



## The Young Adult with Epilepsy: Looking Forward to the Future

Transition to independence and self care  
for young adults with epilepsy

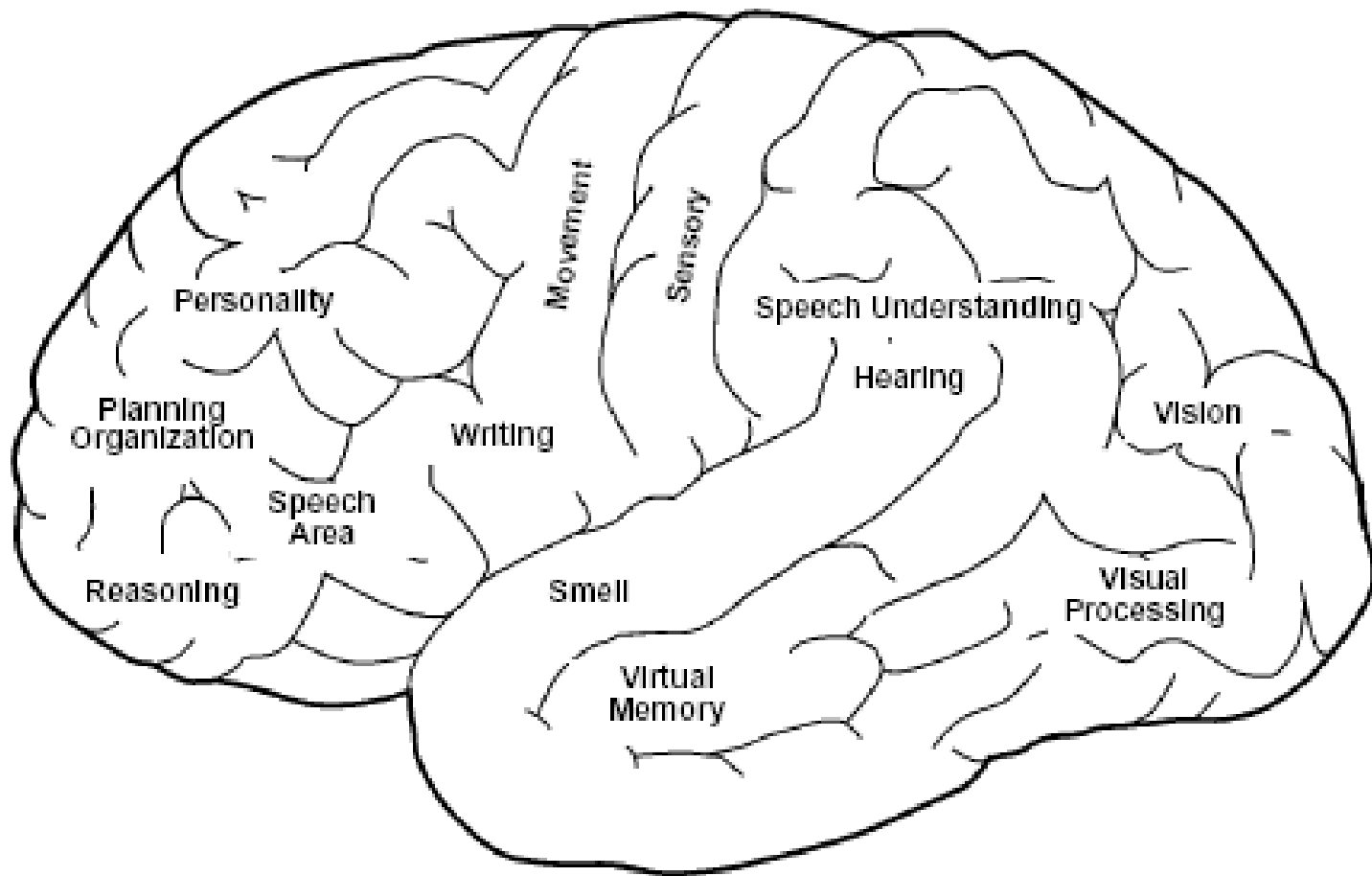
Daniel Costello  
Consultant Neurologist  
Cork University Hospital

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# 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





