

Taking Charge

**A GUIDE TO LIVING WELL WITH EPILEPSY &
GETTING THE MOST OUT OF YOUR CARE**

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Introduction

Over the past few decades, many new treatments for epilepsy have been developed—medications, surgeries, and devices that can help control seizures. This is great news! We are better than ever at treating epilepsy.

However, because our knowledge about epilepsy is changing quickly, it can be hard for many people to know about all of their treatment options. We hope that this handbook can give you more information about the basics of epilepsy and more information about those treatment options.

While your doctors have extensive knowledge about epilepsy, you are the expert when it comes to *your* experience with epilepsy and the treatments that you feel most comfortable with. Sharing that experience with your doctors is very important to help them find the best treatment for you. Finding the best treatment can take some time and may require patience, but it will be easier if you understand the basics of what is available!

How to Use This Handbook

There is a lot of information in this book, which can seem overwhelming! There is no need to read everything at once. You may find it helpful to refer to the table of contents on the prior page and start by reading the sections that you find most relevant or interesting. We also encourage you to discuss the treatment options with your doctor to gain a better understanding of how those options can be tailored to your specific needs. Everyone is different and we take a personalized approach to care, so that you find what works best for you.

What do I need to know?

What is a seizure?

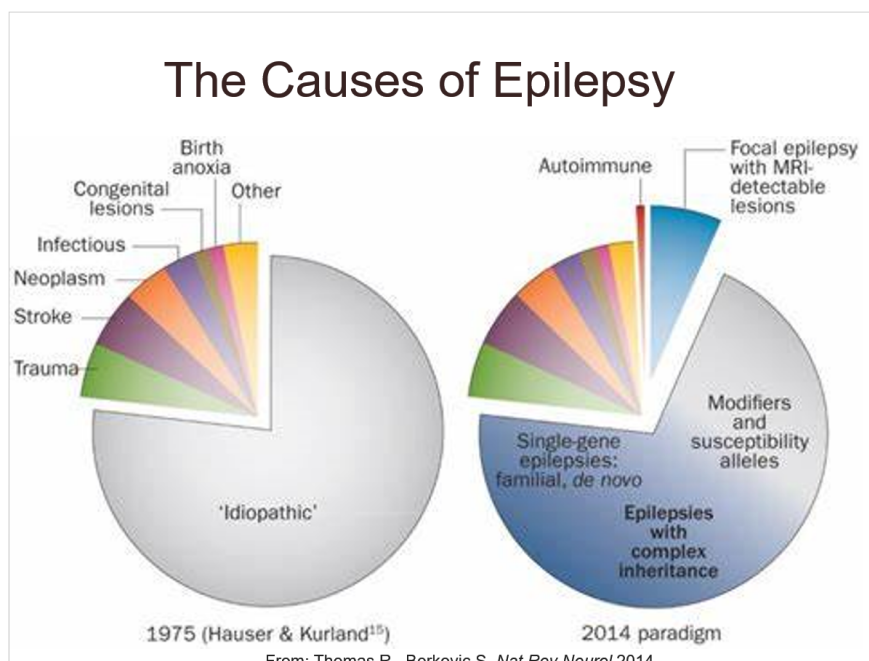
A seizure occurs when too many *nerves* (brain cells) become activated together at the same time, leading to abnormal electrical activity in the brain that may cause a variety of symptoms.

Some seizures produce unusual sensations, like a bad smell or taste, or changes in thoughts or memories like a feeling of *déjà vu*. Seizures may then progress and lead to difficulty communicating, confusion, passing out, falling down, or body shaking. At times, seizures may not produce noticeable symptoms, but still require treatment due to potential long-term effects on thinking, memory, and well-being.

Seizure episodes evolve over time. At the start of a seizure episode, a person may have an *aura*, which is a warning sign that a seizure is about to occur. *Postictal states* are the period of time after a seizure. During this time, people may be confused or tired.

What causes seizures?

In some cases, seizures are caused by genetics or a brain condition, such as a head injury, stroke, prior infection, or tumor. However, in most cases the exact cause of seizures is not fully understood.



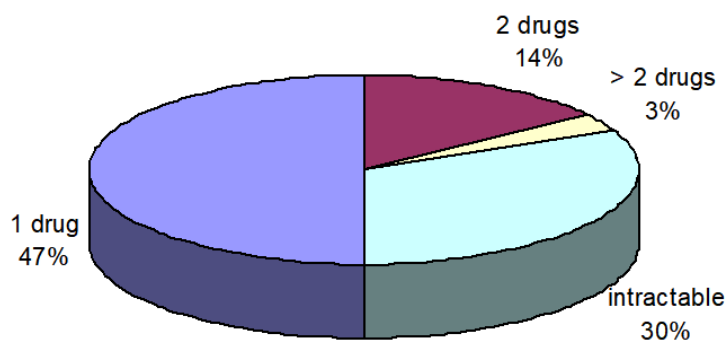
What is epilepsy?

Epilepsy is a brain disorder that causes people to have recurrent seizures. While people may have seizures for other reasons that can be treated (like an infection, high fever, abnormal levels of electrolytes or sugars in the blood, drug use or withdrawal from alcohol or drug use), this is different from having epilepsy.

Epilepsy is a common neurological disorder, affecting about 1 in 100 people worldwide. The condition can develop at any time in life, but it is most common in children and younger adults.

Epilepsy Epidemiology - USA

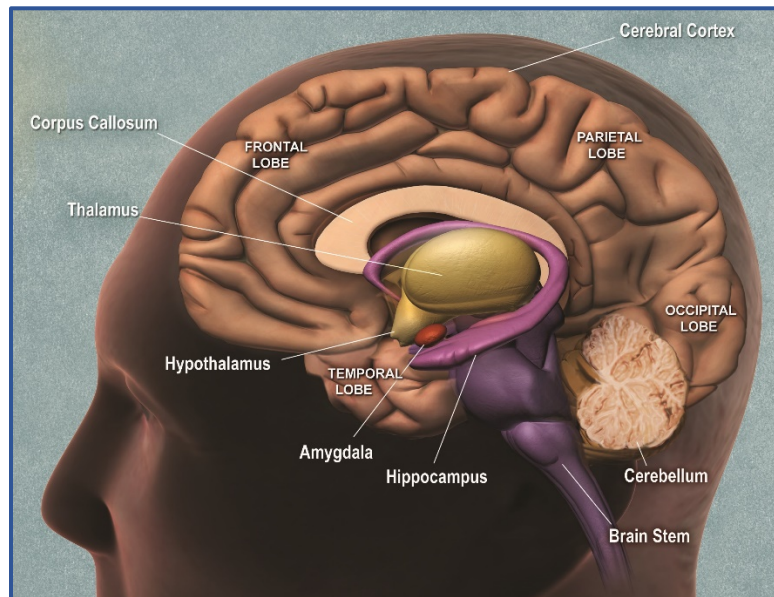
- ~1 of 100 Americans have epilepsy (CDC 2015)
- 30% refractory to Rx = ~1 million people
- >215,000 active epilepsy cases in NY!
- ~20,000 people with intractable epilepsy in L.I.
- **Seizure Freedom Rates on Rx:**



Kwan & Brodie, NEJM 2000

The Brain: What should I know?

The brain is a vital part of the central nervous system. The brain is a complex organ with many different areas and parts. Each brain area has an important job or function. Here, we will focus on describing the functions associated with each brain area.



The brain has three major parts:

- (1) **Cerebrum:** the largest part of the brain important for movement, thinking, language, feeling, and behavior.
- (2) **Cerebellum:** important for balance and movement.
- (3) **Brainstem:** connects the brain and the spinal cord. Controls involuntary functions, and functions out of our conscious control important for living, such as breathing, blood pressure, and sleep patterns.

The *cerebrum* is the largest part of the brain. Sometimes, when people say “the brain,” they are actually referring to the “cerebrum.”

There are different ways to divide the cerebrum. The outermost layer of the cerebrum is called the *cortex*, and the cortex is very important for motor and sensory skills, thinking, language, behavior, and feelings.

The cerebrum has two halves: the left and right hemispheres. Each hemisphere has specialized functions:

- (1) The **left hemisphere** controls the right side of the body (e.g., movement of the right side of the body). In most people, the left hemisphere is considered the “dominant hemisphere” because it is important for language (speaking, understanding others, reading, writing) and remembering conversations, stories, and other verbal information.
- (2) The **right hemisphere** controls the left side of the body (e.g., movement of the left side of the body). In most people, the right hemisphere is called the “non-dominant hemisphere” because it is important for functions other than language, including understanding and expressing emotions, nonverbal memory, and attention.

Each hemisphere is divided into five lobes: the frontal lobe, temporal lobe, parietal lobe, occipital lobe, and insula:

- (1) The **frontal lobes** are large, and at the front of the brain. They are important for movement, speech, problem-solving, planning, as well as behavior and self-control.
- (2) The **temporal lobes** are important for memory, language (especially comprehension or understanding), and processing emotions.
- (3) The **parietal lobes** are important for interpreting sensations, like touch and temperature. They also are important for paying attention to all parts of our world, processing visual information, and knowing where things are in space. This region is also important for reading and writing/spelling.
- (4) The **occipital lobes** are important for vision, seeing and recognizing things in our visual world.
- (5) The **insula** is hidden inside one of the folds of the brain and is important for awareness of sensations inside the body, like hunger, pain, or fatigue.

