Living with Seizures

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Providing and Pursuing Answers: Advances in Brain Tumor Research, Treatment & Care
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SEIZURES AND BRAIN TUMORS
Seizures & Brain Tumors

- 10-40% of patients present with a seizure
- Leads to early detection of tumor
- Up to 60% will have a seizure at some point in their illness
- Seizures are devastating to patients and families
- Treated with anticonvulsant medications
SEIZURES OVERALL IMPACT

- Seizures affect Quality of Life
  - Can cause setbacks, loss of function
  - Depression
  - Anxiety
- Affects ADL’s i.e. driving, employment, recreation and creates social isolation, loss of independence
- Plus you have a tumor
SEIZURES & BRAIN TUMORS

- Seizure frequency is inversely related to the degree of malignancy
  - Very low grade: DNET, ganglioglioma 80%
  - oligodendrogliomas 81%
  - astrocytomas 66%
  - glioblastoma 42%
SEIZURE TRIGGERS

- Not enough sleep
- Skipping meals
- Missed doses of medication
- Alcohol
- Overexertion
- Stress even good stress
- Illness
- Other medications including OTC’S & antacids
SEIZURE PRECAUTIONS

- Driving restrictions (varies by state), includes motorcycles
- Avoid dangerous activities, especially if alone
  - Climbing at heights
  - Swimming or bathing alone
  - Operating dangerous equipment
SEIZURE FIRST AID

- When should I call the office?
- Notify health care team of any seizure
- First ever seizure
- Change in seizure
- Occurring more frequently
SEIZURE FIRST AID

When to go to the emergency room?

- Seizure does not stop
- Lose awareness
- Breathing problems
- Second seizure occurs
SEIZURE FIRST AID

What should I do?

- Prevent injury
- Stay with patient
- Make observations
- Emotional support
- Get an ABTA Sticker
- Get a pill container
Seizure Diary

- Track your seizures
  - There’s an APP for that:
    - Seizure Log
    - My Epilepsy Diary
    - Seizure Diary
    - Cleveland Clinic My Epilepsy
    - all are free
- www.epilepsy.com
  - on-line seizure diary
- Video it, record it (a picture is worth..)
CHOOSING AN ANTICONVULSANT
SEIZURE MEDICATIONS

- Ideal
  - One drug
  - No seizures
  - No side effects
SEIZURES & BRAIN TUMORS

- 60% will fail with first medication tried (not controlled or side effects unacceptable)
- Monotherapy (one drug) preferred
- 72% will have another seizure if taken off medication after seizure free interval
MEDICATION ISSUES

❖ Generics
  ❖ ? May be less effective, more side effects? Varies with drug
  ❖ More of an issue with enzyme inducers
  ❖ Need to consider cost and insurance coverage
  ❖ Patient assistance programs
MEDICATION ISSUES

- Enzyme inducers
  - Go through liver
  - Interact with other drugs
  - Require blood level monitoring

- Preventative/prophylactic use

- Side effects

- Drug interactions
CHOOSING AN ANTICONVULSANT

- Urgency
- IV formulation
- Quick onset
  - Had to rely on 1st generation drugs
  - Now have other options
MEDICATIONS HAVE SIDE EFFECTS
COMMON SIDE EFFECTS

- Rash – can be severe
- Fatigue
- Mental impairment
"If it doesn't itch, don't worry about it."
Skin Reactions

- Dilantin, Tegretol, Lamictal, Zonegran (25%)
- Cross-reactivity
- Can be severe (Stevens-Johnson)
- Usually appear within 60 days
- Masked by steroids
- Increases local response to radiation
- Worse if immune system is compromised (on chemo, long term steroids, low blood counts)
Black Box Warning

- Applies to all anti-seizure medications

- FDA Requires Warnings about Risk of Suicidal Thoughts and Behavior for Antiepileptic Medications

- Issued Dec. 16, 2008
CHOOSING AN ANTICONVULSANT

- Initial (immediate effect, IV)
  - Dilantin - Not good for long term
  - Keppra
  - Vimpat
- Add on or change
  - Newer drugs have less side effects
- Secondary benefits
There are no known side effects to this medication, but several notable SPECIAL effects.
Induce Hepatic Metabolic Enzymes

- Phenytoin (Dilantin)
- Carbamazepine (Tegretol, Carbatrol)
- Phenobarbital (rarely used)
- Primidone (Mysoline), rarely used
- Oxcarbazepine (Trileptal)
Modest or No Induction of Hepatic Enzymes

- Gabapentin (Neurontin)
- Pregabalin (Lyrica)
- Lamotrigine (Lamictal)
- Topiramate (Topamax)
- Valproic Acid (Depakote), some liver clearance
Modest or No Induction of Hepatic Enzymes

- Zonisamide (Zonegran)
- Tiagabine (Gabitril)
- Felbamate (Felbatol) restricted use
- Levetiracetam (Keppra)
- Lacosamide (Vimpat)
DRUG INTERACTIONS

SPEED BUMP  
by Dave Coverly

UH, DAD...YOU MIGHT WANT TO TALK TO YOUR DOCTOR ABOUT DRUG INTERACTION...

@#$!  OH, YEAH? @#$!
DRUG INTERACTIONS

- Interaction with other medications
  - Steroids
  - Chemotherapy
  - Antidepressants
  - Anti-smoking agents
  - Antibiotics, anti-lipid meds
DRUG INTERACTIONS

- Stimulants (fatigue)
- Birth control pills
- Anticoagulants (DVT’s)
- Complementary therapies, supplements, over the counter: (70% of patients do not report use, can worsen seizures)
Preventing Seizures

- 20-40% of all BT patients experience a seizure by the time of diagnosis.
- Of the rest 20-45% will eventually develop a seizure.
- Should we prophylactically be treating those patients to prevent seizures?
Wizard of ID

I'd like this prescription filled.

