of inadequacy and guilt of not being able to be the parent you want to be
- The worry of children taking on more responsibility than other children of the same age

Having an awareness of these concerns means you are likely to want to do everything you can to deal with them. Here are some key things that can help with this:

Thinking about safety

Most parents and carers with epilepsy are able to care for their child safely with a few additional measures in place.

However, there can be more challenges if

- Your seizures don't follow a predictable pattern
- You don't get any warnings before a seizure
- You have seizures where your awareness is altered

There are lots of suggestions below on how to put additional safety measures in place, and where you can get extra support if needed.

Looking after yourself and reducing your risk of seizures

It's easy to lose track of time when you're looking after a baby or young child. But it's important to look after yourself too, and to try to avoid things that trigger seizures, more information at:

epilepsy.org.uk/info/triggers

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 has information about medication alarms and reminders
- If possible, share night-time feeds with your partner, family member or a friend, to avoid interruptions to your sleep. If you're breast feeding, express and build up a milk store for them to do this
- Try to get your baby into an early bedtime routine to enable you to go to bed earlier
- Nap or rest when the baby does. But avoid couch or bed sharing with your baby when you're asleep
- Try to make meals in advance, so you always have a supply of something ready to eat

If you have recently given birth, there are some additional things to be aware of. For more information, visit our page on epilepsy.org.uk/living/having-a-baby

Talking to others

Many parents find it really helpful to talk to others in a similar situation. You can do this through Epilepsy Action's online communities at: healthunlocked.com/epilepsyaction facebook.com/epilepsyaction/ instagram.com/epilepsyaction/ epilepsy.org.uk/info/support/discord twitter.com/epilepsyadvice

or through a variety of other platforms. You can read about the experiences of some mothers with epilepsy on our My Story pages at: epilepsy.org.uk/epilepsy-stories

Keeping a baby or young child safe

Epilepsy can come with some risks to safety. However, by putting some safety measures in place, you can lower this risk for you and your baby. As well as the following suggestions, Epilepsy Action also has information about keeping safe and how to do safety checks when you have epilepsy at: epilepsy.org.uk/living/safety-equipment

There is also general information about baby and child safety on the NHS website at: nhs.uk/conditions/baby/first-aid-and-safety/safety/baby-and-toddler-safety. And you can always seek further advice from your midwife or health visitor if there's anything you're not sure about.

Bathing, changing and dressing

- Don't give your child a bath unless there is another adult there with you. If you are by yourself, wash them with water from a shallow bowl, using a cloth or sponge. Make sure the bowl 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

Feeding a baby

- Whether breast or bottle feeding, sit on the floor, on a thick rug, with your back well supported. This should reduce the risk of the

baby falling onto a hard surface, if you have a seizure

- If your epilepsy medicines make you feel confused, or you have memory problems, keep a note of when you fed the baby and how much they had. There are a number of different apps that could help you with this
- 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 young 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 with the straps secured – this will help to protect them if you fall during a seizure
- Consider using a pushchair to move the baby around so that they don't get hurt if you drop them (especially if you have hard floors)
- If your baby is crawling or has started to walk, consider using properly fitted safety gates at entrances to spaces that might be dangerous for your child like the kitchen, as well to stop them getting onto stairs
- 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 website
- If you are going to be alone with your baby, ask a friend or relative to phone you or call round at an agreed time, to check that you and your child are OK
- If you're alone in the house a lot, let a neighbour or trusted friend know. Then they can look out for anything that seems unusual
- Don't leave the keys in the locked door, and don't use bolts or chains. This will help make sure people can get in, if you need any help.

Consider giving a spare key to a neighbour or getting a key safe for trusted adults to use. Key safes are available from various high street and online suppliers including the Disabled Living Foundation

- Don't use irons, curling tongs or hair straighteners when you are alone with a baby or young child. They stay hot enough to burn a small child even when they have been turned off for some time
- Always keep your medicines out of the reach of children

Keeping a young child safe when you are outside

Prams and pushchairs

No particular type of pram or pushchair is recommended over another 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 more information about pram security at

epilepsy.org.uk/living/safety-equipment/other-safety-aids

If you become confused during a seizure, tie a label with some emergency contact numbers to the handle of the pram or pushchair. Epilepsy Action have a free epilepsy ID card at: **epilepsy.org.uk/product/epilepsy-id-card**

Child carriers and baby slings

The child might not be safe if you have 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
- 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. Epilepsy Action have a free epilepsy ID card you can download or order

Teaching a young 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 epilepsy stories for children to do this visit:

[epilepsy.org.uk/living/parents-and-children/just-for-kids#row-fc-5](https://www.epilepsy.org.uk/living/parents-and-children/just-for-kids#row-fc-5)

Support for you

What can family and friends do to help?

There are a range of ways in which someone might be able to help you.

Here are some times when it might be useful for you to have someone around:

- When the baby needs to be washed
- When you need to recover after a seizure
- When you have had a seizure in the night and need to catch up on sleep
- When you need to do some cooking
- When you need to get out and about, for example to go shopping or for a trip to the park

They could also help by:

- Making meals, including stocking up the freezer
- Giving you their phone number for you or a child to ring and ask for help
- Holding a spare key and letting you know about times when they could come over in an emergency. This could include night time

What can support services do to help?

Some parents and carers may qualify for extra help to look after children.

[nhs.uk/conditions/baby/support-and-services/services-and-support-for-parents](https://www.nhs.uk/conditions/baby/support-and-services/services-and-support-for-parents)

has information for parents about social services and other support that may be available.

You can also ask your healthcare professional for a referral to Home-Start UK at: **[home-start.org.uk](https://www.home-start.org.uk)**

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. Epilepsy Action has information about useful organisations for support with benefits visit: **[epilepsy.org.uk/living/benefits#Useful](https://www.epilepsy.org.uk/living/benefits#Useful)**

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 you would like to know where our information is from, or there is anything you would like to say about the information, please contact us at epilepsy.org.uk/about/feedback

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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:

- Call the Epilepsy Action fundraising team on 0113 210 8851
- Donate online at epilepsy.org.uk/about/feedback
- 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/involved/join or call 0113 210 8800.

Epilepsy Action Helpline

Freephone 0808 800 5050 or email helpline@epilepsy.org.uk

Contact details

Epilepsy Action, Gate Way Drive, Yeadon, Leeds LS19 7XY, UK, +44 (0)113 210 8800. A registered charity in England and Wales (No. 234343) and a company limited by guarantee (Registered in England No. 797997).

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