



EPILEPSY SUPPORT ASSOCIATION UGANDA

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PARENTING THE CHILD WITH EPILEPSY

You and your child

It is always a shock for a family to learn that a child has epilepsy. But out of the initial shock and dismay you can build an understanding, loving and accepting environment in which your child can grow, believing in his own ability to succeed in life

HOW YOU FEEL

Like most parents you are concerned about your child's future. You may find it difficult to accept the word "epilepsy" or talk about it. You may feel angry, depressed, inadequate and even guilt. It may seem to you that in some obscure way you have failed as a parent. Overcome your anxiety by becoming informed- the more you learn about epilepsy, the easier it will be to accept the condition

WHY MY CHILD?

Knowing what epilepsy is and why a seizure occurs still doesn't explain why it has happened to your child. You may be concerned that something in your or your spouse's genetic makeup may have caused the epilepsy to develop and that the condition is therefore someone's fault. In fact unless an individual's family history shows a strong recurring pattern of epilepsy, it is most that an inherited factor was responsible.

POSSIBLE CAUSES OF EPILEPSY

A common cause of epilepsy is head injury. This may occur during childbirth or from a blow to the head sustained in infancy or childhood. Fever convulsions, encephalitis or meningitis are the culprits in some cases but even childhood measles may lead to the child developing seizures. However, in most cases the cause is totally unknown aka idiopathic epilepsy.

VISTS TO THE DOCTOR

An experienced professional who specializes in children with epilepsy probably knows that your mind tried to block out the word "epilepsy" from the first moment that he mentioned it. The doctor is well aware that you have received a major shock. You



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probably have a hundred questions so before subsequent visits to the doctor, while you are relatively calm, you should write down questions that need to be asked. The doctor will prescribe medication based on the age, physical condition and type of seizures experienced by your child. Remember that anti-convulsant medication does not cure epilepsy, but in most cases reduce the number of seizures or the severity of the seizures. Only your doctor can decide when and if to change or decrease your child's medication, but you are more than welcome to seek a second or even third opinion.

WHAT DO I TELL MY CHILD

The child should be made aware of the condition. Children as young as three can understand that the brain is in control of the body and that sometimes the brain sends an incorrect message to the body. Older children should be given a more comprehensive explanation. If the child is old enough he will probably ask you "why me?" and you will have to answer openly and honestly that you don't know. It must however be made very clear that it has nothing to do with anything that the child did that was 'bad'

YOU AND YOUR FAMILY

The anger, depression and possible guilt that you are experiencing will pass. Husbands and wives should be a source of strength and comfort to one another at this time. You both need to be equally involved in your Childs medical and social progress at all times. Tension within the family is the last thing that the family needs at this time. Children pick up on parental tension and the child does not need the additional burden of knowing that his seizures are causing a rift in the family or between his parents. Inform close relatives and your child's friends.

DO I TELL HIS TEACHER?

The fact that child experiences seizures should under no circumstances be kept hidden from the teacher and other responsible school officials. The teacher may be apprehensive and it is therefore all the more important that you take time to explain the condition and any possible first aid procedures. Don't forget that the teacher is your stand –in –while your child is at school.

USEFUL HINTS ON PARENTING THE CHILD WITH EPILEPSY

- Ensure that your child receives a comprehensive medical assessment by a qualified professional



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- Always emphasize your Child's abilities. Concentrate on what your child can do rather than what he can't.
- It is your duty to learn as much as possible about the condition
- Be open and honest about the condition both with yourself and with your child
- Emphasize any activity that will improve your child's self-acceptance, self worth and self-confidence
- Educate family and friends –epilepsy is only an 'illness' when viewed through the eyes of the uninformed
- Equip your child with the correct information about their seizures so that proper care is administered to them while they are in seizure. This will allay unnecessary fears
- Always ensure that medication is administered and taken regularly
- Provide a set routine with plenty of rest, three balanced meals per day and regular exercise.
- A regular routine helps to limit seizures
- When explaining seizures use words that your child will understand. This will remove some of the mystery surrounding epilepsy
- Always remember that there are 365 days in a year. If your child has one seizure per week, that leaves 313 days for your child to live a full life.
- Don't ever allow your child to use seizures as an excuse for getting out of doing chores or accepting responsibility
- Don't ever use epilepsy as an excuse for lowering your expectations of your child
- Don't talk about behind closed doors or as if they are not present
- Don't use or encourage the use of negative words such as 'epileptic' 'suffer', 'attacks' and 'fits'.
- Don't overprotect your child. Overprotection will stifle and smother the child's initiatives.



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