Parker & Hart

Sorry, my friend... can't do it.

Why not?

This drug has so many side effects, you're better off with the disease.
American Academy of Neurology

- In patients with newly diagnosed brain tumors, anticonvulsant medications are not effective in preventing first seizures.
- Because of their lack of efficacy and their potential side effects, prophylactic anticonvulsants should not be used routinely in patients with newly diagnosed brain tumors (standard).
In patients with brain tumors who have not had a seizure, tapering and discontinuing anticonvulsants after the first postoperative week is appropriate, particularly in those patients who are medically stable and who are experiencing side effects (guideline)
Medication Side Effects

B.C. by Johnny Hart

NEVER TAKE A PILL THAT HAS MORE SIDE EFFECTS THAN YOU HAVE SYMPTOMS

ADVICE
PHENYTOIN (DILANTIN)

❖ Pros
❖ IV, quick onset, “old standby”
❖ once a day

❖ Cons
❖ fatigue, mental impairment, ataxia, vision disturbance, nystagmus, skin reactions
❖ Gum changes, bone loss
❖ Interactions, fluctuating levels
Carbamazepine (Tegretol)

- **Cons**
  - Side effects similar to dilantin
  - Skin reactions (cross-reactivity)
  - Can affect blood counts (agranulocytosis)
  - Trileptal (Oxcarbazine): Low sodium levels

- **Pros**
  - Relieves nerve pain
Valproic Acid (Depakote)

❖ Cons
❖ Hepatic clearance
❖ Weight gain, hair loss/thinning, increased bleeding time, thrombocytopenia, tremor

❖ Pros
❖ Mood stabilizer
❖ Headaches
Gabapentin (Neurontin)  
Pregabalin (Lyrica)

❖ Cons
❖ Not good as monotherapy
❖ Weight gain, fluid retention
❖ Lyrica has prescribing restrictions

❖ Pros
❖ Relieves nerve pain
Lamotrigine (Lamictal)

- **Cons**
  - Rash
  - Very slow dose escalation (8 weeks)

- **Pros**
  - Mood stabilizer
Topiramate (Topamax)

- **Cons**
  - Cognitive impairment “dopamax”
  - Very slow dose escalation (8 weeks)
  - Kidney stones
  - Parasthesias (tingling, burning, pins & needles)

- **Pros**
  - Weight loss
  - Headaches
Zonisamide (Zonegran)

- **Cons**
  - Sulfa allergy
  - Rash
  - Kidney stones

- **Pros**
  - Headache
  - Weight loss
  - Once a day
Keppra (Levetiracetam)

✦ Pros
  ✦ Monotherapy
  ✦ Quick start (days)
  ✦ IV form
  ✦ XR once a day dosing
    (compliance & less side effects)
Keppra (Levetiracetam)

- **Cons**
  - Psychological effects: irritability, anger, “Kepprage”
  - Vitamin B6
  - Decrease dose
  - Change therapy
Lacosamide (Vimpat)

❖ Pros
❖ Unique mechanism of action: slow inactivation of sodium channels
❖ Positive interaction as add on with second generation drugs particularly Keppra
❖ Moderate dose escalation (2 weeks)
Lacosamide (Vimpat)

- Cons
  - Partial seizures only as add on
  - Relatively new
  - Dizziness, ataxia, syncope, visual disturbance, increased PR interval (heart rhythm)
  - No generic
  - Prescribing restrictions
New Kids on the Block

- Usually as add on only, must have failed first line drugs
- Require prior authorization or not covered
- Expensive
  - Eslicarbazine acetate (Aptiom)
  - Ezogabine (Potiga)
  - Perampanel (Fycompa)
  - Topiramate XR (Trokendi XR)
  - Oxcarbazine XR (Oxtellar XR)
  - App under Mobile Health Library
FLO and FRIENDS | John Gibel & Jenny Campbell

Dr. Joe said I have to take one of these pills every day for the rest of my life.

That's not unusual, Larry. We all have lots of pills to take every day.

Yeah... but he only gave me 30 pills!
Brain Tumors & Seizures

- Most patients experience seizure control with treatment of the tumor i.e. surgery, radiation, medication and chemotherapy.
- About 15% will continue to have intractable (refractory) seizures.
Intractable Seizures

- Most patients with intractable seizures have low grade tumors can have long periods of remission
- Seizures significantly impact Quality of Life
- Multiple medications cause significant side effects
Patients with Intractable Seizures

- Not controlled by medications, require more than one drug, experiencing side effects
- Have low grade brain tumor
- In remission, doing well
- Consider Epilepsy evaluation
- Medication change or surgery
Tumor Surgery vs Seizure Surgery

- **Tumor Surgery**
  - Diagnosis
  - Remove tumor/decrease swelling
  - Gross Total Resection > 95%
    - removal associated with better outcomes
  - Urgency
Tumor Surgery

- Mapping used to find critical functions: motor/speech/memory, not the seizure focus
- Target is the tumor
- Seizure focus not always in tumor or the portion of tumor removed
Seizure Surgery

- Often done as a second surgery in brain tumor patients
- Extensive & time consuming work-up
- Goal: Remove seizure focus
TALK TO YOUR HEALTHCARE TEAM

- What is important to you – different for everyone
- Your symptoms
- Side effects of the drugs
- Medications you take or are not taking
- Ask questions
TALK TO YOUR HEALTHCARE TEAM

PEANUTS

By Charles Schulz

SNOOPY, THIS HAS BEEN A BAD WEEK FOR ME.

WHAT CAN YOU DO WHEN EVERYTHING SEEMS HOPELESS?

SMAK!!

THAT'S GOOD ADVICE!
THANK YOU

Any Questions?

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