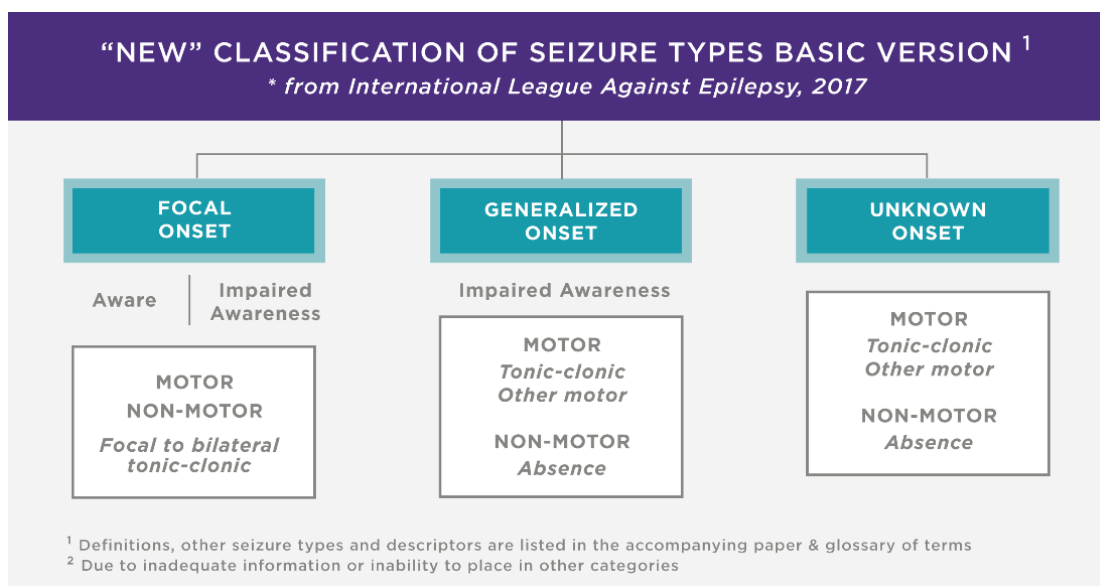
When a specific area of the brain is injured (for example, by seizures), that area may not function well. For instance, seizures in the frontal lobe may lead to behavioral problems or difficulty problem-solving. Seizures in the temporal lobe may cause problems with memory or language. Seizures in the parietal lobe may lead to problems with sensation or processing visual-spatial information. Seizures in the occipital lobe can cause vision problems or even visual hallucinations.

Are there different types of epilepsy/seizures?

Every patient with epilepsy is unique, and there are many different types of seizures. Seizures can be categorized into different types based on where they start in the brain and how they affect the body.

- (1) **Focal seizures** impact only one area on one side of the brain. Sometimes these seizures may be experienced as body twitching or an *aura*, such as a strange smell or taste, or intense emotion. Some people may experience staring into space or repetitive movements, like lip-smacking or blinking. The seizure may end there or it may spread to other parts of the brain. If this occurs, it is called a **focal to bilateral tonic-clonic seizure** or **secondarily generalized seizure**.
- (2) **Generalized seizures** involve both sides of the brain from the onset. People experiencing generalized seizures lose consciousness and may feel confused afterward. There are different types of generalized seizures:

 - **Tonic-Clonic Seizures:** This is the most common type of generalized seizure. *Tonic seizures* cause a person's muscles to stiffen abruptly. *Clonic seizures* result in rhythmic shaking or jerking movements. When both of these occur together, it is called a *tonic-clonic seizure*.
 - **Absence seizures:** These seizures cause a person to briefly lose awareness and stare into space. They are typically short, lasting only seconds.
 - **Atonic seizures:** Also known as drop attacks, these seizures cause a sudden loss of muscle tone, resulting in a person slumping over or falling down. They can be particularly dangerous as they may lead to injuries from falls.
- (3) **Psychogenic Non-Epileptic Seizures (PNES), also known as Functional Seizures:** PNES may resemble epileptic seizures in their outward appearance, but they have a different underlying cause. These seizures are not related to abnormal electrical activity in the brain. Psychological factors, such as trauma and stress, are believed to play a role in PNES. Treatment approaches for PNES differ from those for epileptic seizures. It is also possible for a person to experience both epileptic and non-epileptic seizures.



During and After a Seizure

Doctors refer to the time when you are having the seizure as the **ictal period**. The ictal period can last from several seconds to several minutes. If a seizure lasts longer than five minutes or if the person experiences multiple seizures back-to-back, it is important to call 911. If you are uncertain whether to seek help, it is always better to be cautious and make the call.

The period after a seizure is called the **post-ictal period**. After a seizure ends, it is common to feel tired, confused, nauseous, or behave differently (like being more aggressive or impatient). Often, people have a headache after a seizure. While these symptoms usually improve within about 30 minutes, fatigue and brain fog can sometimes last for several days. Besides the seizures themselves, this post-ictal period can have a big impact on your quality of life. If you encounter difficulties during your recovery from seizures, it is important to discuss them with your doctors, as they may provide advice and guidance on how to help!

How is epilepsy treated?

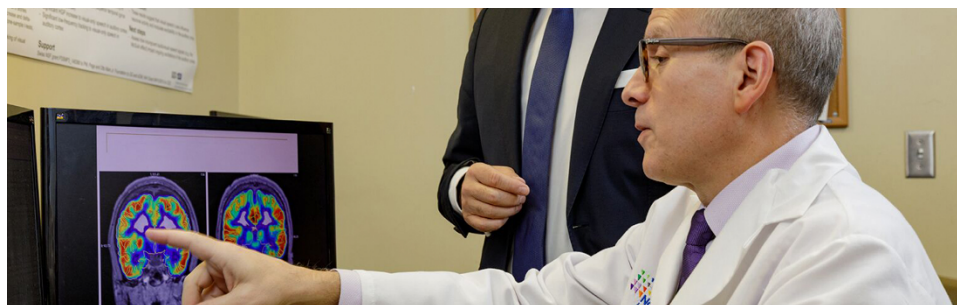
There are many options available to help control seizures. Significant advancements have been made in the treatment of epilepsy, which you and your doctor can discuss in order to find the most suitable approach. These options include:

- **Medicine.** Most people with epilepsy can control their seizures with the first or second medicine they try. If seizures are not 100% controlled after trying two seizure medicines, it is a good idea to talk to an epilepsy specialist sooner rather than later.
- **Lifestyle Change.** Sometimes changes in daily habits, such as diet and sleep can improve seizure control. Managing stress is also important. It is crucial to establish a routine of taking medication regularly as prescribed by your doctor.
- **Surgery.** If medication does not fully control seizures, brain surgery may be considered. There are various types of surgery to deactivate the seizure-causing part of the brain, which you should discuss with an epilepsy specialist.

Sharing information about your seizures with your doctor and providing regular updates are of utmost importance for effective management.

Who treats epilepsy?

Some people may start by meeting with their primary care physician and then are sent to a neurologist for evaluation. If seizures persist, it is best to meet with a neurologist or an epileptologist, which is a neurologist specialized in epilepsy.



What is discussed during health care visits and how can I prepare?

Appointments should be interactive – doctors and other health care providers are willing to share information, discuss choices and options, and collaborate with you! Your doctors need to know how you are doing in all areas of life in order to make the best possible treatment plan for you.

Share as much as you can about your health, such as:

- How often seizures occur (frequency)
- What happens during seizures (how you feel/what you do)
- Medication side effects
- Pre-seizure warnings
- Seizure length
- Time of day
- Recovery time

Other things to discuss:

- Sleep
- Stress
- Mood and anxiety
- Nutrition
- Alcohol and drug use
- Physical health and new medical issues
- If you sometimes forget or avoid taking your medications
- Changes in your thoughts or attitudes towards your current treatment pathway
- Your hopes and goals

There are apps available for seizure tracking and remembering to take medications, such as My Seizure Diary, EpiDiary, and Epsy.

Tips for health care visits:


- Prepare a list of questions ahead of time so nothing is forgotten
- Keep notes about how you are doing between appointments
- If helpful, have a friend or family member come with you to help take notes or have them join remotely by phone or video (if the doctor is comfortable with that option)
- Ask for written instructions at the end of your visit
- Between health care visits, it is important to reach out to your doctor if something important comes up or if you have a question. Use the FollowMyHealth online patient portal or smart phone app for non-urgent messages or call the office. Not all questions should wait for the next appointment.
- If you are interested in additional treatment options, ask your doctor for more information.

EASILY ACCESS YOUR ELECTRONIC HEALTH RECORDS

The FollowMyHealth portal is ready for you

According to federal guidelines, patients must be able to access their electronic personal health information. Northwell Health makes your records available through our patient portal vendor, FollowMyHealth.







FollowMyHealth lets you and your authorized representatives review test results, medications, allergies, conditions, vital signs and other clinical information. You can also access information about upcoming appointments.



