

Briefing paper

Around diagnosis

How parents feel at time of diagnosis

Around the time of diagnosis, parents can go through a range of emotions, including shock, denial, grief and anger. Parents can be anxious about how they are going to cope and provide the care their child needs. Many families say they would like to be able to talk to another family who has a child with a similar condition. Many parents talk about feeling isolated and alone.

Parents often search for information, so they can find out how the condition might affect their child, what support is available and know what the future might hold. This information helps them understand their options, take decisions and feel more in control of the difficult situation they find themselves in.

Finding and managing medical information

Families often search the internet for medical information, which can be a source of both good and misleading information. Inaccurate information can add to a family's confusion and distress and might cause them to lose confidence in the health professionals supporting them.

Overwhelming families with masses of information can add to their stress and feelings of inadequacy. It is better to provide an overview of what information and support is available, and where to go for more details if and when they need to. How a family is supported at this time can impact on how they cope and adjust to their situation.

How can children's centres/family information services help?

- help parents find condition support groups who can provide more detailed information about specific conditions
- help parents judge the reliability of medical information found on the internet
- tell families about additional support which can be provided by both statutory and voluntary local organisations
- let the family know they are welcome to come back for further information or advice, whenever they need to
- make sure families know their child is still welcome and can be supported to take part in *all* activities at the children's centres
- see the child first and foremost as a person, rather than a condition or disability, and talk positively about their achievements.

Contact a Family can provide:

- Our medical directory – See www.cafamily.org.uk/home.html - provides reliable information on many medical conditions, including rare syndromes, and also provides details of UK condition support groups.
- Our family linking scheme helps families find others who have a child with a similar condition. This is particularly helpful in case of rare conditions.
- Our factsheets, including 'When your child has additional needs' tells families about different sources of support.
- Our leaflet 'Finding medical information on the internet' provides guidance to families when searching the internet for medical information.

Around diagnosis: sources of support

Contacts	What can be offered
Contact a Family Helpline Tel: 0808 808 3555 Online medical directory www.cafamily.org.uk/home.html	Advice and information on any aspect of caring for a disabled child and sends out leaflets and factsheets. They can provide details of national and local support groups. Telephone interpreter service is available. <i>Criteria – free to families caring for disabled children aged 0-19 years of age, living in the UK</i>
Contact a Family local support Tel: 0808 808 3555 www.cafamily.org.uk/cafiya	Contact a Family have offices, family support workers and volunteer parent representatives in some areas of the UK. They can provide a listening ear and signpost families to other local support. Family support workers can also arrange to meet families in their own home, or in other venues such as children's centres. <i>Criteria – free to families caring for disabled children aged 0-19 years of age in certain areas of UK.</i>
Early Support www.earlysupport.org.uk	Can provide information for parents on conditions such as autistic spectrum disorder, cerebral palsy, down syndrome, deafness, learning disabilities, speech and language difficulties and visual impairment. <i>Criteria – free to families with disabled children & professionals working in England</i>
Face 2 Face Tel: 0844 800 9189 www.face2facenetwork.org.uk	Provide a network of trained volunteer befrienders who can help parents coming to terms with the news that their child has a disability. <i>Criteria – free to families caring for disabled children in certain areas of England.</i>
Home-Start Tel: 0800 068 63 68 http://www.home-start.org.uk	Have a network of trained parent volunteers who can support parents struggling to cope. <i>Criteria - families of children aged 0-19 years of age living in certain area of UK</i>
Local groups	Research tells us that parents of disabled children often find other parents the best source of information and support. Find out and publicise where families can meet others in your area.

This is one of a series of briefing papers to help children's centres and family information services begin to support families of disabled children on specific issues. You can browse all of these at <http://www.cafamily.org.uk/childcentres.html>

To find out more about how the children's centre team at Contact can help please contact:

Karen Robinson, Senior Children's Centre Adviser tel: 01706 220578 e-mail: karen.robinson@cafamily.org.uk