

‘EPILEPSY AND THE NURSING PROFESSION’

Conference 16th November 2007

*The Local Position:
Awareness about Epilepsy*

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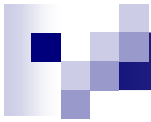


**“You are not an epileptic; You
are a person with epilepsy”**

**“Epilepsy is part of your life;
It is not your whole life”**

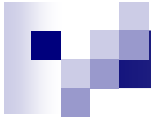


Psychological & social issues



Questions that need an understanding of:

- ☐ **How does epilepsy affects one's life?**
- ☐ **What is the public's attitude to epilepsy.**
- ☐ **What impact can epilepsy have on social relations & employment?**
- ☐ **What effects can epilepsy have on family and friends of the person with epilepsy?**
- ☐ **What can I do to manage my seizure & cope?**
- ☐ **What about my relationship with my doctor and others?**

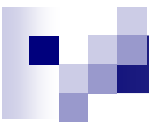


Impact on family :

- **parents pass through feelings of fear, grief, guilt, anger and frustration.**
- **find difficulty in dealing with uncertainty of seizures, prejudice and ignorance.**
- **become overprotective and restrictive.**
- **siblings may feel left out, afraid or be made to feel responsible for the safety of their brother or sister.**
- **in a relationship they may encounter lack of sensitivity and understanding.**
- **maintaining friendship can be difficult as the disorder may challenge ongoing social activities by its very nature.**



Facts about Epilepsy

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- **Epilepsy can be inherited, result from birth defect, birth or head injury, brain tumor or infection of the brain. For 50% of people with epilepsy, a cause is not found. It can begin from birth or occur for first time in old age. It is not contagious.**
 - **75% have their first seizure before they turn 18.**
 - **Not every seizure is an epileptic seizure.**
 - **About 1 in 200 suffers from recurrent epilepsy...if we include infants who suffer from seizures caused by fever and adults who have only had one seizure, the figure rises to about 1 in 80**



“Epilepsy can strike at any age”


Table adapted from EFA Publication shows, that some age groups are more susceptible to others


Age groups of first seizures (Years)	Percentage (%)
0-9	47%
10-19	30%
20-29	13%
30-39	6%
40+	4%

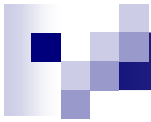
- **50 % of all cases develop before 10 years of age**



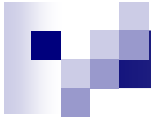
Interesting statistics related to Epilepsy

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- **In UK 450,000 have epilepsy (40 million people worldwide)**
 - **In USA Epilepsy affects 2.5 million Americans. More than 180,000 people are diagnosed every year.**
 - **1 in 131 affected**
 - **1 in 242 children & young people under 18 has epilepsy**
 - **1 in 91 aged 65 and over have epilepsy**
 - **1 in 50 will develop epilepsy at some time in their life. 1 in 20 will have a single epileptic seizure.**

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- **Epilepsy is more than 3 times as common as multiple sclerosis, Parkinson's disease and Cerebral Palsy.**
 - **1000 epilepsy related deaths a year, approx 600 of which are attributed to sudden unexpected death from epilepsy (SUDEP)**
 - **More mortality than asthma**
 - **More lives claimed than (HIV) Aids and cot death.**
 - **Up to 70% of people with epilepsy could achieve, full seizure control through medication.**



- **3% eligible for surgery...backlog exist and 300-500 new cases yearly.**
- **70% of people who have epilepsy surgery become seizure free.**
- **25% newly diagnosed are under the age of 20.**
- **25% newly diagnosed are over the age of 60.**
- **1 in 10 who have a stroke will develop some form of epilepsy.**



- **9 in 10 who develop epilepsy in later life are found to have a physical cause in the brain for seizure.**
- **Misdiagnosis in UK are between 20-30%**
- **30% of people with a learning disabilities have epilepsy. 50% with severe disability have epilepsy.**
- **More than 1-5 people with epilepsy have learning or intellectual disability.**



Issues associated with adolescence include:

- **driving**
- **part-time employment**
- **career prospects**
- **dating**
- **sexual activity**
- **alcohol**
- **illicit drug use.**



**“To-day people with epilepsy
are still trying to prove
themselves to the world.**

**With the right attitude and
support, they should be able
to prove themselves
successfully.”**



**From the Disabkids Study
(European Group) areas of
concern were:**

- 1. School**
- 2. Family**
- 3. Medicine**



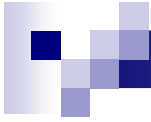
Disabkids study

Sweden: 8-12 year olds



School

- **Stigma present...need to develop skills to deal with stigma**
- **Worst thing for kids was having to tell others about their epilepsy**
- **Mothers often had to go to child's school to explain**
- **Teachers understanding but none explained about epilepsy**
- **Bullying and teasing**
- **Cognitive effects of the medicine on schoolwork**



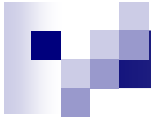
Family

- **family raise issue of sibling rivalry**
- **family disharmony**
- **multi disciplinary intervention**



Medicine

- 8-12 year old problem due to taste
- adolescent less concern on taste and more on routine medications daily
- concern for parents with regards long-term effects of medication
- neuropsychological evaluation might be appropriate in such concerns
- antiepileptic drug interactions with alcohol / recreational drugs used by older children
- need for information at times of diagnosis and support
- the need of the Specialist Epilepsy Nurse to bridge the gap.



Depression in epileptic adults is one of the social issues.

In 1995, the prevalence of depression in adult epilepsy fluctuated from 34 to 78% (Journal of American Academy of Child and Adolescent Psychiatry, Sept 1999: David W. Dunn).

Along with depression, mood swings, irritability, arrogance and explosive bursts of anger are present.



We need to:

- **develop new ways of working**
- **improve self-confidence**
- **exchange experiences and information**
- **eliminate prejudice**
- **have more interaction between all concerned**



Conclusion




- **epilepsy is a multi-faceted condition**
- **many disciplines need to be blended together in solving problems**
- **we must develop a comprehensive approach to the treatment of epilepsy**
- **we need to develop a significant positive cultural change in outcome**
- **so as to be effective, we need to have a trans-disciplinary approach**



Epilepsy sounds frightening, but managing it can be simple.

If you have epilepsy:

- **follow your treatment plan.**
- **get plenty of sleep.**
- **eat right and exercise to reduce stress and stay in shape.**



We as professionals as well as the public in general, by its understanding can do all this by treating the whole child and the family and not just the seizures.

We can do this by putting the child with epilepsy at the centre of what we do.



Thank you for
listening