Scan the code
to sign in or
sign up

This fact sheet covers FollowMyHealth highlights. Please [visit our website](#) to learn more.

FollowMyHealth benefits

| | | |
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|  <p>24/7 access to your health information</p> |  <p>Ability to track your care and progress</p> |  <p>Greater control over your health</p> |
|  <p>Improved care coordination and follow-up</p> |  <p>Improved understanding of conditions and outcomes</p> |  <p>Stronger patient- provider relationships, bridging connections</p> |

Primary Effects of Epilepsy

Frequent or recurrent seizures can injure the brain. During seizures, the brain releases a significant amount of a chemical called glutamate. Glutamate is a normal part of the brain's chemistry, but excessive amounts can injure cells.

When seizures start at a young age, the brain can sometimes adapt. For example, if language areas of the brain are affected, a different area of the brain may compensate for language functions. As we get older, the brain becomes less flexible and less capable of adjusting to seizures.

Secondary Effects of Epilepsy

Depending on what parts of the brain are affected, epilepsy can have lots of different neurological effects. But epilepsy can impact more than just the brain. Other areas of functioning are also very important to take into account.

Physical

When some people have seizures, they may fall to the ground or forcefully shake their arms and legs. With falls, you may injure your head or other parts of your body. People around you should clear away large or sharp objects that you may accidentally hit or knock over because these can also cause physical harm. Seizures can also affect sleep, leading to tiredness or difficulty falling and staying asleep. Medications can also affect hunger levels and appetite.

Mood

Epilepsy is a chronic health condition that can disrupt your life if it is not well-controlled. It can also cause a lot of stress for you or your loved ones. Many people with epilepsy feel stress, anxiety, or depression as they cope with the condition. Epilepsy can also change brain chemistry, increasing the risk of anxiety and depression. Luckily, there are lots of ways to address these concerns, like meditation and other relaxation techniques, talk therapy, or medications. Talking to your doctor about your mood is very important to receive appropriate support.

Medication Side Effects

Anti-seizure medications can have side effects. While the exact side effects depend on your specific medicine, fatigue and changes in mood or thinking are not uncommon. It is important to talk to your doctor about potential side effects before you begin a new medication. You should also let them know if you have any side effects that are interfering with your daily life.

Cognitive

During and immediately after a seizure, it is common to feel confused. This usually improves quickly. However, if you have had many seizures, you may notice day-to-day changes in thinking skills, including memory, language, attention, and thinking speed. There are lots of strategies that can help overcome these challenges, and it's beneficial to work with healthcare professionals to explore these options.

Social

One of the most common complaints of people living with epilepsy is *social stigma*. The term “social stigma” can refer to a lot of different things, including people not understanding the disorder or relying on inaccurate stereotypes about epilepsy (e.g., people’s bodies always visibly shake during seizures or associating seizures with low intelligence).

Some people with epilepsy can feel very lonely or believe that no one understands them. They may also feel embarrassed by changes in speech, memory, or thinking skills. As a result, sometimes people with epilepsy talk less with friends and family. But social support is crucial for mood and well-being. If you experience these feelings, you may benefit from joining a support group for people with epilepsy. Your doctor can provide you with more information about these options.

What can I do?

What do I want for myself living with epilepsy?

This is a very personal question -- not everyone will answer it the same way.

Personal values and beliefs affect the way different individuals manage their health and medical issues, including epilepsy. That is OK, and it is important to discuss these values and beliefs with your doctor because it can affect your care plan, and just generally how comfortable you feel.

Personal values and beliefs related to medical care are a huge topic and cover a lot. Examples of this include, but are not limited to:

- (1) How cautiously/conservatively or aggressively you want to pursue epilepsy treatment
- (2) What kinds of treatment options (e.g., medications, surgery, behavioral treatments) are comfortable or acceptable.
- (3) What are the spiritual, religious, or cultural values or beliefs that affect how you think about medical conditions and treatment
- (4) How much involvement you would like from family and friends in discussions with doctors about your medical condition and treatment options.

Personal goals may also affect the way that you live with epilepsy and the treatment options that you consider for yourself. Examples of goals that people living with epilepsy may have are below:

- (1) Reduce the frequency and/or severity of my seizures
- (2) Reduce the amount of medication that I have to take for seizures
- (3) Reduce the unwanted side-effects (e.g., fatigue, foggy thinking, headaches, irritability) that I experience from medication
- (4) Improve my independence and quality of life

Sleep and Epilepsy

The relationship between sleep and epilepsy is complex. Some people only experience seizures while awake; others only or usually experience seizures while asleep, or while falling asleep, or waking up from sleep. The relationship between sleep/wakefulness and your seizures should be discussed with your doctor.

For most people with epilepsy, lack of sleep makes seizures more likely. Good sleep is also important for healthy mood and thinking skills.

You should try to get at least 7 hours of sleep per night. Also, some people need more than 7 hours of sleep. If you are having trouble, try these strategies:

- Try to go to sleep and wake up at the same time each day.
- Avoid napping as much as possible. If you need to nap, try not to nap for more than 30 minutes so that you are still tired at night and can fall asleep more easily.
- Make sure your bedroom is quiet, dark, and at a comfortable temperature.
- Limit the amount of time you spend in bed while you are awake. Do not use your phone or watch TV/movies in bed.
- If you cannot fall asleep after 30 minutes, get up and do something relaxing like listening to music or reading in low light before trying to fall asleep again.
- Add relaxing activities to your nighttime routine, such as taking a warm bath or meditating.

Sleep Disorders

If you are still struggling to get enough sleep, you may need an evaluation for a sleep disorder, like insomnia. Up to 30% of people with epilepsy may have another disorder called obstructive sleep apnea, a disorder which makes it hard to breathe at night and can cause snoring, tiredness, and problems with thinking or cognition.

The good news is that there are treatments for these problems. You can ask your neurologist or primary care doctor for a referral to see a sleep specialist, who can talk to you about your options.

Importance of Exercise

For some people with epilepsy, exercise can help make seizures less likely.

Exercise can have a lot of other positive effects on your health too, including:

- Better sleep
- Improved cognition (such as attention, thinking speed, memory)
- Positive effect on mood, like depression, anxiety, and stress

Exercise: How to Get Started

1. **Talk to your doctor** before you get started, to make sure that your exercise plan is safe. For some people with epilepsy, strenuous exercise can make seizures more likely, so it's important to start slow and have a plan for what to do if a seizure occurs. Sometimes physical therapy is recommended.
2. **Make a plan** for what kind of exercise you want to do and how often. Try to do things you enjoy! Having an exercise routine will make it easier to keep going long term.
3. **Start small.** Sometimes it can feel overwhelming if you haven't exercised in a while. It's better to start slow, as long as you are exercising consistently. For example, try walking every day before you start to run.
4. **Exercise with a friend.** Exercising with someone else is a great way to make it more fun. Meeting with someone else will also help you to be more consistent.

Reducing Seizures with Diet

A special diet called the ketogenic (or keto) diet has been shown since the 1920s to help reduce seizures. The ketogenic diet is a low carbohydrate, high fat diet. On this diet you reduce carbohydrates (like bread, pasta, and cereal), sugars (like sodas, candy, and cakes), and fruits. You increase foods like eggs, meats, cheese, and non-starchy vegetables (like broccoli, mushrooms, and peppers).

However, if you've ever tried to diet you know how hard it can be to stick to these changes. The keto diet is particularly hard, because it is very strict. Similar but less strict diets, such as the Modified Atkins diet, may also be effective, but all diets come with challenges.

Diets: Setting Yourself Up for Success

1. **Talk to your neurologist** to see if changes to your diet are a good idea for you.
2. **Work with a dietician** if you are interested in dietary options to control your seizures. They will make sure you are getting enough important nutrients and can help come up with a plan. Your neurologist can help give you a referral.
3. **Change Takes Time.** It can be overwhelming to change your diet all at once. Making small changes over time is more likely to be successful and sustainable.
4. **Work with Others.** Talk to the people you live with about the changes you are making in your eating, so they can help. It can be a good idea to keep foods you are trying to avoid out of the house, if possible.

Dietary Side Effects

While around half of people see some reduction in their seizures, there are side effects of these kinds of diets. Some patients may experience an increase in their cholesterol levels from consuming more fat. These changes can also make some people feel ill. That is why it is important to talk with your doctors before you make these changes and to check in with your doctor once you have implemented the new diet.

Managing Your Mood and Psychological Well-being

Epilepsy can sometimes feel overwhelming. Unfortunately, stress can also make seizures worse for some people. Luckily, there are good ways to manage stress and therapies that can help to improve your mood too.

Ways to manage stress and improve mood:

- Think about what kinds of activities make you feel happy and relaxed. Some people like going for walks, playing games, practicing a musical instrument, or listening to music. Try to make time each day (15-30 minutes) to do something you enjoy.
- Spending time with people you love can also help your mood. Make a list of friends and family, and call them when you are feeling stressed.
- Meditation is a great way to focus the mind and relax. Apps like *Calm* and *Headspace* are great options to help learn the basics.
- Keeping a journal can help you think through challenging situations and make worries seem more manageable. Sometimes seeing your worries written down makes them feel less scary and can help you think of solutions.

