

## What is a syndrome?

A syndrome is a group of signs and symptoms which, if they occur together, can suggest a particular condition.

Many children and young people will have a set of related symptoms which fit a particular pattern and this will determine which syndrome they have.

Knowing which syndrome will help the doctors to choose the appropriate antiepileptic drug (if needed) and also give a more accurate prognosis for the child/young person. It can also help to point parents in the right direction to get help and support.

Knowing the syndrome will be useful for understanding:

- whether the child/young person's seizures are likely to be controlled
- which medication is likely to work best
- whether there are likely to be any other problems, for example with behaviour, learning or social functioning
- long term prognosis

## West Syndrome

West syndrome is a type of epilepsy that develops within the first year of life and typically between four to eight months old.

Key characteristics of West Syndrome include:

- infantile spasms in early infancy;
- developmental regression;
- and a characteristic EEG pattern

## Seizures

Children with West Syndrome experience infantile spasms. At the onset of these seizures, the child will suddenly jerk and then their muscles become stiff - resulting in them bending forward with elevated arms or legs. Initially, seizures are usually brief and infrequent but overtime can occur in clusters lasting several minutes with 5-15 seconds in-between seizures.

They typically occur when the child is going to sleep or on awakening.

They may be subtle and can be mistaken for 'infantile colic' initially.

## The causes

West Syndrome is a symptom of many possible different brain disorders and in

## Better futures for young lives with epilepsy

the majority of cases, the underlying cause can be identified.

Possible causes include:

- brain injury due to complications during birth;
- brain malformation during pregnancy;
- inheritance of faulty genes (genetic) like Tuberous sclerosis;
- infections passed from mother to baby during pregnancy;
- rare metabolic disorders.

## Diagnosis

Diagnosis of West Syndrome is based on several factors including:

- the onset of infantile spasms within the first year of life;
- a characteristic pattern on an EEG (a non-invasive painless test that record brain activity by picking up electrical signals given off by nerve cells);
- and the results of other investigations, such as blood tests and MR/CT brain scans.

## Treatment

Corticosteroids and the antiepileptic drug vigabatrin (particularly for Tuberous sclerosis) or are commonly used treatments for West Syndrome. Although seizure control may be initially achieved, children commonly relapse and require alternative medication including the Ketogenic Diet.

## Prognosis

The long term prognosis is poor in the majority, however early treatment can improve prognosis.

Many children with West Syndrome will have moderate to severe learning difficulties and some degree of developmental delay. Even if the child's infantile spasms are well controlled by medication, many will go on to develop other types of seizures in later life. The overall long-term prognosis is directly related to the cause of the condition.

## For information and support:

Contact a Family  
www.cafamily.org.uk or ring 0808 808 35555.

## Young Epilepsy Helpline

If you would like to know more about epilepsy, treatments, causes or for general information about medication – we are here to answer your questions.

Talk privately with our experienced team in complete confidence, we can also provide information and support.

Simply contact us on:

**Phone:** 01342 831842, from 9am – 1pm, Monday to Friday.

**Email:** [helpline@youngepilepsy.org.uk](mailto:helpline@youngepilepsy.org.uk)

**Text:** 07860 023 789, texts are charged at your standard rate.