

## 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

## Ohtahara Syndrome

Ohtahara syndrome is a very rare epilepsy syndrome. Seizures often develop within the first ten days of life and usually before three months old. Some babies may have seizures in the womb during the last three months of pregnancy.

## Seizures

Seizure types frequently include brief tonic seizures (stiffening of the body), focal seizures and sometimes myoclonic seizures. It is not uncommon for infantile spasms to develop months later.

## The causes

The majority of children born with this condition show underdevelopment of one or both halves of their brain (the cerebral hemispheres). The possible reasons for this are:

- the inheritance of faulty genes (genetic)
- a metabolic disorder
- brain malformations
- complications during pregnancy or birth.

## Diagnosis

Diagnosis of Ohtahara syndrome is based on several factors including:

- the nature of the child's seizures and their age of onset;
- the results of brain scans - such as MRI and CT scans;
- the outcome of EEG investigations ((a non-invasive painless test that record brain activity by picking up electrical signals given off by nerve cells).

## Treatment

Antiepileptic drugs that may have some effect include phenobarbital, clobazam, clonazepam and vigabatrin. Corticosteroids have also been tried. However, seizures are often resistant to medication.

## Prognosis

Babies with this condition will often have problems feeding, be very sleep, have floppy limbs and show very little developmental progress. Over time, seizures often persist and stiffness of the limbs often develops.

The majority of infants affected by this condition will not live past two years of age, often due to complications such as chest infections.

## For information and support:

Contact a Family  
[www.cafamily.org.uk](http://www.cafamily.org.uk) or ring 0808 808 3555.

## 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.