Depression and Anxiety

People with epilepsy more often have serious mood concerns, like depression and anxiety. There are lots of treatments that can help.

- Cognitive Behavioral Therapy (CBT) is a kind of talk therapy that can help with depression and anxiety, often in just 2-3 months, and longer if needed.
- There are also lots of medications that can help with mood. Even if you are on the fence about medication, you should talk with your neurologist about this option. Your neurologist may prescribe medication for low mood or anxiety. You may also consider consulting a psychiatrist, a medical doctor that specializes in medication treatment for mood.
- Some seizure medications can also have a big impact on your mood. Make sure to talk with your neurologist about problems with mood, because they may be able to change your medications to help.
- If you are having thoughts about suicide, you can always call the suicide hotline (800-273-8255) or 911, or go to your local hospital.

Substance Use

People with epilepsy often experience stress, anxiety, and depression. They may use substances such as alcohol, marijuana, or other drugs to help manage these feelings. While people sometimes think that substances help control their seizures, they can be a big risk and can even worsen mood and anxiety over time. Sometimes these substances may make it *more* likely for you to have a seizure. Or they may interact with your medications to cause problems.

There are resources available to help stop using substances if you are struggling to cut back on your own. Your doctor can help you find what resources would work best for you.

Hallucinations and Other Unusual Experiences

A small number of people with epilepsy may also have unusual experiences, such as hearing/seeing things that are not there, or believing things that are not based in reality. These experiences may be related to epilepsy, medication side effects, or a separate (but related) condition. People may be more likely to have these experiences around the time that they have a seizure. You should always bring these experiences up with your doctor, if they occur.

Cognitive Changes in Epilepsy

Cognition refers to all of your brain's thinking skills, like paying attention, learning new information, staying organized, and solving problems. It is common for people with epilepsy to notice some changes in cognition, especially if their seizures happen frequently or have happened for many years.

The exact kind of change (or changes) you may experience depend on where in the brain your seizures occur. However, the following changes are among the most common:

- **Memory:** It may be harder to learn and remember new information, like people's names, conversations, or directions.
- **Executive Functioning:** The executive functions include many complex skills, such as staying organized, impulse control, multi-tasking, and problem solving.
- **Processing Speed:** Sometimes, people with epilepsy find that it takes more time to think through complicated problems or understand what others are saying.
- **Language:** In some cases, it may be hard to speak or find the right word to say. In other cases, it may be hard to understand what other people are trying to say.

Other Causes of Cognitive Change

Cognitive changes can also be a side effect of seizure treatments, like some medications or surgery. Your doctors want to make sure to keep these side effects as mild as possible. If you are worried about the side effects of your medications, you should always bring them up to your doctor.

Memory Strategies

Memory changes can make many day-to-day activities more difficult, like taking your medications correctly, talking with friends and family, and doing chores. However, there is a lot you can do to make these things easier and help your memory!

- **Reminders:** Using technology can be a great way to help remind you of important information. Setting an alarm on your phone can make sure you take your medication at the right time. Some apps may also help (see appendix)
- **Memory Notebook:** Writing down information is a great way to help remember. But it is important to keep your notes organized! Try to buy a single notebook to keep track of important information.
- **Repetition:** Repeating information again and again can help learning. It helps if you think about the information in different ways. For example, when you want to learn someone's name, you might *hear* the name, *say* it back to them, *write* it down, and *picture* their face in your mind.
- **Chunking:** Try to remember information in groups. When going to the store, it may be hard to remember 6 things. But it is easier to remember two groups: breakfast foods (eggs, cereal, orange juice) and pasta ingredients (pasta, tomatoes, garlic).
- **Routine:** Even people who have very large challenges with learning can benefit from routines. Try to keep important objects (like medicine) in the same place and try to practice a daily routine.
- **Pillbox:** If it is hard to keep track of whether or not you have taken your medications each day, using a pill box can help you make sure you are not taking too much medication and also lets you see when you accidentally forgot a dose.
- **Ask for Help:** It can be hard sometimes to ask for help. But it's important to remember that there are people who care about you. For some people, family or friends can really help to remember appointments and medications. Your doctors may be able to offer other solutions to help too!

Executive Functioning Tips: Staying Organized

People who have trouble with executive functioning may struggle to stay organized, feel overwhelmed, or have trouble starting tasks. These challenges can also make it harder to remember information. Try these tips if you're having trouble with executive functioning:

- **Reduce Distractions:** When doing something important or having a conversation, try to reduce distractions—turn off background sounds and try to finish one thing before starting the next.
- **Break Things Down:** If you have a big job to do, it can feel overwhelming and hard to know how to start. Before you begin, try to break the job into smaller steps. It can help to write these steps down and cross them off one-by-one.
- **Avoid Multi-Tasking:** As much as you can, try to only do one thing at a time. When we do too much at the same time, we are more likely to make mistakes.
- **Use a Calendar/Planner:** Remembering your appointments can be challenging, but it is very important. Using a calendar or planner can help stay organized. Be sure to check your calendar every day to see what appointments you have in the next week.
- **Keep Things Tidy:** Keeping your home clean and free of clutter can make it easier to find important objects. It is much easier to remember your medications or find your keys if they are the only thing on top of your dresser!

Neuropsychology

When you or your doctors are concerned about changes in your thinking, they may recommend you see a *neuropsychologist*. A neuropsychologist is a type of doctor who can assess your thinking skills to identify your strengths and weaknesses.

This is important for two reasons. First, seeing what thinking skills do not work well can help your doctors identify where problems may exist in your brain. This is especially important if you are considering brain surgery. Second, the neuropsychologist can recommend strategies to help you cope with or improve areas of thinking that are more difficult.

What is a neuropsychological evaluation?

A neuropsychological evaluation has two parts. First, the doctor will talk to you to learn about any changes you have noticed in your thinking. Then they will ask you to do many activities to look at brain functions—they may ask you to remember things, draw things, follow directions, or solve puzzles. Because your brain has many different functions, this evaluation often takes between 4-8 hours. This evaluation is often done across multiple appointments with lots of chances for breaks.



Getting a referral

If you or your family are worried that your thinking skills are changing, you should bring these concerns up with your doctor. If they believe a neuropsychological evaluation would be helpful, they can request that an evaluation be completed.

Treatment for cognitive difficulties

Epilepsy can contribute to trouble in thinking abilities (memory, speech, attention/concentration, problem solving, etc.) or a decline in thinking abilities over time. There are many factors that can affect thinking abilities in individuals with epilepsy, and these include the seizures themselves, abnormal brain activity between seizure episodes, side-effects of anti-seizure medications, or subtle cognitive changes after neurosurgery. Depression, anxiety, and stress can also affect thinking. When we are feeling sad, down, or anxious, it can be much more difficult to think clearly and process information well.

There is treatment available for managing cognitive or thinking difficulties. Cognitive therapy is a form of therapy that helps people with epilepsy learn how to manage their problems with memory, attention, language (speaking and understanding), and other areas of thinking.

Sometimes, the goal of cognitive therapy is to recover or improve functions, like after a brain injury or neurosurgery. But, in many other cases, the goal is to learn ways to manage cognitive weaknesses that are likely to last over time. In all cases, though, the goal is certainly to improve overall quality of life and ability to function at one's best.

The focus of cognitive therapy is learning ways to make use of cognitive strengths to make up for any areas of weakness, and also to use compensatory strategies and external aides (e.g., calendar or planner to keep a schedule and remember appointments).

There are a few different types of clinicians that can provide cognitive therapy. Neuropsychologists, speech/language therapists, and occupational therapists are the providers that typically provide cognitive therapy. The most important thing is finding a provider that has training and expertise in this area!

Cognitive therapy can be considered "cognitive rehabilitation" or "cognitive prehabilitation." "Rehabilitation" versus "prehabilitation" just refers to when the cognitive therapy takes place (i.e., after an event or before an event).

Care Scripts

It can be important to let others in your life know what to do in case you have a seizure. While you may not be able to communicate during a seizure, people can help if they are prepared, and they can help prevent serious injuries. But sometimes, it can feel hard to have this conversation.

Writing a *care script* is a great way to start. A care script is a short statement that explains your condition and the kind of help you might need.

Care Script Tips

1. **Be Clear.** Your script should clearly explain that you have epilepsy and what symptoms someone might expect if you have a seizure.
2. **Be Specific.** Provide specific things that people should and should not do. For example, often bystanders may not know to time how long a seizure lasts or when they need to call for help.
3. **Don't Over-Elaborate.** Your script does not have to include your whole medical history. If you provide just the information someone really needs, it will be easier for them to remember.
4. **Practice your Statement.** Practicing in the mirror is a great way to feel more confident during the conversation. While it may feel silly to some, it really works!
5. **Pick a Trusted Helper.** These conversations can sometimes feel difficult with people outside of your family. If you work, try to pick a co-worker who you trust and who you feel would step in to help.

Care Script Example

Hi Maria, there is something I wanted to talk to you about. I have a diagnosis of epilepsy. While my seizures are rare now, there may be a time when I have a seizure, and I'd like you to know what to do. It may look like I'm zoning out, and I won't respond when people are talking. If this happens, I should snap out of it after a minute or two. You don't need to do anything right away, but if I haven't come back around after five minutes, would you please call 911? Do you have any questions?

