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Sent: 15 June 2009 11:42
To: funddev.no@epilepsy.org.za
Subject: South Africa National Epilepsy Week, Day 2 - Preview



June 2009

Dear Epilepsy Advocate

Today is the second day of South Africa National Epilepsy Week. We will be celebrating this time by sharing information on the different aspects of the lives of people with epilepsy. Each day will be accompanied by a short video to be viewed on you tube. Something that can easily be sent to friends and colleagues. Here is the link to today's video
<http://www.youtube.com/watch?v=v8JdyfQINPs>

Let's talk Epilepsy!

June E-news Contents:

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South Africa National Epilepsy Week Day 2:Children with epilepsy have the right to quality education

If a child with epilepsy is exposed to educational opportunities they will have the chance to develop lasting social relationships with other children, both able-bodied and disabled. Such children with epilepsy will be more likely to feel like an able-bodied child instead of a child with a disability.

Most people are diagnosed with epilepsy before the age of twenty. However, epilepsy can

occur at any time and is not linked to a specific age, gender, class or race. It is a serious yet common neurological condition, and the effects on children are immeasurable if not handled correctly by the people closest to them.

In principle, our leadership and society in general agrees on the importance and value of education in a child's life. Correct information of good quality can assist greatly in keeping children with epilepsy in school if applied appropriately.

The majority of children with epilepsy can and should attend mainstream schools. Teasing by other children and/or fellow learners may lead to social isolation, behavior changes (depression, anxiety, anger, frustration) and a lack of achievement by children with epilepsy. On the other hand, the child with epilepsy can flourish if possible discrimination is immediately addressed and eradicated.

It is important to remember that any underachievement or behavior change displayed by children with epilepsy may well be due to reasons other than epilepsy, similar to any able-bodied child. In both cases the situation must immediately receive attention and be addressed in a supportive manner.

It is advisable that parents inform the child's school, teacher and friends about epilepsy to prevent any stigmatization or misconceptions about epilepsy. Parents have the right to be directly involved in the planning of their child's education and related needs. Everybody should also be informed about what to do in the event of a seizure.

Children with epilepsy have to learn to cope with the inherent unpredictability of the condition as this presents huge emotional strains. Some children find it very difficult and spend a lot of time worrying about having a seizure in the presence of others while others simply deal with having the seizure when it happens. Some children feel angry and frustrated about having epilepsy, which can often be seen in reckless, defiant or aggressive behavior. These children do not need additional pressure from society due to stigmatization and discrimination.

Many children with epilepsy outgrow the condition and are able to live drug- and seizure-free lives as adults. However, the emotional impact remains and affects them for the rest of their lives. Ignorance, stigmatization, discrimination and lack of knowledge evident in society impacts negatively to a far greater degree on the lives of children rather than the seizures themselves. Imagine what a change of attitude can do to a child growing up with epilepsy!

Epilepsy does not affect the physical/neurological development of a child except in the case of certain severe childhood syndromes. Anti-convulsant medications could also have side effects which could impact on the functioning and development of the child. In about 80% of cases it is possible to control seizures with anti epileptic. This is a very positive experience for the child with epilepsy It is strongly recommended that parents work hand-in-hand with the child's neurologist when developing a medical treatment plan as this will ensure quality of life.

The focus should optimally remain with ensuring that the child lives a happy and integrated life where having epilepsy becomes a secondary focal point.

The following simple guidelines should assist parents, teachers, family members and

friends to support the child with epilepsy:

- Emphasize what the child can do rather than what he/she cannot do while simultaneously taking sensible precautions.
- Treat the child like all other children.
- Help the child to integrate into as many social activities as possible which will help him/her to develop the required social skills like all other children.
- Do not overprotect the child.
- Do not make the child or his/her condition the centre of attention or every discussion.
- Do not blame the child or his/her epilepsy if the family experiences difficulties.

What to do during a seizure

DO...

- Remain calm and note the time and duration of the seizure.
- Clear a space around the person and prevent others from crowding around.
- Loosen tight clothing/neckwear and remove spectacles.
- Cushion the person's head to prevent injury.
- Put the person into the shock recovery position (i.e. roll the person onto his/her side with the top leg bent and the bottom arm slightly extended).
- Wipe away any excess saliva to facilitate breathing.
- Reassure and assist the person until he/she has recovered or become re-orientated.
- Allow the person to rest/sleep if necessary, covering him/her with a blanket.
- Note the duration of the seizure and the time it took place. Provide this information to the person who had the seizure after he/she has recovered fully. This will allow him/her to record the information in his/her seizure diary.

DO NOT...

- Restrict or restrain the person's movements.
- Move the person unless the person might hurt him/herself or is in immediate danger (i.e. in a busy road).
- Put anything between the person's teeth or in the person's mouth.
- Give anything to eat or drink during the seizure.
- Give extra anti-convulsants unless instructed to do so by a neurologist.
- Call a doctor or an ambulance unless the person has injured him/herself badly, the seizure lasts longer than 6 minutes or the person has repeated seizures without recovering!

OUR NATIONAL CONTACT NUMBER 0860374537

Please see the article on day one for:

- Information on epilepsy

- Rights to correct information

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