

## **Factsheet - CG04**

### **Helping children with CHARGE to learn**

As with many conditions, children and adults who have CHARGE have a wide range of abilities. No two individuals are the same and all of them will experience different things as they make their way through life.

Many will have to undergo numerous surgical interventions from a very early age, and they will often continue to experience a large number of medical problems. They also have to cope with a range of sensory difficulties – often including combined vision and hearing impairments – which will affect how they develop and learn.

But despite these difficulties, people with CHARGE often show a remarkable capacity to overcome difficulties, to make relationships and to develop their talents.

### **Learning to communicate**

The natural development of communication in children very much depends on their early, pre-verbal experiences - when they form an emotional and physical bond with their family.

When a child has CHARGE, they may have fewer opportunities for bonding with their families through feeding, touching and other sensory stimulation – especially when urgent medical problems need to be attended to.

The following conditions, often associated with CHARGE, will also affect how a child learns to communicate:

- Hearing impairment – if a child cannot hear sounds, they have partial hearing, or they have difficulties in processing sound this will affect how quickly they are able to learn. It will also influence the development of speech and communication skills.
- Visual impairment – if a child has impaired vision this will greatly affect their ability to learn about the world around them, to interact with others, to understand facial expression or sign and so on.

If someone has combined sight and hearing difficulties, then they are said to be deafblind. People who are deafblind are rarely completely

deaf and blind; most will have some sight and/or hearing that they can be helped to make the best use of.

- Some children with CHARGE will have a cleft palate which will affect a their ability to form sounds.
- Some children will have facial palsy which can cause their face to appear flat and expressionless. This can impede two-way communication and also result in slurred speech.

## **Different ways of communicating**

Despite these difficulties, children with CHARGE can be helped to learn to use a range of different ways to communicate – including speech, using sign language, writing, and using body language, gesture, touch and the use of computers. Children also often like to communicate by using pictures, symbols or objects (objects of reference and/or object cues). For example, they might use a mug, or a picture of a mug, to say that they want a drink.

Many children will use more than one way of communicating. For example:

- A child may use body language, objects of reference and make some sounds;
- Another child might hear and understand speech and use sign language to communicate.

Over time, some children may change how they like to communicate. The systems of communication that they use now (or that are used with them) should not be seen as fixed, but as a set of resources that will change and develop over time.

It is the responsibility of professionals (such as speech therapists, teachers of the deaf, teachers of the visually impaired, multi-sensory impaired teachers) to help a child to develop the way that they communicate – if this is appropriate. This means that the child's changing sensory and cognitive abilities must always be under review.

How a child learns to communicate must also fit into their lives as a whole - into their families, friendships and social relationships, the games they like to play, their physical abilities and disabilities, and so on.

## **Letting the child lead**

Although children with CHARGE are vulnerable because of their sensory impairments, their capacity for play and imagination should not be underestimated. Like all children, children with CHARGE, will be enormously helped by sensitive, nurturing and encouraging carers who can help them through their early development – people who know their strengths and weaknesses, the games they like to play and how they use their bodies to explore the world around them.

Professionals should have a good understanding of a child's history as well as **understanding the impact of combined sight and hearing difficulties.**

They should get to know the child so that they can recognise and adapt to the child's style and pace of learning and help them develop to their full potential.

## **Taking it gently**

People with CHARGE have a complicated range of sensory impairments. This can make seemingly basic tasks quite difficult.

A child may have to cope with conflicting demands placed upon them by the combination of their sensory impairments. For example, s/he may have difficulty controlling their balance whilst attending to another task, or may find it difficult to look and listen at the same time. It is important to recognize how fatigued a child can become simply coping with everyday activities and situations.

As basic tasks are often more demanding than they appear, many children with CHARGE will tend to avoid situations where they are overloaded with stimulation. They may withdraw from groups and prefer one-to-one interaction.

Carers should try to make sure that a child with CHARGE has an environment that they can cope with:

- Undertaking one task or activity at a time
- Allowing time for the child to process the information they receive
- Making sure that there is enough time to rest.

Whatever their level of development, people with CHARGE need time and space to restore their attention and concentration.

## **Joining in**

Because many children with CHARGE prefer one-to-one situations it can be difficult to introduce them to a situations where there are groups of people.

Before a child is introduced to a more complicated social situation (such as a play group, for example) the people involved in a child's care should work together to establish how the child is able to cope with more complex information and sources of stimulation.

Family members, teachers and other professionals need to ensure that the child is provided with a sense of safety, security and predictability in any new games, social interactions or other activities they are introduced to. This will provide the child with the best opportunity to develop their social and communication skills.

## **Hyperactivity, frustration and boredom**

It has often been observed that children with CHARGE like to keep active – interspersed with clear pauses. It is beginning to be understood that this may be due to the child's efforts to regulate and maintain the balance of their sensory system.

The challenge for carers is to help a child to channel this need to keep on the go, into activities that will help their development as a whole. When this is not possible, as can be the case, a child can suffer from a lack of stimulation. Their curiosity and need for wider social contact grows, and yet they have difficulty taking part in games and playing with other children.

It can be quite a challenge for carers to channel a child's need for activity in a positive and social way - and to nourish their curiosity and interest in imaginative and more demanding activities,

## **Things that can help:**

### **A stable environment** where:

- There are reliable people that the child knows and trusts
- There is predictable and organised context for activities
- It is realized that a child may, at times, use challenging behaviour to express themselves as a response to what they are experiencing.

**Good relationships** (from parents, family members and professionals) that can adapt to the particular needs of each child, particularly in terms of:

- Timing – sensitivity to a child's need for periods of activity and rest and to work at the child's pace.
- Taking in information through different sensory channels, being able to draw this together in a meaningful way, and to create appropriate responses.
- Resources (toys, games etc) that can stimulate and aid a child's development.

## **What does the future hold?**

No one can accurately predict how a person is going to turn out in life. With or without CHARGE, all people have the right to develop to the full extent of their potential. Living with CHARGE is a challenge, to which many people with CHARGE respond positively.

## **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 supporting 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