What can I expect?

Diagnosing Seizures: The First Steps

If you suspect that you have seizures, the first step will often be to meet with a neurologist, who will complete an evaluation of your medical history, a neurologic exam, and order an *electroencephalography (EEG)*.

An EEG is a safe and painless procedure that is used to diagnose seizures and help find where seizures occur in the brain. During this procedure, small electrodes are pasted on your scalp and are used to detect small electrical changes that result from seizures. Your doctor may also order some other tests, including different kinds of brain scans (e.g., MRI), which are described in more detail below.

A diagnosis of epilepsy is usually made after someone has had repeated seizures. If you are newly diagnosed with epilepsy, you may see different people to help you manage your epilepsy, including a neurologist, an epileptologist (a neurologist specializing in epilepsy), a epilepsy specialist nurse, your general practitioner, and other health care providers.



Seizure Medications

You and your neurologist and/or your epileptologist will work together to decide how to go about treating seizures. The typical first option and the most common way of treating epilepsy is with *anti-seizure medications (ASM)*. Seizures are well controlled with ASMs for most people with epilepsy and there are a wide range of ASMs. Some may work better for certain kinds of seizures than others. If one ASM does not work, another may be more effective or a combination of multiple ASMs may be tried. *See below for a list of commonly used ASMs.*

ASMs do not cure epilepsy. Instead, they are preventative medications that must be taken every day to stop seizures from happening. They work by reducing the abnormal electrical activity in the brain that causes seizures.

When you and your doctors make decisions on medications, a lot will be discussed, including other medical conditions you have or medications you take. Since it is possible you may be on these medications for years, it will also be important to consider not just what is best for you now, but also for the future.

There are over 30 different ASMs and each has a particular type or types of seizures that it works best for. Many advancements have been made in recent years to reduce side-effects of medications. However, before making any decisions, it will be important to discuss any potential side-effects with your doctors.

There are many anti-seizure medications (ASM) available. Your doctor will take a few things into account when selecting medications to treat your seizures:

- (1) **Your specific type of seizure disorder:** Some medications work better for focal seizures, some medications work better for generalized seizures, some medications work for both. It's most important how seizures *start* – either focal or generalized.
- (2) **The main mechanism of action:** how the medication works. Sometimes, giving two or more medications that have different mechanisms is best. Side effects occur more commonly when taking medications that use the same mechanism of action.

- (3) **The ‘half-life’ of the seizure medication:** how long the medication lasts in your body. A medication with a short half-life is removed by the body quickly, and so a person has to take the medication more often. A medication with a long half-life disappears from the body slowly.
- (4) **The medication cost:** being able to afford the medication is very important. The newest seizure medications are available only as brand medications, and are often more costly. Insurance companies require special approvals to use the medication, and even with approval, copayments are often very high. Sometimes, patient financial assistance programs are available.
- (5) **Side-effects and allergies:** Some seizure medications sometimes trigger allergic reactions, like a rash with itchy skin redness and hives on the chest, abdomen or back. Rarely the rash may progress to more serious involvement of the skin or liver abnormalities. In most cases, the rash goes away a few days after stopping the medication.

For a detailed list of medications, please see the Appendix.

Epilepsy Center

Anti-seizure medications (ASMs) can effectively control seizures in the majority of people with epilepsy. However, for about 30% of people with epilepsy, seizures cannot be adequately controlled with medications alone, and it is recommended to consult with a team at a *comprehensive epilepsy center*.

An evaluation at an epilepsy center involves further testing to investigate potential causes of seizures and where in the brain they originate from. This information gives you and your doctor the most accurate understanding of your condition and what medications or non-drug treatments may be appropriate, including various types of epilepsy surgery.

Epilepsy surgery is typically not the initial treatment for epilepsy, but your doctor should discuss it with you when medications aren't effective. The goal of surgery is to stop seizures or to reduce their frequency and severity.

While some people hope to become completely seizure-free and no longer need medications after surgery, it's important to know that surgery is not a cure for everyone. Even if seizures are significantly reduced, some people may continue to have rare breakthrough seizures. Although you may be able to eventually reduce your medications as well, most people who undergo surgery will need to continue to take medications, at least for a certain period of time. Despite this, many people show significant improvement and satisfaction after surgery.

Remember, **this is ultimately your decision!** If you are considering surgery, it is important to be as informed as possible about options, discuss the pros and cons with your doctors, and actively participate in the treatment decision-making process. **Your voice should be heard!**

There are multiple different types of epilepsy surgeries including minimally-invasive procedures that don't require big incisions. Other surgeries involve implanting devices used to reduce seizure occurrence.

Everyone's seizures are different, and the types of surgeries considered depend on things like the type(s) of seizures you have, the location of where seizures start, your other medical conditions, and your age. Your healthcare team will conduct a thorough evaluation to determine the most suitable surgery for you.

Surgical Work-up

If you are a possible candidate for surgery, you will work with a team of experts at the comprehensive epilepsy center. The team will perform various tests and work with you to better understand your brain, your seizures, and your overall condition. Some tests will be outpatient, while some may require a hospital stay.

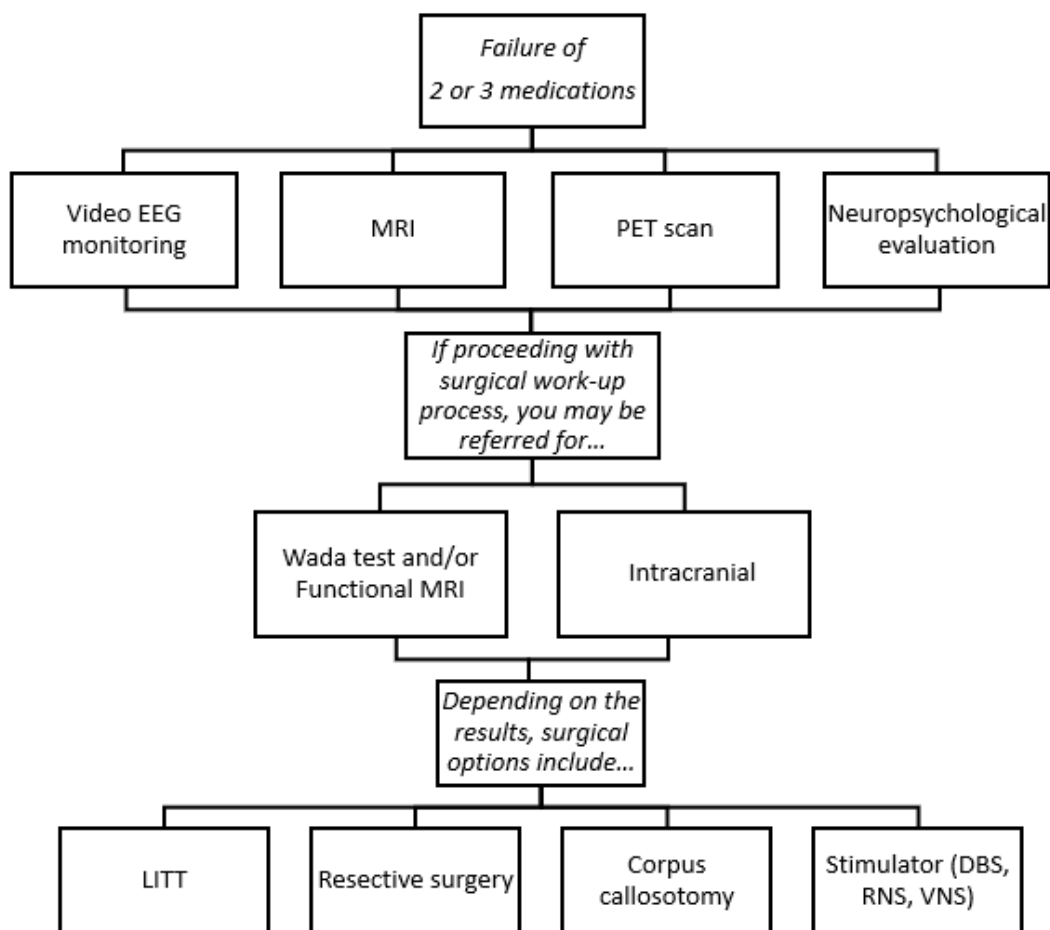
This process takes time and should be done carefully and safely. Your team of doctors need to understand as much as possible about your brain and how it functions before you have surgery.

It is important to note that completing presurgical testing does not automatically mean that you will have surgery. You and your doctor may decide that surgery is not the best option for you, and that is okay. You may also need more time to think through the treatment options. Your neurologist is available to discuss all of your questions, concerns, and worries about undergoing neurosurgery.

The risks of uncontrolled seizures and their effects on health, cognition, day to day functioning, and independence usually outweigh the risks of surgical intervention. These risks, such as those from anesthesia, bleeding, infection, or injury to areas of the brain near the seizure focus should be considered and discussed with you in detail.

