The Young Adult with Epilepsy: Looking Forward to the Future

Transition to independence and self care for young adults with epilepsy

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March 10th 2010
What is a Seizure?

• What a person experiences when a group of nerve cells temporarily become abnormally over-active

[many causes for nerve cell ‘excitability’]

• The experience for the person depends on which part of the brain is involved, how much of the brain is involved, and how long the seizure lasts
Normal electrical activity of brain (electroencephalogram)
Electrical Brain activity during seizure

Medications suppress the electrical ‘surges’
What is Epilepsy?

• Two or more seizure seizures
  (simple definition)

• ‘A chronic condition of the brain characterized by an enduring propensity to generate epileptic seizures, and by the neurobiological, cognitive, psychological, and social consequences of this condition’ (long definition)
How common is Epilepsy?

- Epilepsy is the most common neurological problem in childhood
  - 4-10% of children have a seizure by 20 years of age
  - 1% of children will develop epilepsy

- Stroke, Dementia and Epilepsy are the most common Neurological disorders in adulthood
  - 0.7% of adults have Epilepsy
If 1,000,000 people aged 18-30 years, then ~7000 will have Epilepsy
How good is the treatment (medications)?

- 1/3\(^{rd}\) of people: easy to control
- 1/3\(^{rd}\) of people: not so easy to control but control is achieved
- 1/3\(^{rd}\) of people: medications do not control the seizures
‘Cure’ vs. Control
POSSIBLE impact of Epilepsy on life

• Loss of control
• Vulnerable
• Fear of seizures
• Need to take medications every day
• Lifestyle restrictions
• Feeling physically unwell after seizures
• Restriction of autonomy and independence
• Perceptions of others
Other people’s understanding of Epilepsy

• Epilepsy is a ‘hidden’ problem unlike stroke, Parkinson’s disease etc where problem is visible

• People may not be able to conceptualise what is wrong
‘Normal’ Young adulthood

- Period of self development
- Establishment of independence
- Education & Training
- Sexual relationships
- Early career
- Employment
- Changing relationships with friends
- Changing relationships with family
- Sports, hobbies, recreation, travel
Epilepsy in Young Adults

Entering adulthood with Epilepsy that began in childhood

versus

Developing Epilepsy as a young adult
Entering Adulthood with Epilepsy
[Changing from Child to Adult Neurology services]

- Different hospital & doctor
- May not be a clinical nurse specialist
- Can be intimidating - busy clinic; older people
- Increasing self-reliance (rather than parents)
- Different ‘procedure’ in clinic
- May have less time with doctor
- Epilepsy nurses and doctors often dedicate most time to people with poorly controlled Epilepsy
- People with well controlled epilepsy often left to fend for themselves
Developing Epilepsy as a young adult can be more difficult to cope with than becoming an adult with Epilepsy that began in childhood.

Restriction of autonomy and freedom at a time of life defined by increasing independence.
### POSSIBLE impact of Epilepsy on young adult

<table>
<thead>
<tr>
<th>ASPECT OF LIFE</th>
<th>IMPACT OF EPILEPSY</th>
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</thead>
<tbody>
<tr>
<td>Self development</td>
<td>Loss of confidence &amp; self-esteem; demoralisation; negative self-perception; isolation</td>
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<tr>
<td>Establishment of independence</td>
<td>Loss of confidence</td>
</tr>
<tr>
<td>Education &amp; Training</td>
<td>Less likely to achieve potential</td>
</tr>
<tr>
<td>Relationships</td>
<td>May be difficult to form stable relationships</td>
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<tr>
<td>Early career &amp; employment</td>
<td>May not achieve potential or be given same opportunities</td>
</tr>
<tr>
<td>Relationships with friends &amp; family</td>
<td>May be unstable</td>
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<tr>
<td>Sports, hobbies, recreation, travel</td>
<td>Rarely restricted</td>
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</tbody>
</table>
What can you do?

• Educate & empower yourself
  - ‘Brainwave’ (www.epilepsy.ie)
• Get help from friends, family, support groups
• Advocating for yourself when navigating the healthcare system & outside world
• Learn to talk about Epilepsy
• Learn to deal with people who know little about epilepsy
• Use seizure diary
• Learn about medications
Expectations for the future….

• Your expectations of life should not be limited by Epilepsy
• Don’t let Epilepsy define who or what you are
• Don’t endure difficulties in silence
• Enlist the help of others when you need it