Coping With Epilepsy
Epilepsy Facts

- Epilepsy is known as a seizure disorder and is diagnosed after a person has had at least two seizures.
- 2.7 million Americans were treated for epilepsy within the past five years. More men than women have epilepsy.
- You are most likely to be diagnosed with epilepsy before the age of ten and after the age of 55 or 60, but epilepsy can start at any age.

Source: www.epilepsy.com
I have been diagnosed with Epilepsy, now what?

- It is necessary to understand the medical situation
- It is necessary to have access to medical care
- It is necessary to become a part of the team
- It is necessary to be aware of the psychosocial challenges
- It is necessary to have a support network
- It is necessary to be aware of laws and resources
Understanding the Medical Situation

- Gather information from medical professionals and also agencies like the EFA
- Understand the various treatment options
- Understand medication, the side effects of this medication, and the consequence of noncompliance
- It is important to recognize the difference between an acute illness and a chronic one
Access to Medical Care

- Can be limited by lack of insurance, but there are clinics for the uninsured.
- Research and find the centers treating Epilepsy near you.
- The state of Tennessee has an insurance program for the uninsurable called AccessTN (http://www.covertn.gov/web/access_tn.html)
- Sometimes you can get insurance through the commercial insurance companies
To be a member of the team, you...

- Keep appointments
- Share information
- Comply with medical regimen
- Trust the physician
- Take ownership for your part in controlling your seizures
Psychosocial Challenges Associated with Epilepsy

- Employment
- Driving
- Financial cost
- Grief and loss
- Social Stigma/Discrimination
- Quality of Life Issues
- Disclosure
- Safety/potential for injury
Employment with Epilepsy
EFA survey in mid ‘90s revealed

- 25% of working age respondents were unemployed
  - 64% of those indicated it was result of epilepsy
  - General unemployment rate was at 5%

- Population was reasonably well educated:
  - 56% had High School Education
  - 38% had some college
  - 15% had completed college
Employment of Persons with Epilepsy

- Among people whose seizures continue despite treatment the probability of work is reduced.

- With better control, the probability of continued employment still substantially affected.
What has been done by Government

• Rehabilitation Act of ‘73
• Americans with Disabilities Act of 1990 (update in 2008)
• Acts to try to prevent employment discrimination
• Businesses with more than fifteen employees must provide reasonable accommodation to protect the rights of an individual with disabilities in all aspects of employment
Under ADA

- An employer must make reasonable accommodations for a known disability, unless it would pose an “undue burden”.
- Categories of Reasonable Accommodations:
  - Modifications to job application process that enables disabled individuals to be considered for the jobs
  - Accommodations on the job
  - Accommodations made to allow disabled individuals to enjoy equal benefits and privileges of employment
Americans with Disabilities Act

• Employers may not exclude employees for safety reasons unless there is specific medical documentation, reflecting current medical knowledge, that the individual would pose a “direct threat” to health and safety.

• To determine if an individual would pose a direct threat, an employer should consider…
  – duration of risk
  – nature and severity of the potential harm
  – the likelihood that the potential harm will occur
  – the imminence of the potential harm
Definition of Direct Threat

- A significant risk of substantial harm to the health or safety of the individual or others that cannot be eliminated or reduced by reasonable accommodation.
- To be considered when making this determination:
  - Type of job/required tasks
  - Degree of seizure control
  - Type of seizures
  - Whether a person has an aura
  - Person’s reliability in taking medicine
  - Side effects of medicine
  - Accommodations which would help person do job
An employer may not ask

- Whether an applicant has a disability
- inquire about the severity of a disability
- make any inquiry that is likely to elicit information about a disability
- third parties about an applicant’s disability status
- if applicant has informed the employer regarding disability employer cannot ask prognosis
An employer can ask

- Whether the applicant can perform job-related functions
- If there is a known disability the employer may ask the applicant to describe or demonstrate how he or she will perform specific job duties
Things that you can do

• Get as Much Education/Training as you can
• Spend time with guidance counselor or employment specialist
• Know what your strengths are. Train to those strengths
• Use common sense in choosing a career or job
• Be proactive/anticipate
• Self Employment
Substantial impairment for persons with Epilepsy may result from