Overview of surgical work-up and surgical options

This flowchart shows a typical work-up for individuals considering epilepsy surgery. However, each person's work-up is specific to their needs, and again, completing presurgical testing does not automatically mean that you will have surgery. This can be discussed in detail with your neurologist and neurosurgeon.



Parts of the Non-Invasive Surgical Work-up

The goal of the presurgical work-up is to classify the type of epilepsy you have, to locate the origin of your seizures, and determine if you are a good candidate for surgery. This work-up may include the following, tailored to your situation:

- **Ambulatory EEG:** Recording brain activity over several hours or days while you go about your usual daily routine, noting in a diary what you do and if you've had any seizures.
- **Video EEG:** Continuous recording of your brain activity, combined with video recording to observe any symptoms or behaviors during seizures. An *Epilepsy Monitoring Unit (EMU)* is a specialized hospital unit where patients with epilepsy undergo monitoring and evaluation. It is designed with equipment and staff to observe and record a patient's brain activity over an extended period, typically several days or longer. The medical team may lower your anti-seizure medications to make seizures more likely to occur. Sometimes other things are done to bring about seizures, such as sleep deprivation, breathing exercises, flashing lights, or other specific triggers.



- **MRI:** Creates a detailed picture of your brain anatomy. This procedure can help identify abnormalities in brain structure that may be causing or associated with seizures. For example, an MRI can find the location of “sclerosis” (i.e., scarring and hardening of brain tissue), and “atrophy” (i.e., shrinkage).
- **PET:** Creates an image of your brain. A very low, safe dose of a radioactive tracer substance is injected and is used to show the brain’s metabolism by measuring how it uses sugar. This can help identify areas of low metabolism that indicate where brain tissue is malfunctioning and where seizures may be coming from or affecting.
- **Neuropsychological evaluation:** Assesses thinking skills to help identify strengths and weaknesses. This evaluation also gives insight into localizing where seizures come from in the brain by identifying which areas of the brain are not functioning as well as the rest of the brain. More information about this evaluation is described below.

The Wada Procedure

Your neurologist or neurosurgeon may refer you for a Wada procedure as part of a work-up when brain surgery is a consideration. The Wada procedure is named after the doctor who developed it, Juhn Wada. It helps your care team to better understand how language and memory are organized in the brain. Sometimes these abilities are organized differently in patients with conditions affecting brain functioning, such as epilepsy.

In the Wada procedure, we examine language and memory in one side, or *hemisphere*, of the brain at a time. To do this, a medication is given to temporarily suppress activity in one side of the brain in order to examine functioning in the active side of the brain.

Pre-Wada appointment with a neuropsychologist: This appointment will occur in the neuropsychologist's office to discuss the purpose of the Wada procedure and practice the language and memory tasks that will be given during the procedure. This helps people become more comfortable in preparation for the Wada test, so that they know what to expect on the day of the Wada procedure. You may have other appointments to prepare you for the medical aspects of the procedure (e.g., with your neurologist).

Day of the Wada procedure: The Wada test is an outpatient procedure conducted at the hospital. There are a few professionals involved in your care during the procedure, including interventional neuroradiology, neurology, and neuropsychology. There are a few steps that we take before the formal Wada test, including placement of a scalp EEG and angiography to visualize the blood vessels in your brain through which medication can flow.

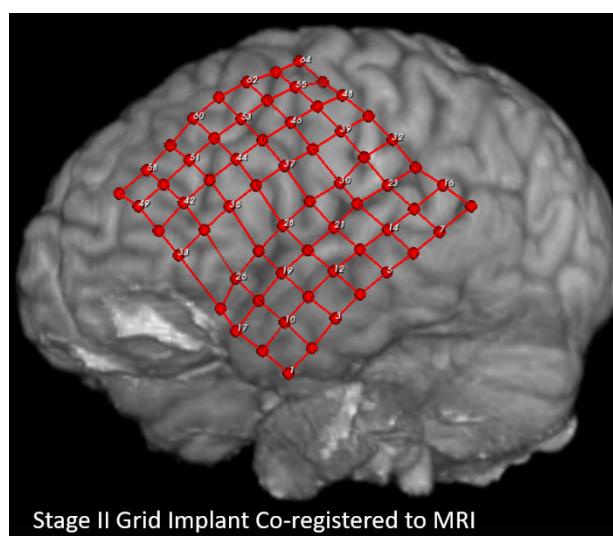
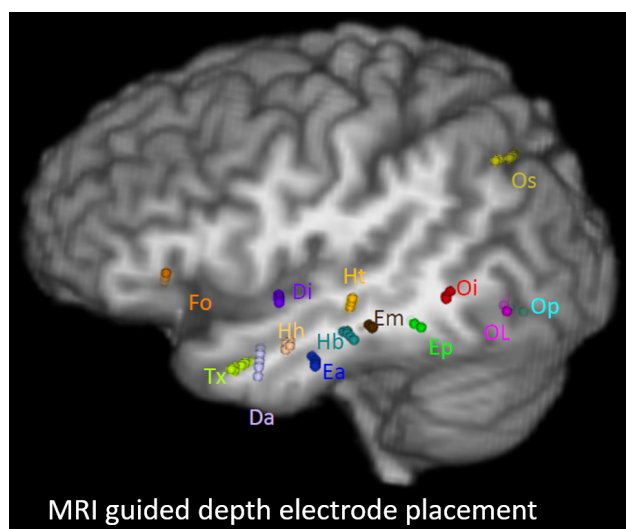
During the actual Wada test, you will be awake and communicating with the neuropsychologist. Simple language abilities will be tested and you will be shown various items to remember while one side of the brain is temporarily "asleep." We will repeat this same procedure to evaluate the other side of the brain. A supportive team will be present to make this process comfortable.

You will be discharged later that day from the hospital and should avoid strenuous activity. This procedure has a low-risk of complications that can be discussed with your neurologist and/or neurosurgeon.

Parts of the Invasive Surgical Work-up

Intracranial EEG monitoring: After the non-invasive work-up, it is often possible to identify where seizures originate and pursue surgical treatment. In other cases, doctors may still need more information to pinpoint where your seizures start. They may recommend intracranial EEG monitoring, a procedure where small electrodes are placed inside your skull instead of on your scalp. This allows for more accurate monitoring of brain activity.

- **Stereoelectroencephalography (sEEG):** The sEEG is a minimally invasive surgical procedure where electrodes are placed directly in the brain with wires through tiny holes in the skull. After the surgery, you'll be transferred to the EMU in the hospital where you'll be monitored for several days to gather more information about your seizures.
- **Intracranial strip and grid electrodes:** This procedure involves placing strips or grids of electrodes on the surface of the brain. A neurosurgeon *may* need to perform a craniotomy, which is a surgical procedure where a small section of the skull is temporarily removed to access the brain.



Extra- and Intra-Operative Cortical Mapping

Your neurologist or neurosurgeon may recommend inpatient extra-operative cortical mapping to get a more precise understanding of where certain critical functions, such as motor and language abilities, are located in the brain. The mapping procedure takes place at bedside in the hospital after electrodes are implanted in your brain to detect brain activity. During the procedure, the electrodes are used to deliver small electrical pulses while you perform specific tasks, like speaking or reading, helping the doctors map the locations of these critical functions. Typically, a neurologist and neuropsychologist will be involved in this process.

In some cases, it is necessary to assess motor ability, language or other cognitive functions *during* brain surgery to ensure the best possible outcome. The benefits and reasons for intra-operative cortical mapping will be discussed in advance with your neurologist and neurosurgeon. Your neuropsychologist will also evaluate your cognitive functions during the surgery to ensure your safety and well-being.

Surgical Options

Once the comprehensive work-up is complete, your medical team will discuss whether you are a good candidate for surgery. Different surgeries are available depending on the specific characteristics of your seizures and the areas of your brain they originate from.

Types of surgeries include:

- **Laser interstitial thermal therapy (LITT):** A minimally-invasive surgery where a laser probe is used to precisely target and heat up or inactivate the brain tissue responsible for seizures.
- **Resective surgery:** Brain tissue is removed from the area where seizures occur. This is the most common and often most effective epilepsy surgery.
- **Corpus callosotomy:** A surgery that partially or completely disconnects the right and left sides of the brain to prevent seizures from spreading rapidly and causing sudden drops, falls, or convulsions to occur.
- **Deep brain stimulation (DBS):** A device is implanted deep in the brain that releases regularly timed electrical signals that disrupt seizure-related activity.
- **Responsive neurostimulation (RNS):** A device is implanted in the brain that continuously monitors brain waves at the seizure focus. It responds quickly to seizure activity by delivering small bursts or pulses of stimulation, aiming to return brainwaves to normal before a seizure fully develops.
- **Vagus nerve stimulation (VNS):** A device is implanted under the skin in the left chest area and sends mild electrical pulses to the brain via the vagus nerve in the neck. The goal is to prevent or reduce the occurrence of seizures.

Outcomes of epilepsy surgery vary depending on the type of surgery performed. The desired outcome is improved seizure control, often in combination with medication. In some cases, people become completely seizure-free after surgery.

