

## Factsheet - CG08

### Sources of support

#### The CHARGE Family Support Group

For most families, caring for a child with CHARGE is extremely demanding – especially in the very early days when they are having to come to terms with this diagnosis, and when their child may well have to undergo multiple medical treatments and interventions.

This can be very physically demanding for parents – especially if there are other children to look after. It can also be lonely to care for a child who has a rare condition which prevents them from joining in with their sighted and hearing peers.

The CHARGE Family Support Group brings together parents, carers, brothers and sisters and individuals with CHARGE. Talking to other parents and carers provides a unique and much-needed opportunity to share information and ideas. It offers people the chance to tell their own stories and to offer support to one other.

**“It’s so important to be offered hope and to know you are not alone”**

Getting to meet children and adults who are affected by CHARGE in different ways also helps parents to learn more about the condition. It serves to break down the isolation that can be felt by many carers.

For parents of very young children it offers hope for the future which is crucial, especially in the early days after a child has been diagnosed. But the Support Group is not just for families - it is there for anyone involved with CHARGE who needs support, advice, or who in turn wants to give support to others.

**“The Group enables parents to network and meet face-to-face because we learn so much from each other”**

#### Keeping in touch

There are currently about 175 families who are involved in the CHARGE Family Support Group. Parents contact with each other by phone, by email or by letter to offer encouragement and support, and to share information.

There is a newsletter which comes out four times of year which includes all sorts of information about CHARGE – including providing pen portraits of children which describe the challenges they face and the progress they are making.

The group also runs a very helpful website – <http://www.chargesyndrome.org.uk/>

- which includes all sorts of useful information and offers a forum where parents share information and ideas and support one another.

## **Coming together**

The members of the Support Group aim to get together at least once each year, although this does depend of the circumstances of parents at the time. Over the years there have also been get-togethers in various places including Birmingham, Manchester, and Cambridgeshire. Families also meet up at a range of events run by Sense, including Saturday clubs and family events which are open to children with a wide range of disabilities and their families.

Recently the group worked with Sense on the Young Person's Project, organising a creative weekend for 16 - 26 year-olds called 'The Shape of Things to Come'.

## **Getting involved**

New families are very much welcomed to the group, and membership is free. Now a registered charity, the group relies on goodwill, the efforts of volunteers and voluntary fundraising to run it.

New members are sent articles that have been written about CHARGE and given a mailing list of other group members. Members are encouraged to be as active within the group as they like or simply add their names to the mailing list to receive newsletters.

**“The people who get involved – giving support, sitting on committees, organising family days – gain a strong sense of empowerment”**

Members are also sent questionnaires to complete and this information is part of a database that is used to help families give each other support and advice. It is also a good source of information for any professional who may want to research into the condition.

## **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)

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