

Factsheet - CG03

CHARGE and multi-sensory impairment

Sight and hearing difficulties

Many people with CHARGE have difficulties with their hearing and vision.

Surveys in the UK & USA indicate that more than 75% of people with CHARGE have a visual impairment and as many as 92% have a hearing impairment. This means that the frequency of people who are 'deafblind' is more than 60%.

By 'deafblind' we mean that an individual has a combination of significant hearing and vision problems – rather than that they can see and hear nothing at all. Fortunately complete deafblindness is relatively rare.

Deafblindness is a distinct impairment that is more than simply vision loss plus hearing loss. A combination of these two impairments will multiply the difficulties an individual experiences since they will be unable to compensate for the lack of one sense with another.

Multi-sensory impairment

Children affected by CHARGE Syndrome will experience multi-sensory impairment in its most extreme form. They are likely to encounter difficulties not only with hearing and vision but also with the senses of balance, touch, smell, pain, pressure and temperature.

This is why we use the term multi-sensory impairment or (MSI) when talking about people with CHARGE. This can be helpful to:

- remind us that other senses apart from vision and hearing may not be working properly;
- explain features of a person's development or behaviour which may otherwise seem unusual or inexplicable;
- alert people to the need to assess and monitor these other sensory channels so that appropriate support (e.g. different therapeutic approaches, surgery, aids, etc) is provided;
- ensure that the communication system, and educational programme, devised for an individual are appropriate and do not attempt to compensate for vision and hearing loss by relying on sensory channels which may themselves not be functioning properly.

It is important to recognise that people with CHARGE nearly always experience multi-sensory impairment.

Functional deafblindness and early intervention

Even when there is no apparent physical cause, infants with CHARGE can behave as if they have no sight or hearing. There can be many reasons for this `functional deafblindness.

Most children with CHARGE have a tough start to life - birth difficulties, breathing problems, swallowing and feeding problems, surgery, invasive medical procedures, long periods in hospital, sometimes inconsistent and insensitive handling by different professionals - all of which may have a detrimental effect on a child's early development.

However, early intervention by professionals skilled in multi-sensory impairment can help to reverse this process, reduce developmental delay, and thus improve the child's prospects for the future.

Developmental delay

Children with CHARGE often take longer to go through life's milestones - such as crawling, sitting, standing, etc. Developmental delay is very common in people with CHARGE. However, with the right support and encouragement many are able to achieve milestones in their own way. This is an important point to remember so as not to limit the potential of children with CHARGE.

1. This delay is most likely due to a combination of factors, namely:
2. Visual impairment which decreases a child's motivation to lift the head and explore beyond the immediate body space, and also inhibits many normal early communicative and social interactions.
3. Facial palsy, which especially in conjunction with visual impairment, may lead to an expressionless face and an apparent lack of interest or responsiveness. This will also add to communication, social and feeding difficulties.
4. Hearing loss resulting in language delay and overall difficulty in communication and in social interactions.
5. Absent or reduced sense of balance resulting in very delayed or abnormal infant mobility and walking.
6. Low muscle tone, often more apparent in the upper body, leading to delay in pushing up into the crawl, sitting, and standing positions. This can lead to tiredness with the effort involved in sitting etc. It can also create difficulties using skills acquired when lying down, once the child is upright.
7. Frequent acute and chronic medical problems, hospital admissions, and surgery.
8. Problems of sensory defensiveness (eg tactile - dislike of soft toys; visual – dislike of bright lights; auditory – dislike of certain sounds, etc) which may lead to people with CHARGE `shutting-down', seeking solitude, or becoming self-stimulating.
9. Psychological and other testing by professionals who are unfamiliar with the complexities and subtleties of multisensory impairment will produce an inaccurate assessment of someone with CHARGE. This in turn leads to low expectations of that person's potential.

The need for careful monitoring

- Many people with CHARGE can improve the use of any or all of their senses as they get older. However, it is important to remember that for anyone with CHARGE there is also the possibility of a deterioration of their senses. With vision and hearing in particular the following may be noticed:

- Retinal detachments, glaucoma, corneal abrasions, and cataracts can cause sudden or gradual loss of vision.
- Hearing levels can fall temporarily or permanently due to repeated ear infections and glue ear, or problems in the cochlea.
- Any deterioration can also be aggravated by repeated bangs to the head or external pressure on the eyes. This can be caused by severe balance problems and/or poor motor co-ordination which is common in people with CHARGE. Some individuals may have self-stimulating behaviours like eye-poking which can also damage the eye.

In spite of all these difficulties, it is important to remember that most people with CHARGE have the potential to go through life's milestones in their own way, however long that may take. They may often take a different route to other people but they can still fulfil their potential.

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 – 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

Website: www.sense.org.uk

This factsheet was produced by: Sense, 101, Pentonville Road, London N1 9LG

Copyright Sense 2008