



**epilepsy**  
SOUTH AFRICA

# Epilepsy and Children

(First 2 Years)

[www.epilepsy.org.za](http://www.epilepsy.org.za)

## What do seizures look like in the first two years?

As children are learning labels associated with Babies engage in many random movements as coordination starts developing. What one side of the body is doing may not match what the other side is doing. Early in life babies have reflexes that are triggered by how they are moved or positioned. Twitches, jerks, staring and stretching are all part of normal infant behaviour. Seizures frequently look exactly like this normal behaviour.

Often, when parents find out that their baby is having seizures they feel guilty for not recognising this sooner. This is particularly true if it is your first child and you are working very hard to be a good parent.

It is natural to think that you should have known something is wrong. However, seizures during infancy are difficult to diagnose by only observing the baby. Even doctors can make mistakes and generally need an EEG to be able to definitively diagnose epilepsy.

Sometimes a video EEG is used which involves videotaping your baby for 24 hours or longer during EEG monitoring. It allows you to mark the EEG record by pressing a button when you see the behaviour that concerns you.

## How do I know what my baby needs?

As you get to know your baby you will develop a sense of what he/she needs. Some cries sound different from others and you will get a sense of how your baby looks when he/she is happy and content or when something is wrong. This is a normal process that all parents go through.

While pediatric neurologists may well suspect something might be wrong with the nervous system, you will develop “soft signs” about your baby’s health and needs.

A diagnosis of epilepsy may shake your confidence in your ability to read these “soft signs”. Don’t worry. Your confidence will soon return and you will be able to identify the needs of your baby as you become familiar with seizures and the effects of medication.

## What can I do to comfort my baby during and after seizures?

It is natural to want to protect your baby from any discomfort or pain. During a seizure your child is typically unaware what is happening. Although you may see your child’s body jerk uncontrollably, he/she is not uncomfortable or in pain. However, there may be things you can do during a seizure and immediately afterwards to make sure that your child is safe.

Your doctor will be able to tell you what is important for you to do for your child’s specific type of seizures. It is unlikely that your baby will remember having a seizure, but may be upset after a seizure because he/she is confused.

When a baby experiences sudden body jerks (myoclonic jerks) he/she may be distressed because of something that happened (e.g. dropping food or knocking over toys). You can help your child re-engage in the activity (e.g. eating or playing). Because babies operate in the present your reaction is critical.

If you are calm, your baby will soon return to calmness as well and readily return to being happy. Long before they can understand words, babies can sense your emotions from the tone of your voice, facial expressions and the quality of your touch. Comfort your child with the same things that work when he/she is irritable or upset. Holding, rocking and having a reassuring tone of voice will help your baby feel secure.

It is helpful to reassure toddlers by telling them that all is well. During the toddler years you can use a word or phrase that describes what occurs during a seizure (e.g. jerks or

shakes) to explain what just happened. If you can be matter-of-fact (e.g. 'That was just one of your jerks') your child will learn to feel that way about his/her seizures as well.

Your doctor and pharmacist will help you to find medication appropriate to the age of your child. Anti-epileptic drugs in liquid form are generally prescribed for babies and small children. Your pharmacy will be able to provide you with a bottle stopper that allows you to attach a medical syringe. This will make it easy for you to draw the correct dose for your baby while reducing the likelihood of spills. With a little patience you and your baby will find a method that works best to get the medication into his/her mouth and swallowed. The times when medication coated your baby's face, went up his/her nose or ended up in your hair will become funny memories.

Some medication is available as "sprinkles" for toddlers or can be crushed and mixed with foods such as applesauce, yogurt or ice cream. Your toddler may find this tastes better than the liquid form. Your attitude when giving medication is also important. Remember, your child can tell when you are tense or become more irritable in response to this tension, so relax. Medicine is important and you need to successfully administer each dose.

Make giving medication a routine activity like bathing or changing a nappy. The more this become part of your baby's routine, the less resistance you will encounter as he/she grows up. If you approach medication in a confident, matter-of-fact manner, your child will be more likely to cooperate. While most babies take medication easily, giving medication can become more challenging as your baby grows into a toddler. Once children learn to use the word 'no' they typically test out its use in many settings.

Most parents encounter at least a few occasions when their child objects to taking medication. However, if this becomes a daily problem you need to take action to reverse this as quickly as possible. Talk with your neurologist as a change in medication or supplier resulted in a product that tastes bad to your child. A different form of medication may work better. If talking with the neurologist does not solve the problem ask for a referral to a pediatric psychologist who can serve as a coach in helping you and your child work through this problem.

## How will I find childcare while I work or a babysitter so I can go out?

Finding good childcare is challenging for all parents. As you interview childcare providers start by asking whether they have experience in taking care of children with disabilities or chronic medical conditions. You want to get a sense of the provider's attitude and ability to accommodate children with special needs. Next ask about the provider's specific experience with epilepsy. You want to assess their knowledge of epilepsy, their openness to learning more and their ability to meet your baby's needs. Good caregivers may not necessarily have a lot of experience with seizures. However, they should be open to learning more about your child's seizures and his/her special needs.

## How can I help my child if he/she is slow to develop skills?

If your baby is having difficulty with the development of motor coordination skills (sitting, crawling, walking, holding objects) your neurologist can refer you to a physical therapist or occupational therapist for evaluation.

If your baby does not seem to understand what you say or is slow to learn to talk, evaluation by an audiologist and a speech and language therapist is appropriate.

These therapists can develop and carry out a treatment programme or refer you to the agency in your area that provides such services. Between birth and the age of three these services may be provided in your home or daycare setting. Besides working directly with your child the therapists will give you and your daycare provider activities to do with your baby between therapy sessions.

## How will I manage my relationship with my partner?

The infant years are a challenge for all couples. Every couple goes through a period of adjustment with their first child as they integrate this new life into their relationship. The adjustment becomes more family-focused with subsequent children. The introduction of a seizure disorder (like epilepsy) into the picture tends to prolong the period of adjustment. For every couple with a new baby the key to adjustment is communication. Good communication depends on having time together to talk to one another and time together when you are too tired to talk. You may need to schedule time together or call on family and friends to help you to have the time you need.

## How do I keep my toddler safe during a tantrum?

Parents worry about toddlers being seriously hurt during a tantrum, but parents of toddlers with epilepsy have the additional concern of seizures occurring during or after a tantrum. Ignoring a tantrum means that you are not interacting with the child. It does not mean that you have stopped listening to him/her or that you never 'peek' to see what he/she is doing. If your child is headed for danger interrupt the action, move him/her to safety and resume ignoring the tantrum. If your child has a seizure, deal with the seizure as you would at any other time.

## Who can help me during the infant/toddler years?

Your neurologist and family doctor or paediatrician can help you to know if your baby is developing at a typical rate during these early years. Early Childhood Development (ECD) services will help you and your baby if development is slow. Your family doctor and paediatrician may also be able to help you develop plans to deal with some of the common problems which may occur during this period. A pediatric psychologist or clinical psychologist can help you with behavioural problems despite your best attempts to address these.

**Contact us: 0860 EPILEPSY (0860 374 537) | [info@epilepsy.org.za](mailto:info@epilepsy.org.za)**

(Source/reference: Growing up with epilepsy - L Blackburn, 2003)



**TOTAL**