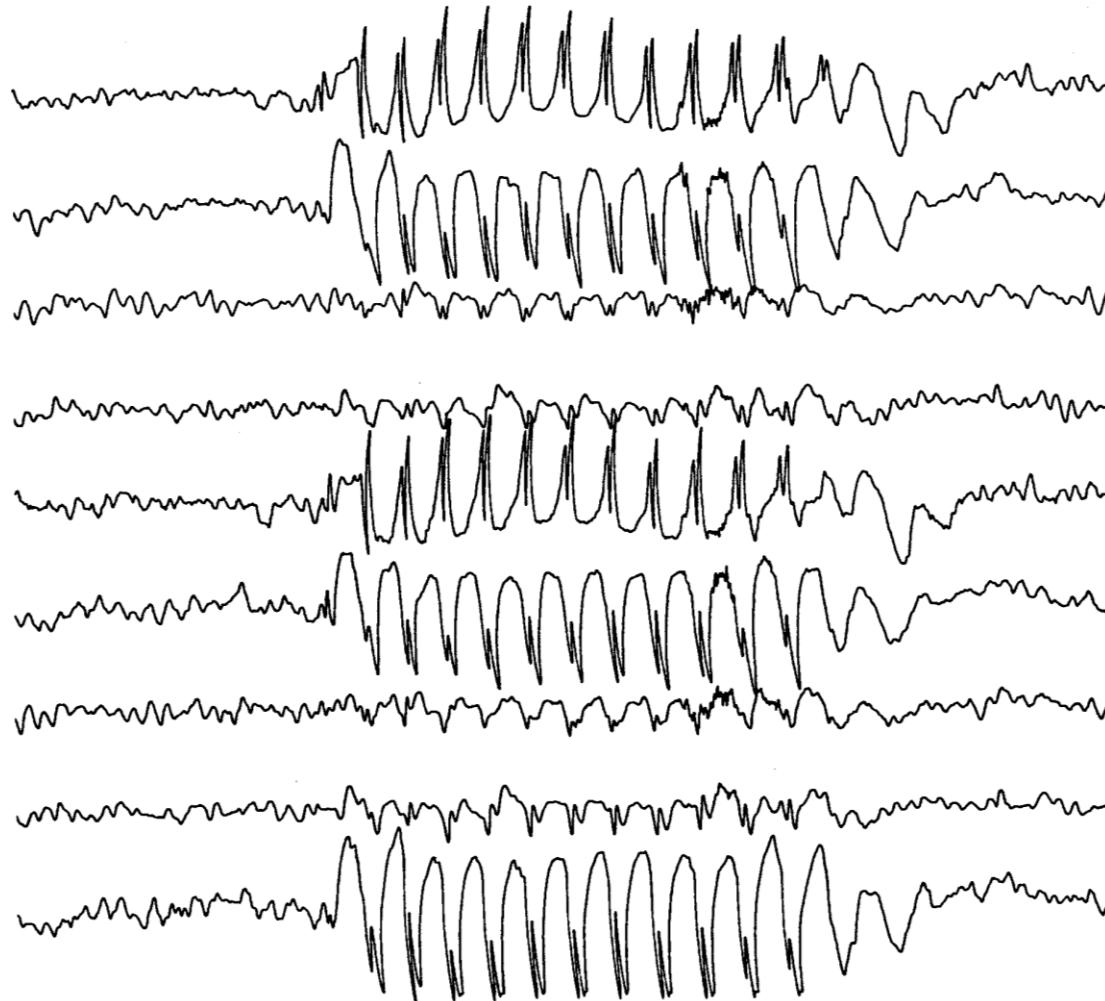
# Normal electrical activity of brain (electroencephalogram)





# 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*



## CSO 2006

| Age group | Males     | Females   | Persons   |
|-----------|-----------|-----------|-----------|
| 0-14      | 443,044   | 421,405   | 864,449   |
| 15-24     | 321,007   | 311,725   | 632,732   |
| 25-44     | 681,988   | 663,885   | 1,345,873 |
| 45-64     | 468,037   | 460,831   | 928,868   |
| 65+yrs    | 207,095   | 260,831   | 467,926   |
|           | <hr/>     | <hr/>     | <hr/>     |
|           | 2,121,171 | 2,118,677 | 4,239,848 |

If 1,000,000 people aged 18-30 years, then ~7000 will have Epilepsy



## How good is the treatment (medications)?

- 1/3<sup>rd</sup> of people: easy to control
- 1/3<sup>rd</sup> of people: not so easy to control but control is achieved
- 1/3<sup>rd</sup> 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**

### ASPECT OF LIFE

Self development

Establishment of independence

Education & Training

Relationships

Early career & employment

Relationships with friends & family

Sports, hobbies, recreation, travel

### IMPACT OF EPILEPSY

Loss of confidence & self-esteem; demoralisation; negative self-perception; isolation

Loss of confidence

Less likely to achieve potential

May be difficult to form stable relationships

May not achieve potential or be given same opportunities

May be unstable

Rarely restricted



# What can you do?

- Educate & empower yourself
  - 'Brainwave' ([www.epilepsy.ie](http://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