Cognitive rehabilitation

Cognitive rehabilitation is a form of cognitive therapy that aims to improve a person's ability to function at their best in daily life. Cognitive rehabilitation is not just for people who have had a sudden, unexpected injury. It can also be helpful for individuals with epilepsy who have had frequent or severe seizures that have affected their thinking skills, or have undergone neurosurgery and need to exercise some of their thinking skills and learn ways to manage cognitive changes after surgery.

Cognitive prehabilitation

Cognitive prehabilitation is also a form of cognitive therapy that helps with *preparing* for an upcoming event, like neurosurgery. Think of preparing for a marathon or race and wanting to be in the best possible shape for it.

It is important to know that your care team will do everything possible to avoid or minimize change in cognitive abilities. Sometimes there is still a risk of cognitive decline with surgery aimed at achieving seizure reduction.

For patients with epilepsy who will be undergoing neurosurgery, it is important to go in for surgery in the best possible shape and with a plan for the recovery period. Prehabilitation is designed to do just that. Prehabilitation uses intact cognitive functions prior to surgery to get the compensatory strategies and routines in place prior to surgery, in preparation for possible cognitive changes after neurosurgery.

Prehabilitation involves the following:

- (1) Understanding your baseline cognitive strengths and weaknesses.
- (2) Discussing the possible or likely changes in functioning after surgery.
- (3) Identifying the ways in which a change in functioning could affect one's life after surgery (e.g, at home, work, school, etc.).
- (4) Putting together a plan or set of strategies for how to handle these potential changes in functioning if they occur after surgery.
- (5) Practicing these strategies and changes to routine before surgery so that they are familiar and comfortable to use after surgery, if needed.

Appendix

Types of Medications

Medications are grouped by the type of seizure they work for best, though in some cases medications may work for both focal and generalized onset seizures. For each medication, the main mechanism of action is listed. While it's not important to know the details about each mechanism, it is helpful to know which medications share a major mechanism of action, since side effects are more common when two medications have similar mechanisms of action.

Medications for Focal Onset Seizures

Brivaracetam (Briviact)

Brivaracetam is available only as a branded medication. Like levetiracetam, which is closely related, brivaracetam works mainly through the "SV2A" mechanism. Brivaracetam lasts only a short time, with half of the medication eliminated in 9 hours. There is no extended-release version of brivaracetam. There is insufficient data to know whether brivaracetam is safe or unsafe for pregnancy. The main side effect of brivaracetam, like levetiracetam, is risk of increased irritability and anxiety, though it is reported to be less common than with levetiracetam. In a small number of individuals, there is an increased risk of depression. Like levetiracetam, brivaracetam may also be used to treat primary generalized seizures.

Carbamazepine (Tegretol) / carbamazepine ER (Tegretol XR, Carbatrol)

Carbamazepine is available as a generic and works through a 'sodium channel mechanism'. It lasts about 12 hours in the body and is given twice a day, preferably using the 'ER' formulation. Carbamazepine does not usually have any long-term effects on weight or mood. It can cause low sodium levels in the blood. Carbamazepine may cause gradual bone density loss with long-term use. This problem can be detected with a DEXA (bone density) scan – a type of x-ray – and treated if present. It can also cause mild anemia (decreased red blood cell count) and leukopenia (decreased white blood cell count), though these side effects are rarely a problem. It has several important interactions with other medications, most importantly warfarin-type blood thinners, anti-HIV medications, other anti-seizure medications and oral birth control medications. Although the data are not entirely clear or consistent, carbamazepine may increase the risk of some serious birth defects if taken during pregnancy and increase the risk of bleeding in the mother or baby at delivery. Women who may wish to be pregnant in the future, should discuss with their doctor alternative seizure medications.

Cenobamate (Xcopri)

This medication is available only as a brand medication. It works through both 'sodium channel' and 'GABA' mechanisms and lasts about 60 hours in the body. It's usually given once a day. It has to be started slowly over 3 months to avoid triggering an allergy to the medication and other side effects. It can have interactions with other seizure medications, so it may be necessary to lower the dose of other seizure medications as you increase the dose of cenobamate. There is insufficient information about cenobamate to know whether it is safe or unsafe for pregnancy.

Eslicarbazepine (Aptiom)

Eslicarbazepine is available only as a branded medication. It works through a 'sodium channel mechanism' and is very similar to oxcarbazepine. Eslicarbazepine lasts longer than oxcarbazepine, about

15 hours in the body and may be given once or twice a day. Eslicarbazepine does not usually have any long-term effects on weight or mood. It can cause low sodium levels in the blood. There isn't enough experience with eslicarbazepine in pregnancy to be certain that it is safe. Eslicarbazepine also causes gradual bone density loss with long-term use. It has several important interactions with other medications, most importantly warfarin-type blood thinners, anti-HIV medications, other anti-seizure medications, and oral birth control medications.

Felbamate (Felbatol)

Felbamate is available as a generic and works mainly through the 'sodium channel' mechanism of action. Felbamate lasts 22 hours and is usually given twice a day. Felbamate may rarely cause weight loss and is associated with risk of other relatively uncommon side effects. Felbamate is used with caution by doctors because it has a small risk of serious side effects like liver failure and 'aplastic' anemia – when the bone marrow fails and stops producing blood cells. It is, however, considered to be an effective antiseizure medication, so that the decision to use it should balance potential benefits of seizure control against risks. There is insufficient data to decide whether felbamate is safe for pregnancy.

Gabapentin (Neurontin)

Gabapentin acts through a 'calcium' channel mechanism that last about 6 hours in the body. Because the duration of gabapentin is short, it must be taken 3 or 4 times a day. It is a medication that is most commonly used for pain arising from pinched or irritated nerves, as can happen in sciatica. The doses used to treat seizures are usually much higher than the doses used for nerve pain. When given at high dose, gabapentin may cause sleepiness, leg swelling, and weight gain. Gabapentin has very few interactions with other medications. Individuals with kidney failure or on dialysis, should use gabapentin only cautiously at reduced dosage. Because of the high doses and frequency required to treat seizures, gabapentin is not commonly used to treat seizures.

Lacosamide (Vimpat)

This medication is available as a generic and works through a 'sodium channel mechanism.' It lasts about 15 hours in the body and is usually given twice a day. Sometimes your doctor will ask for an electrocardiogram (ECG) to check your heart rate after starting lacosamide. Lacosamide does not usually have any long-term effects on weight, mood or bone density. It has no significant interactions with other medications. There is not enough data to say for certain that lacosamide is safe for pregnancy, but the data available so far do not identify any increased risks. Lacosamide may also be used to treat primary generalized seizures.

Lamotrigine (Lamictal) / Lamotrigine ER (Lamictal XR)

Lamotrigine is available as a generic medication and works through multiple mechanisms, but the 'sodium channel mechanism' is one of the main mechanisms. Lamotrigine lasts about 24 hours in the body but is usually still given twice a day so blood levels are steady. The extended release (ER) form of the medication may be given once a day. It is usually started slowly in order to prevent the onset of a rash. Lamotrigine does not usually have any long-term effects on weight or mood. Lamotrigine is one of the safest medications for use during pregnancy. It also is one of the best tolerated anti-seizure medications overall. It is safe to use with other medications, but in individuals taking valproate or divalproex, the dose of lamotrigine needs to be lowered to avoid side effects. Lamotrigine may also be used to treat primary generalized seizures.

Levetiracetam (Keppra) / levetiracetam ER (Keppra XR)

Levetiracetam is available as a generic medication and works through the “SV2A” mechanism. Levetiracetam lasts only a very short time, with most of the medication eliminated in 7 hours, and nearly 70% of the medication eliminated after 12 hours, when most individuals take the next dose. For this reason, levetiracetam should ideally be prescribed as extended-release form, taken twice a day. Levetiracetam is the most prescribed antiseizure medication in the USA because it is safe and can be effective from the first dose without need to gradually buildup the dose, as must be done with many antiseizure medications. Levetiracetam is also one of the safest medications for pregnancy. Levetiracetam has no significant interactions with other medications. In individuals with kidney failure, the dose of levetiracetam should be lowered, but the medication is not toxic to the kidney. The main side effects of levetiracetam are fatigue and risk of increased irritability and anxiety. In a small number of individuals, there is an increased risk of depression. Levetiracetam may also be used to treat primary generalized seizures.

Oxcarbazepine (Trileptal) / Oxcarbazepine extended release (Oxtellar XR)

Oxcarbazepine is available as a generic and works through a ‘sodium channel mechanism’. It lasts about 9 hours in the body and is given twice a day. Though it sometimes may be best to use the extended-release formulation, it is only available as a branded medication, which can make it costly. Oxcarbazepine does not usually have any long-term effects on weight or mood. There isn’t enough experience with oxcarbazepine in pregnancy to be certain that it is safe, however, it is also not associated with high risks for pregnancy. Oxcarbazepine can cause low sodium levels in the blood. Oxcarbazepine causes gradual bone density loss with long-term use. It has several important interactions with other medications, most importantly warfarin-type blood thinners, anti-HIV medications, other anti-seizure medications, and oral birth control medications.

