



Epilepsy and seizures

Epilepsy is the term used to describe recurrent symptoms that are caused by a sudden burst of excess electrical activity in the brain

Many of those affected by NP-C, but not all, can experience seizures at some point during their disease progression. Sometimes seizures are so brief and mild that they do not need treatment with medication. In most cases however, the person will experience a range of different types of seizure, some of which may be severe or disruptive enough to require medication.

The brain is made up of millions of nerve cells that control the body's functions, senses and thoughts. The nerve cells do this by passing electrical signals to each other. If there is a mistake sending or receiving signals, a brief break in some, or all, of the brain's tasks can happen. If this happens a person may have an epileptic seizure.

What may happen

Seizures can be triggered by loud or unfamiliar noises, flashing or bright lights, lack of sleep, hunger or strong emotions.

Depending on the severity and type of seizure, the affected person may either be alert throughout or lose awareness or consciousness, causing them to fall over. The person may experience stiffened or twitching muscles, jerking movements (convulsions), or difficulty breathing. Their eyelids may flutter, they may look blank, stare, or be unresponsive. Seizures do not usually last more than a few minutes; however they can cause the person to feel confused, frightened or sleepy.



There are three groups of seizures: partial, generalised and secondary generalised.

Partial seizures involve epileptic activity in just one part of the brain. Partial seizures can be divided into simple partial and complex partial.

- in a simple partial seizure the person is fully conscious. They remain fully aware of their surroundings, despite seizure activity
- in a complex partial seizure a person partly loses consciousness and they are not aware of what they are doing. Because of this, they may not remember the seizure afterwards, or their memory of it will be unclear

Generalised seizures involve epileptic activity in both halves of the brain. The person loses consciousness during the seizure. The main types of generalised seizure are: tonic-clonic, absences, myoclonic, tonic and atonic.

- tonic-clonic seizures may start with a sudden cry, staring and stiffening of the body and difficulty in breathing which is followed by convulsions
- with absence seizures the person looks blank and stares, the eyelids may twitch or flutter
- with myoclonic seizures or jerks the person will experience jerking movements of the body or limbs
- with tonic seizures the person will experience stiffening muscles, may have difficulty breathing and may fall over
- an atonic seizure is a very brief seizure in which all muscle tone is lost, sometimes leading to falls





Secondary generalised seizures involve epileptic activity that starts as a partial seizure which can then spread to the rest of the brain.

What you can do

- do not try to stop a seizure – you could harm the person
- remove any harmful objects and try to make the environment safe
- protect from injury, cushion the head, and ensure nothing is placed in the mouth
- if outdoors, try to guide the person to a place of safety
- talk quietly, reassure the person and explain what has happened
- if necessary, place them in the recovery position
- keep a close watch on their breathing and colour
- stay with them until they recover

If a seizure lasts for more than a few minutes, or if one seizure closely follows another, it is advisable to seek medical advice.

Keeping a 'seizure diary' can be very helpful in determining the correct treatment and medication to use. You should keep careful records of the type of seizure, the time it happened, how long it lasted and how long it took for the person to recover. How frequent are the seizures? What happened just before they occurred?





How we managed ... one family's story

At first we did not realise that our daughter was having seizures – she made small jerky movements with her arms and they only lasted for a few seconds. It wasn't until she did this during a clinic appointment that we found out what they were. Gradually the seizures got worse and our medical team tried many different medications to help. It took time to find the right combination of medicines, and still the seizures were not totally diminished, but we were able to cope much better.

Who can help?

Your consultant will be able to offer advice and may refer you to a neurologist for a number of simple tests, such as an electroencephalogram (EEG). It can take time to determine the most effective treatment for seizures and which medication to use. Your care team will discuss the best options with you, and the NPDG (UK) clinical nurse specialist can advise as to which medications have been successful in other cases.

This leaflet forms part of a resource pack published by the Niemann-Pick Disease Group (UK). It is intended to be read in conjunction with the other parts of the pack. If you do not have the other documents in the pack or you would like further information, please contact us at the email address below.

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