

Factsheet - CGO6

CHARGE – supporting parents in the early years

This factsheet has been based upon the experiences and views of a group of parents of children with CHARGE.

Along with all the rewards, looking after any child is tiring, sometimes exhausting. And the same is true for children with CHARGE – only more so. Looking after a child with CHARGE is extremely demanding and pushes many parents to their limit.

Yet despite this, people do come through. Many parents say that it does get easier as your child gets older, and that their child has achieved far more than they ever thought possible at first.

Providing information

It always comes as a shock to any parent to discover that their baby has a problem. With CHARGE this is even harder because the problems are multiple and complex. Finding out about these problems usually takes weeks, sometimes even months and years.

If there is a failure to disclose information this will only cause upset and create distrust. Professionals who think they are being kind or responsible by not 'overloading' the parents can be doing a great disservice. Unfortunately this happens much more often with CHARGE because there is so much more to disclose than with other conditions, and so many more professionals are involved.

Although it can feel overwhelming, parents do want to know as much as possible about their child's condition. They need as much information as possible to help them make the difficult decisions that every carer of someone with CHARGE faces.

How to offer information

Please consider the following when offering information to parents and carers:

Planning

- Use a comfortable, preferably private room and arrange for no interruptions.

Value the child

- Respect and value the child concerned as a person not a condition.
- Have the child present and use their name

Respect parents

- Show understanding and warmth, and work in partnership with parents.
- Be honest in sharing information with parents, and acknowledge the limitations of professional knowledge.
- If at all possible, offer information when both parents are present.
- Help parents to feel that they are in control rather than victims of circumstance and that there is something they can actually do to improve the situation.
- Treat concerns seriously and respond to them quickly and honestly.
- Be realistic but also positive about what a child might achieve.

Providing information

- Be prepared to repeat information over the following weeks and months - and ensure families can easily contact doctors and specialists to ask further questions.
- Where possible write down the information given – especially any technical or medical terms. Use plain understandable language wherever possible.
- Give families details of support groups, useful organisations and relevant statutory authorities
- Respect cultural and language differences, or any other communication difficulties, e.g. deafness.

Keeping an open mind

If information is offered in a sensitive and understanding way this will help parents. By giving them the full range of possibilities, and explaining that there are many factors that will affect how a child will develop, a professional helps parents to keep an open mind about their child's future. For example, blunt statements such as *'your child will never be able to xxx'*, when there is a possibility that they might, can be very damaging and even become a self-fulfilling prophecy.

If, on the other hand, a doctor explains that *'although your child's XXXX is in poor condition now, there are some children in a similar condition whose xxxx has improved'*, this allows parents to realise the gravity of the situation but to be encouraged to seek ways of maximising their child's potential. If a parent feels positive towards their child, and the future of their child, then the outcome is likely to be better.

Putting it together

When a child has CHARGE they may be seen by a large number of different professionals.

The immediate problems facing most newborn children with CHARGE are life threatening, which means that medical intervention has to be carefully co-ordinated between different medical professionals. For example, most of these children need repeated surgery and investigations, which means that they will have to undergo several general anaesthetics in a very short space of time. Some of these children have had more than ten in less than two years. The risk from such procedures is always high, so it would be helpful whenever possible to combine them under one general anaesthetic.

Visits to different specialists/departments should also be co-ordinated to help reduce the number of journeys and visits a family has to make.

Unfortunately, in many parents' experience, the different professionals involved in their child's care often fail to work together in a co-ordinated way - leaving it to them to organise and make sense of all the advice and information that they receive. Often parents find that they have to educate professionals - many of whom may not have met a child with CHARGE before.

All of this requires a lot of hard work on the part of the parents, to be assertive and to organise a lot of different things. Additional support from somewhere outside the family is therefore crucial for some parents so as to minimise stress and to maximise success.

Coping with hospital

Many children with CHARGE spend long periods in hospital. Here are some useful strategies for making the best of it:

- Change the position of the child's cot so that main light sources are behind the child rather than shining directly on their face.
- Try to reduce noise levels within the hospital room – for example, by keeping the door closed whenever possible, and encouraging people to speak to the child before the child is picked up and whilst the child is in an adult's arms.
- Provide a safe, potentially interesting, and not over-stimulating environment inside the child's cot to encourage use of vision, touch and hearing.
- Encourage all those involved to use a simple but consistent touch cue each time they are about to lift the child. For example: slowly, but firmly, place a hand on the child's right shoulder, pause, then carefully continue with the lifting process.
- Encourage simple reciprocal interaction games with the infant. For example: gently and rhythmically rock or bounce the child then stop to see if there is any change in the child's behaviour, such as a vocalisation or physical movement. This can be their way of asking for more.

Getting help early

Fortunately, thanks to the Early Support Programme, young infants with CHARGE now receive early input from therapists and educationalists. It is important that professionals become part of the child's support team as soon as possible after diagnosis. This is not just to ensure the best possible development for the child but also to help to minimise the devastating impact of repeated hospitalisation, and surgery, which are so characteristic of the early lives of these children. It cannot be stressed strongly enough, that as well as keeping families informed, professionals also need to explain to carers the importance of establishing a consistent and appropriate communication system with their child as early as possible.

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. If you would like to find out more about CHARGE, or the support that is available in your area, please contact Sense.

See also - 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 else 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.

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