

## **Factsheet - CG02**

### **About CHARGE**

CHARGE is a very challenging condition that affects children, young people and adults. People who have CHARGE often have to cope with a wide range of physical difficulties, including sight and hearing problems.

But despite the complexity of this condition, Sense knows many individuals with CHARGE who have been supported to rise above their difficulties and achieve far more than was originally thought possible.

There is also a CHARGE Family Support Group which brings together families to share information, ideas and to offer mutual support.

### **Common effects**

CHARGE is a rare condition that can affect different parts of the body. The most common problems are with the eyes, ears, heart, nasal passages, feeding and with growth - although the condition, and its severity, does vary from person to person.

It is believed that CHARGE is a genetic condition and very recently a mutation in the gene CHD7 has been found in approximately 50% of some children with CHARGE. Research into this is ongoing, and criteria for diagnosis are constantly under review. A diagnosis of CHARGE must be given by an appropriate health professional – such as a paediatrician, geneticist, endocrinologist, etc.

Some of the most common conditions associated with CHARGE are described below. It is important to emphasise that not all these features are seen in every person with the condition, nor are these problems always severe. For more detailed information about these conditions, and other conditions associated with CHARGE see factsheet 4.

#### **Coloboma**

This is an eye deformity where part of the eye has failed to develop properly and is missing. This is a notch-like defect (commonly described as a 'keyhole') in any part of the eye. It is present at birth and is non-progressive.

#### **Choanal atresia**

This is a closure of one, or both, of the openings at the back of the nose.

#### **Characteristic ear anomalies**

Most children with CHARGE have problems with hearing ranging from mild to profound hearing loss; unusually shaped ears and/or low-set ears; and malformed or absent semi-circular canals.

**Nerve dysfunction**

Nerve damage that effects the sense of smell, balance and ability to swallow. Some children have facial palsy which means that their face may appear to be flat and expressionless.

**Heart defects**

Children experience a range of heart problems – which may require heart surgery in a child's early life.

**Orofacial cleft**

Children with CHARGE may have a cleft lip and palate

**Genital differences,**

It is common for boys to have a small penis and/or undescended testicles, and some girls with CHARGE have small minora (inner vaginal lips).

**Growth deficiency**

This means that the child grows and develops more slowly than expected. S/he may not go through puberty without the support of hormone treatment.

**Tracheoeseophageal fistula**

The oesophagus, or gullet, may not be connected to the stomach and may just have a blind ending. Or it can be abnormally narrow or floppy leading to a range of feeding problems including reflux.

As a result of all these factors, children with CHARGE commonly have delays in development.

**Early years**

Because of the range of physical problems associated with CHARGE, babies will often need emergency surgery and may experience long periods in hospital in their early life. Understandably, parents describe this as a very difficult time for themselves and their child.

Usually the need for surgery and other medical intervention decreases over time, so that parents start to address the other challenges that their child faces. This difficult process will be greatly helped if parents are offered appropriate specialist help and are able to make contact with other parents in the same position.

Parents often say that after the very difficult early part of their child's life, their next concern is with communication. Most children with CHARGE will have a sight or hearing impairment, and around 60% will have a combined sight and hearing impairment. This means that it is an enormous challenge for them to learn to communicate.

With the right support, children with CHARGE can learn to communicate in a number of different ways. This includes using sign language, object cues and objects of reference (where an object represents a word or activity), body language, gesture, touch use of computer technology. Some children are able to hear speech and learn to speak. Many children will use a combination of methods of communication depending on their particular needs and preferences.

Because of the complex range of physical problems that children with CHARGE have to cope with, most will develop and reach their milestones more slowly. It is likely to take them longer to learn to stand and walk for example, and it may be that parents and professionals have to teach these skills more actively than they would with other children.

## **Development and education**

It is important that specialist educational professionals (teachers with a specialist qualification in multi-sensory impairment) are involved with a child as soon as possible - even when medical issues seem to be the top priority. Right from the start they should be included in the team supporting the family. Because of their specialist training and experience their role is to offer practical insights into the impact of CHARGE on development and learning. They use their skills and knowledge to support each child's development both at home and in a range of different early years educational settings

Ideally an individual programme will be devised for each child, which is designed to maximize sensory, cognitive and motor development and focus on communication needs. These programmes are also useful to the family, and other professionals, as they encourage closer partnership working, a more consistent pattern of support and the development of a deeper shared understanding of the child's needs.

As children grow older it's very important that specialist advice and support continues to be available to both family, and changing professionals, throughout the school years.

The UK education system supports children who may have special educational needs, like those with CHARGE, by providing a structure that must be observed by law. However, the way that education and schools operate depends on the local authority where the family lives. This means that services vary across the country. A Parent Partnership Service exists in all authorities and they hold information and can answer questions and offer support. See also Sense's factsheet: Your right to education services for your deafblind child.

With the right education and support an increasing number of people with CHARGE are working their way through life's milestones. Just like anyone else they have what it takes to make the most of themselves given the opportunity.

## **How many people have CHARGE?**

Very little is known about the precise numbers of people with CHARGE. Most of the people identified as having this condition are children, although Sense is now in contact with increasing numbers of children and adults who are living with this condition. Since CHARGE has only been recognised since 1979, there are probably many adults who have the condition who have not been diagnosed.

CHARGE is a low incidence disability and it is difficult to ascertain exact numbers of people affected. Brown (2002) suggested 1:12000 births and Heffner (2005) suggested 1:10000 births.

In the United Kingdom the CHARGE Family Support Group has recorded over 250 people with CHARGE.

## **Where to go for help**

Sense specialists have many years experience of providing assessments of babies and children affected by conditions that cause dual sensory impairment - including CHARGE. They also support families and offer consultancy services to schools. If you would like to find out more about CHARGE, or the support that is available in your area, please contact Sense.

See also Sense's website – [www.sense.org.uk](http://www.sense.org.uk) – which contains further information about CHARGE.

Sense also helps families by working in partnership with a number of groups for families – including the CHARGE Family Support Group. This enables parents, children and others affected by CHARGE to come together, share information and offer mutual support.

The CHARGE Family Support Group: <http://www.chargesyndrome.org.uk/>  
Or telephone Simon Howard on 020 8265 3604

## **Where can I go for help?**

If you:

- would like to find out more about deafblindness or the services for deafblind people in your area
- require information in alternative formats including braille, large print, audio or disk - or would like this factsheet to be translated into your first language - please contact Sense's Information Team.

Telephone: 0845 127 0060

Textphone: 0845 127 0062

Fax: 0845 127 0061

Email: [info@sense.org.uk](mailto:info@sense.org.uk)

Website: [www.sense.org.uk](http://www.sense.org.uk)

This factsheet was produced by:

Sense  
101, Pentonville Road  
London N1 9LG

Copyright Sense 2008