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Sent: 10 July 2009 13:59
To: funddev.no@epilepsy.org.za
Subject: South Africa National Epilepsy Day - Preview



July 2009

Dear Epilepsy Advocate

We are celebrating National Epilepsy Day today in South Africa and discussed a number of issues relevant to people with epilepsy during this week. More information is available on our website (www.epilepsy.org.za) or can be requested by calling the nearest Branch (0860 EPILEPSY). We are passionate to assist people with epilepsy by helping to change obstacles into true potential.

Today is the fourth 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=DcZ4fmd9Ye4>

Let's talk Epilepsy!

July E-news Contents:

- [People with epilepsy have rights!](#)

People with epilepsy have rights!

The rights of people with epilepsy differ from those of people with other disabilities (e.g. special parking close to an entrance or wheelchair accessibility for mobility-impaired people). However, understanding such rights will help you to understand how to include people with epilepsy in day-to-day life. A small change can often make the world of difference to a person with epilepsy. These changes differ from issues such as architectural changes to buildings but ask people to change their attitude toward people with epilepsy.

A person with epilepsy needs to understand the condition, its causes, the triggers for seizures and coping mechanisms to be able to lead a good quality of life. They must consider many factors in terms of safety, time management and interaction with people as these can present barriers demanding specific attention.

People with epilepsy often experience discrimination in the following areas:

- Travelling,
- Employment,
- Protection in the workplace,
- Respect,
- Information of their diagnoses,
- Support,
- Treatment options.

Most people with epilepsy are diagnosed before age 20, but the onset can be at any age. Many children with epilepsy outgrow the condition and are able to live drug-free and seizure-free lives as adults. It is interesting to note that many people with epilepsy report the negative impact on their lives due to ignorance, stigmatisation, discrimination and lack of knowledge evident in society as more problematic than the actual seizures. Because people do not understand epilepsy as a condition and often fear it, they discriminate against people with epilepsy by excluding them from social events and the world of work.

It is important to know that people with epilepsy (both adults and children) can live active and normal lives as long as society is willing to accept them and learn more about epilepsy.

Ensure that you, your whole family and your friends receive adequate information about epilepsy, as well as counselling which can prevent any long term psychosocial impact.

The most important thing to remember is that every person's seizures are different and that every person experiences living with epilepsy differently from another person. Thus it is not possible to generalize when talking about epilepsy.

These simple guidelines should assist parents, teachers, family members and friend to support the person with epilepsy:

- Emphasise what the person can do, not what he or she cannot do while at the same time taking sensible precautions
- Treat the person like all other people.
- Help the person to integrate into as many social activities as possible as this will help him/her to develop the required social skills like all other people.
- Do not overprotect the person with epilepsy.
- Do not make the person/child or his/her condition the centre of attention or every discussion.

- Do not blame the child/person or his/her epilepsy if the family experiences difficulties.

Should someone in your family or a friend experience a seizure consult a medical practitioner (preferably a neurologist) in order to obtain an accurate and specific diagnosis. Should the person be diagnosed with epilepsy you, all the friends and family members of that person and the person him/herself need to learn more about the condition. This will help you to accept the diagnosis and carry on with life.

You can call Epilepsy South Africa for information and support services. Epilepsy South Africa is a Non-Profit Human Services Organisation that renders services to persons with epilepsy and/or other disabilities as well as persons affected by the condition.

To contact your closest epilepsy South Africa branch please call:

0860 EPILEPSY

0860 374537

Your call will automatically be routed to the closest Epilepsy South Africa Branch.

You can also send an e-mail to: info@epilepsy.org.za

Or visit the web-site: www.epilepsy.org.za

Or contact the National Office at: Tel: 021 – 447 3014, Fax: 021 – 448 5053

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:

- The right to correct information
- Please see the article on day two for:
- Children with epilepsy have the right to quality education
- Please see the article on day three for:
- The right to quality medical treatment
- Please see the article on day four for:
- The right not to be stigmatized
- Please see the article on day five for:
- The right to employment
- Please see the article on day six for:
- The right to be included in community

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Visit our website or to contact any of our Branches or National Office.
 Website: www.epilepsy.org.za

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PLEASE CONTACT 0860 EPILEPSY (0860 374537)
 TO GET IN CONTACT WITH YOUR CLOSEST BRANCH OF EPILEPSY SOUTH AFRICA

This is the electronic newsletter of Epilepsy South Africa, compiled by the National Office.

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