CONDITION

Refractory epilepsy

Refractory epilepsy is epilepsy in which seizures continue despite trials of two suitable, well-tolerated antiseizure medicine plans.

WHAT IT IS
Epilepsy that continues despite two appropriate medicine plans

BODY SYSTEM
Nervous system

MAIN SYMPTOMS
Repeated seizures, altered awareness, unusual movements, confusion afterward

WHAT CAUSES IT
Underlying epilepsy causes; drug resistance often remains unexplained

HOW IT IS DIAGNOSED
Seizure history, treatment review, EEG, and brain MRI

MAIN TREATMENT
Specialist review, medicines, surgery, devices, or dietary therapy

CAN IT BE CURED?
Sometimes - surgery can stop seizures

IS IT AN EMERGENCY?
Sometimes - seizures lasting five minutes or repeating without recovery

LONG-TERM OUTLOOK
Seizure control may improve, but ongoing care is often needed

Overview

Refractory epilepsy means that seizures continue even after adequate trials of two appropriate antiseizure medicine plans. These medicines were previously called antiepileptic drugs. Specialists now often use the term drug-resistant epilepsy .

The two medicine plans may have involved one medicine at a time or a combination. Each medicine must have been suitable for the type of epilepsy, taken as intended, and tolerated at an appropriate treatment level. Having one seizure after starting a first medicine does not automatically mean epilepsy is refractory.

Ongoing seizures matter because they can affect driving, work, education, relationships, independence, and emotional health. They also raise the risk of falls, injuries, prolonged seizures, and, rarely, sudden unexpected death in epilepsy, known as SUDEP.

Drug resistance does not mean that treatment has failed completely or that nothing else can help. A specialist epilepsy centre can review the diagnosis and offer options beyond further medicine changes. These may include epilepsy surgery, implanted devices, or medically supervised dietary treatment.

Symptoms

The symptoms are the seizures caused by the underlying epilepsy. They differ according to where abnormal electrical activity begins in the brain and how far it spreads.

A seizure may cause:

Some people remain aware during seizures. Others lose awareness or have a tonic-clonic seizure , which causes loss of consciousness followed by body stiffening and rhythmic jerking.

After a seizure, you may feel confused, sleepy, weak, sore, or have a headache. Recovery may take minutes or hours. Some focal seizures cause temporary weakness in one part of the body.

Refractory epilepsy may involve frequent seizures, but frequency alone does not define it. A person who has occasional seizures despite two suitable medicine plans may still have drug-resistant epilepsy.

- Loss of awareness or an inability to respond
- Staring, confusion, or repeated automatic movements
- Jerking, stiffening, or sudden loss of muscle control
- Unusual sensations, emotions, smells, tastes, or visual changes

Causes and risk factors

Epileptic seizures happen because of bursts of abnormal electrical activity in the brain. The reason seizures resist medicine is often unclear.

Drug-resistant epilepsy can occur with many kinds of epilepsy. Possible underlying causes include:

Certain structural causes, including scarring in the temporal lobe, may be more likely to produce medicine-resistant focal seizures. However, no single risk factor can predict exactly whose epilepsy will become refractory.

Sometimes ongoing events have another explanation. The medicine may not match the seizure type, doses may have been missed, or side effects may have prevented an adequate

trial. Fainting, sleep disorders, heart rhythm problems, migraine, and functional seizures can sometimes look like epilepsy. Functional seizures are real episodes, but they are not caused by epileptic electrical activity. They can also occur alongside epilepsy.

- Scar tissue or structural changes in the brain
- A previous stroke, head injury, or brain infection
- Changes in brain development
- A brain tumour
- Genetic changes that affect brain cells
- An epilepsy syndrome without a visible structural cause

Diagnosis

There is no single blood test that confirms refractory epilepsy. Diagnosis combines your seizure history with a detailed review of the treatments already tried.

A neurologist may ask what happens before, during, and after each event. A description or safe video from someone who witnessed an event can be valuable. The review usually covers medicine names, treatment duration, side effects, missed doses, and whether each medicine was appropriate for the seizure type.

Tests may include:

A normal routine EEG does not rule out epilepsy. Abnormal activity may not occur during a short recording.

If surgery might be an option, further tests help identify where seizures begin and whether treatment could affect important abilities. These tests may include specialised brain imaging, memory and thinking assessments, and longer video EEG monitoring. In selected cases, electrodes are placed inside or on the surface of the skull to record seizures more precisely.

- EEG: records electrical activity from the brain
- Video EEG monitoring: records events and brain activity together, often over several days
- MRI: provides detailed pictures that may show a structural cause
- Blood tests: look for metabolic problems or monitor the effects of treatment

Treatment and management

Treatment aims to achieve freedom from seizures when possible, while limiting side effects and protecting quality of life. A review at a specialist epilepsy centre is important after two suitable medicine plans have not controlled seizures.

The team will first check the diagnosis, seizure type, epilepsy syndrome, and previous treatments. Another antiseizure medicine or combination may help some people. Choice is based on seizure type, other health conditions, possible pregnancy, interactions, and previous side effects.

Do not stop or change antiseizure medicine suddenly unless you have been given specific medical instructions. Sudden withdrawal can cause more frequent or prolonged seizures.

For some focal epilepsies, surgery can remove or disconnect the area where seizures start. Before surgery, detailed testing checks whether this can be done with an acceptable risk to movement, language, memory, vision, and other functions. Surgery can sometimes stop seizures, but outcomes differ according to the cause and seizure location.