Phenobarbital (Luminal, Sezaby, Solfoton)

Phenobarbital is available as a generic and works mainly through a ‘GABA’ mechanism of action. Phenobarbital lasts 79 hours (3+ days). Phenobarbital does not usually have any long-term effects on weight but may increase risk of depression. Phenobarbital can cause sleepiness and tiredness, especially when first starting the medications. Even after the sleepiness has gone away, after using the medication for a long time, phenobarbital can have subtle effects on awareness, effects that have been compared to living in a house with dirty windows. A person may not notice the effect until the phenobarbital is replaced with a different medication, allowing a person to see that things seem brighter and crisper – as when dirty windows get cleaned. Phenobarbital often causes gradual bone density loss with long-term use. This problem can be detected with a DEXA (bone density) scan – a type of x-ray – and treated if present. Phenobarbital has numerous important interactions with other medications, most importantly warfarin-type blood thinners, anti-HIV medications, other anti-seizure medications, and oral birth control medications. Phenobarbital increases the risk of some serious birth defects if taken during pregnancy and increases risk of bleeding in the mother or baby at delivery. Women who may wish to be pregnant in the future, should discuss with their doctor alternative seizure medications. Phenobarbital should be reduced and stopped gradually. Severe seizures can result from abruptly stopping phenobarbital.

Phenytoin delayed release (Dilantin, Phenytek)

Phenytoin is available as a generic and works through multiple mechanism. The ‘sodium channel mechanism’ is one of the main mechanisms of action. Phenytoin may last as little as 7 hours or longer

than a day – the results vary between individuals. It is usually given in an extended-release capsule (Dilantin-brand phenytoin is an extended release formulation) and the immediate release formulation should be avoided. Phenytoin does not usually have any long-term effects on weight or mood. Phenytoin may cause gradual bone density loss with long-term use. This problem can be detected with a DEXA (bone density) scan – a type of x-ray – and treated if present. It can also cause mild anemia (decreased red blood cell count) and leukopenia (decreased white blood cell count), though these side effects are rarely a problem, in addition to possible changes in the gums (gingival hypertrophy). It has several important interactions with other medications, most importantly warfarin-type blood thinners, anti-HIV medications, other anti-seizure medications, and oral birth control medications. Phenytoin increases the risk of some serious birth defects if taken during pregnancy and increases risk of bleeding in the mother or baby at delivery. Women who may wish to be pregnant in the future, should discuss with their doctor alternative seizure medications.

Pregabalin (Lyrica)

Pregabalin is like gabapentin and also acts through a 'calcium' channel mechanism. Pregabalin is converted by the body into gabapentin. The duration of benefit from pregabalin is short – like gabapentin – lasting about 6 hours in the body. Because the duration of Pregabalin is short, it must be taken 3 or 4 times a day. Like gabapentin, pregabalin is most used for pain arising from pinched or irritated nerves, as can happen in sciatica; it is also approved for use in patients with fibromyalgia. The dose of pregabalin used to treat seizures is usually higher than the doses used for nerve pain. When given at high dose, pregabalin may cause sleepiness and weight gain. When taken with other medications that can also cause sleepiness, pregabalin can cause even greater sleepiness. There is not enough data to know whether pregabalin is safe in pregnancy.

Vigabatrin (Sabril)

Vigabatrin works through the GABA mechanism. It lasts in the body about 10 hours and is usually given twice a day. Like other medications that act via the GABA mechanism (e.g., phenobarbital or clobazam), it cannot be stopped abruptly for risk of causing strong withdrawal seizures. Instead, it should be gradually decreased over several weeks or months. Common side effects of vigabatrin are sleepiness, tiredness, and weight gain. It may also cause irritability or increased aggressiveness. Vigabatrin can also sometimes cause progressive loss of peripheral vision. Because the loss of vision is irreversible, vigabatrin can only be prescribed to individuals who get regular eye exams and vision testing to detect any vision loss before it is significant.

Medications for Generalized Onset Seizures

Cannabidiol (Epidiolex)

Cannabidiol (CBD) is one of the two major chemical compounds in marijuana. Cannabidiol has been shown to reduce the frequency of “drop” seizures and tonic-clonic convulsions in several rare forms of epilepsy – Dravet Syndrome, Lennox-Gastaut Syndrome, and seizure arising from Tuberous Sclerosis. Although cannabidiol is sometimes regarded by patients as a more ‘natural’ type of antiseizure medication, medicinal cannabidiol is administered at doses much higher than what is found naturally. What is more, medicinal cannabidiol may produce abnormalities of liver function and is often associated with loose stool and stomach cramps. Cannabidiol has some important medication interactions – most notably increasing the effects of clobazam in patients taking both medications. There is no data on whether cannabidiol is safe for pregnancy.

Clobazam (Onfi)

Clobazam is a member of the benzodiazepine family of medications that includes diazepam (Valium), lorazepam (Ativan), alprazolam (Xanax) and clonazepam (Klonopin). This family of medications acts through the “GABA” mechanism of action. GABA is a major neurotransmitter responsible for turning brain cells off. The side effects of clobazam are consistent with “turning off” brain cells – tiredness, sleepiness, lack of energy. Fortunately, for most people, these side effects go away after a couple of weeks when the person’s body gets used to the medication. Clobazam should be reduced and stopped gradually. Severe seizures can result from abruptly stopping clobazam.

Ethosuximide (Zarontin)

Ethosuximide is used in the treatment of absence seizures only, and not used for most seizure types. Ethosuximide lasts in circulation up to 60 hours. It is often given twice a day, though once a day may be sufficient. The main side effect seen with ethosuximide is stomach upset and nausea. Ethosuximide may rarely also result in disturbed sleep, increased irritability, and hyperactivity. There is not enough data to know whether ethosuximide is safe for pregnancy. Ethosuximide has been in use for nearly 50 years, and there is also no clear evidence that it is risky for pregnancy.

Perampanel (Fycompa)

Perampanel works through a ‘glutamate’ mechanism, and may last in circulation between 24 – 105 hours depending on which other seizure medications are taken with it. Because of this long time of action in blood, it can be given once a day. There is not enough data on perampanel to know whether it is safe in pregnancy or not. The most common side effect with perampanel is increased irritability. In developmentally disabled individuals, this increased irritability may be expressed as more oppositional behavior or anger.

Primidone (Mysoline)

Primidone is very similar in almost every way to phenobarbital. In fact, primidone is broken down by the body into phenobarbital. Primidone action is through the ‘GABA’ mechanism. Like phenobarbital, primidone is only rarely used now for treatment of seizures. It is used in some patients for treatment of essential tremor – subtle shaking of the hands and head. Like phenobarbital, primidone can cause sleepiness, especially shortly after starting the medication before the body has time to adjust to the sedative effect. Primidone should not be stopped suddenly, instead it needs to be gradually reduced and removed over the course of several months to avoid triggering severe seizures.

Rufinamide (Banzel)

Rufinamide acts through a 'sodium channel' mechanism. The absorption of rufinamide may be helped by taking it with food. Once in the body, rufinamide lasts 6-10 hours and is usually given 2-3 times day. The most common side effects of rufinamide are fatigue, sleepiness and stomach upset.

Topiramate (Topamax) / topiramate extended release (Trokendi)

Topiramate acts through multiple mechanisms of action, including 'sodium', 'glutamate', 'GABA', as well as others. It lasts about 21 hours in the body and can be used as well in the treatment of migraine. The main side effects are cognitive – difficulty finding the right word, 'fogginess', poor attention and concentration – that are worse with higher doses. Topiramate may also cause significant weight loss and tiredness, and it may increase anxiety or risk of depression. Topiramate also increases the risk of forming kidney stones – a risk that can be reduced by drinking plenty of water to keep the calcium in urine diluted and unable to form stones. You may notice that topiramate causes a tingling feeling in fingertips or lips. This is not dangerous, but some individuals are bothered by it.

Valproic Acid / Divalproex (Depakote DR) / Divalproex Extended Release (Depakote ER)

Divalproex is the most commonly prescribed form of valproic acid. Valproic acid is one of the most effective medications available for primary generalized seizures. It acts through a 'calcium channel' mechanism as well as 'GABA' and 'sodium channel' mechanism, among others. However, although it is highly effective against some types of seizures, valproic acid is also one of the medications with highest risk for causing problems in pregnancy. Valproic acid is associated with fetal malformation in 10% of pregnancies including a high incidence of spina bifida. For these reasons, doctors generally avoid prescribing valproic acid (or divalproex) to women of childbearing age. In cases where women prefer to continue taking valproic acid because it is the only medication to fully control seizures, it is essential to use a form of contraception. Valproic acid may also cause increased appetite and weight gain. In some individuals, valproic acid may cause hair loss.

Zonisamide (Zonegran)

Zonisamide acts through multiple mechanisms of action, including 'sodium', 'calcium', 'GABA', as well as others. It lasts about 69 hours in the body. Zonisamide may also cause significant weight loss and tiredness, and it may increase anxiety or risk of depression. Zonisamide also increases the risk of forming kidney stones – a risk that can be reduced by drinking plenty of water to keep the calcium in urine diluted and unable to form stones. Zonisamide reduces sweating, so individuals taking this medication must take precautions on hot days to stay cool out of the sun. Individuals taking zonisamide may notice that it causes a tingling feeling in fingertips or lips. This is not dangerous, but some individuals are bothered by it.