- side effects of medications
- frequency of seizures or the effects of seizures when they do occur
- breakthrough seizures requiring medication adjustment
- not able to drive
- discrimination
Services available to assist with employment

- School guidance counselor
- Counselor at college/university
- Vocational Rehabilitation
- Local Epilepsy program
Problems associated with working and driving

- Increased dependency
- Social isolation
- Decrease in quality of life
Driving and Epilepsy
Reporting Requirements

- When applying for or renewing a driver’s license
- When seizures occur between license renewals
Licensing

• Every state regulates the eligibility of person with certain medical conditions, including epilepsy.
• Medical information must be submitted. This information will be reviewed by personnel within the licensing department.
• Restricted license available.
Responsible parties related to licensing

- Person with seizure disorder
- Neurologist/physician
- State
Physician is responsible

• For reporting the diagnosis of seizure disorder/epilepsy in some states.
• For providing the warnings and advice that are required under current standards of care
• Education regarding possible side effects of medication.
Alternatives to Driving

- Public Transportation
- Paying to be a part of a car pool
- Van service
- Biking with helmet and pads
- Walking
- Cab
Safe Transportation

- Do not drive without license and your neurologist’s approval
- If biking wear necessary protection
- If biking try to use side roads and paths
- If waiting for bus or subway stand well back from road or platform edge
You are liable in seizure-related accidents

- If you drive without the approval of your physician.
- If you do not have a valid drivers license.
- If you do not disclose your medical condition to the state.
- Or if you have a particular knowledge of a reason why you should not be driving
Financial Cost of Epilepsy
Cost to family and society

- Direct costs
  - Medications
  - Hospitalizations
- Indirect costs
  - Lost wages
  - Decreased productivity at home
Grief and Loss
Characteristics of Grief in Chronic Illness

• Not all patients and families go through all stages at the same rate and in the same order.
• In Chronic illness people generally feel more is to come. (They are waiting for the other shoe to drop)
• Grief can block the ability to hear and internalize what is said to patient or family. (Information must be repeated)
• Person often have a “mish-mash” of feelings depending on the age level or intellectual development, how problems were solved in the past, the characteristic of present condition, i.e., nature acuity and severity
Grief in Children

- Is dependent on:
  a) Level of intellectual development
  b) Parents’ reaction
  c) How previous problems were handled
  d) Nature of chronic condition (acute flare up, severity)
  e) Limitations that are imposed
Kubler-Ross Phases of Grief

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance
1. Denial

- Not keeping appointments
- Stopping medication
- Driving when seizures not controlled
- Inability to participate in treatment plan
- Inability to understand medical plan

Why Denial?

- Need to protect themselves emotionally
- Not ready to handle the information and imposed life style changes
2. Anger

- Can manifest in many different ways
- Can be angry with themselves and others
3. Bargaining

- Magical hope that things will change.
- Attempt to seek out things that will avoid having the bad thing happen again.
  - Can include experimental treatments and medications.
4. Depression

- Feelings of sadness, loneliness
- Feelings of uncertainty
Coping With Depression

- Seek professional help
- Avoid isolation
- Avoid immobilization
- Exercise is a must
- Pursue a hobby or interest
- Social Activities are a must
- Evaluation of medication’s side effects
5. Acceptance

- Some emotional detachment and objectivity
- Adaptive Coping Behaviors
  - Using guidance to deal with feelings and understanding their own reaction
  - Learning about the condition/disease to be able to make use of medical care and to make good decisions regarding treatment
  - Family not blocking as member moves through developmental stages
  - Ability to manage daily routines
  - Achieving as much independence as possible
Maladaptive Responses

- Denial
- Overprotection/Over control
  - Managing medications
  - Asking “Are you okay”?
  - Restriction of friends and environment
  - Constant supervision
- Reduced expectations
- Emotional withdrawal
Maladaptive responses result in

- Person feeling a burden
- Constant feeling of fear/anxiety
- Self-doubt
- Social disability
- Isolation
- Regression
- Creates resentment
- Constant focus on Epilepsy and not on living
Resources

- Home based care services
- Medicaid waiver
- Pharmaceutical assistance program
- Area agency on aging and disability
- Epilepsy Foundation of America

www.needymeds.org
www.tennessee.gov
www.tennhelp.com
www.211tn.org