When removal of the seizure-producing area is not suitable, options may include:

These treatments often aim to reduce seizure frequency or severity rather than guarantee seizure freedom. Device availability and approval differ by age and location.

Your care plan may also include treatment for anxiety, depression, memory difficulties, sleep problems, or medicine side effects. A written seizure action plan can explain first aid and when to use prescribed rescue medicine. Rescue medicine is intended for specific prolonged or repeated seizures and requires individual training.

- Vagus nerve stimulation: a device sends electrical signals through a nerve in the neck
- Responsive neurostimulation: a device detects certain brain activity and responds with stimulation
- Deep brain stimulation: electrodes stimulate selected areas deep within the brain
- Ketogenic dietary therapy: a high-fat, low-carbohydrate diet supervised by an experienced clinical team

Complications

Uncontrolled seizures can cause falls, burns, cuts, fractures, drowning, or road injuries. Risk depends on the seizure type, setting, and whether awareness is lost.

A seizure lasting five minutes or longer, or repeated seizures without recovery, may be status epilepticus . This is a medical emergency because prolonged seizure activity can harm the brain and affect breathing.

Refractory epilepsy may also affect memory, concentration, mood, sleep, education, employment, and social life. Medicine side effects can add tiredness, dizziness, balance problems, or slowed thinking.

SUDEP is a rare event in which a person with epilepsy dies unexpectedly, without another clear cause. The risk is higher with ongoing tonic-clonic seizures, especially at night. Better control of these seizures and taking medicine consistently may lower risk. Your epilepsy team can discuss your personal risk without assuming the same risk applies to everyone.

Prevention

Refractory epilepsy often cannot be prevented. Many causes, including genetic changes and early brain development differences, are outside a person's control.

You can reduce some breakthrough seizures by taking medicine consistently and discussing side effects before they lead to missed doses. Regular sleep and avoiding personal seizure triggers may help. Alcohol and recreational drugs can worsen control for some people and may interact with treatment.

Safety measures do not prevent epilepsy, but they can reduce harm. Examples include showering rather than bathing alone, using guards around heat or machinery, and following local driving restrictions. Water activities require close, informed supervision.

Living with it and what to expect

Refractory epilepsy is usually a long-term condition, but seizure patterns can change over months and years. Some people gain better control after specialist reassessment, surgery, a device, dietary therapy, or a different medicine combination. Others continue to have seizures despite several treatments.

Keeping a seizure record can show changes in frequency, duration, recovery, possible triggers, and medicine side effects. Wearable devices may help detect some movement-related seizures, but they do not identify every seizure and do not replace a clinical review.

Regular follow-up is used to review seizure control, side effects, safety, mental health, and whether new treatment options are appropriate. Follow-up is also important after long stable periods because life changes, other medicines, and pregnancy planning can affect treatment.

Many people with refractory epilepsy work, study, have relationships, and take part in family and community life. Some need adjustments such as flexible schedules, supervision for certain activities, transport support, or help with memory. Laws covering driving and some

occupations differ by location.

When to get medical help

Arrange routine follow-up if seizures continue, become more frequent, change in pattern, or cause troublesome side effects. Contact your epilepsy team if you are missing medicine because of cost, swallowing problems, pregnancy, or side effects. Do not wait for the next scheduled visit if treatment has become difficult to follow.

Seek urgent medical advice after a significant seizure-related injury, a first seizure during pregnancy, or a seizure pattern that is clearly different from usual. Follow your individual seizure action plan if you have one.

Call emergency services if:

During a convulsive seizure, move nearby hazards, cushion the head, and time the event. Do not restrain the person or put anything in their mouth. When the shaking stops, turn them onto their side if it is safe to do so and stay with them while they recover.

- A seizure lasts five minutes or longer
- Another seizure starts before the person recovers
- Breathing remains difficult after the shaking stops
- The seizure occurs in water
- There is a serious injury
- It is the person's first known seizure

Common questions

Is refractory epilepsy the same as drug-resistant epilepsy?

Yes. Drug-resistant epilepsy is the term now commonly used. "Intractable" and "pharmacoresistant" epilepsy are older terms that may still appear in medical records.

Does refractory epilepsy mean no medicine will ever work?

No. It means that two appropriate medicine plans have not produced lasting seizure freedom. Further medicines may still help, although the chance of complete control generally becomes lower after repeated unsuccessful trials. Non-medicine treatments should also be considered.

Can brain surgery cure refractory epilepsy?

Sometimes. Surgery can stop seizures in selected people when tests identify a seizure-producing area that can be treated safely. Other people have fewer seizures rather than complete seizure freedom. Surgery is not suitable for every epilepsy type.

Can I drive with refractory epilepsy?

Driving rules are based on seizure control and local law. Ongoing seizures that affect awareness usually mean you must stop driving. Your licensing authority provides the rules for where you live.

Will I always have refractory epilepsy?

Not necessarily, but it is often long term. Some people later become seizure-free through surgery, medicine changes, devices, or dietary treatment. Others continue to need support for ongoing seizures.

Can stress cause my seizures?

Stress does not usually explain the underlying epilepsy, but some people notice more seizures during stressful periods. Poor sleep, missed medicine, illness, or alcohol use may occur at the same time and also affect seizure control.

Sources

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