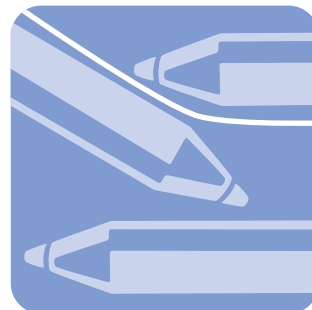
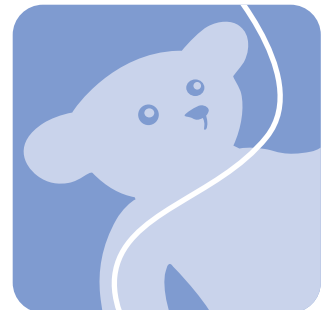


Early Support

Helping every child succeed

Information for parents If your child has a rare condition







Discovering that your child has a disability or a health problem is always difficult and the feeling of isolation can often be acute. If your child is diagnosed with a rare condition, these feelings can be magnified. Perhaps the doctor does not know very much about the disorder, has never seen another affected child and can give you little advice about what you might expect over the coming months and years.

'When they said that my daughter had a rare condition which would affect her growth, I was stunned and totally knocked back by the news. The worst thing was not knowing anything about her condition. I started to panic, thinking that she would never go to school, have a boyfriend or get married.'

(Mother)

A family's greatest need is for good quality information. This includes information about entitlements to support and provision for special educational needs. And, perhaps more importantly for those with a child only recently diagnosed with a rare condition, there is a desperate need for clear medical information and also contact with other families in a similar situation, to share experiences and benefit from mutual support.

Where to find out more

The UK-wide charity [Contact a Family](#) provides support, advice and information to families with disabled children, whatever the child's diagnosis – whether your child has acquired aplastic anaemia or Zellweger syndrome.

[Contact a Family](#) can:

- put you in touch with support groups. They are in contact with hundreds of small national support groups, which cover many rare conditions
- where there isn't a group, as is the case with some very rare disorders, try to link you directly on a one-to-one basis with another family
- put you in touch with other specialist voluntary organisations which may be able to help

Information for parents If your child has a rare condition

- give you medical information on all conditions affecting children and young people
- provide free factsheets on subjects which may be relevant – for example, *Living without a diagnosis* or *A genetic condition in the family*
- provide leaflets for grandparents, brother and sisters
- talk to you via an interpreter in over 100 languages if you prefer to use a language other than English.

The Contact a Family website www.cafamily.org.uk has lots of useful information and includes an online *Directory of rare conditions and syndromes affecting children*.

If you cannot find a particular condition listed in the directory, or do not have access to a computer, call the Contact a Family Helpline. Their advisers can go through information with you and will research a particular condition for you if it's something they do not already hold information on. You can talk things through with a parent adviser, order free factsheets, and find out about the support and help that is available in your area. The service is free and confidential.

Contact a Family

209–211 City Road
London
EC1V 1JN

National Freephone Helpline: 0808 808 3555

Textphone Helpline: 0808 808 3556

Email: info@cafamily.org.uk

Web: www.cafamily.org.uk



Early Support is a Government funded programme involving the Department for Education and Skills, Sure Start and the Department of Health. The purpose of the programme is to improve the delivery of services to disabled children under three and their families. It promotes service development in partnership with health, education and social services, service users and organisations in the voluntary sector. For more information, visit www.earllysupport.org.uk

Early Support is putting into practice the principles outlined in the Government guidance document *Together from the Start* which was published in May 2003. The guidance recognises that where children have special needs and disabilities, it is important that these are identified at an early stage and that identification leads directly to effective early intervention and support for families and children.

This booklet is one in a series produced by **Early Support** in response to requests from parents and voluntary organisations for better information for parents. The programme has produced booklets about a number of disabilities or known conditions and expects to develop more as the programme progresses. The following titles are currently available:

Autistic spectrum disorders (12)	Cerebral palsy (10)
Learning disabilities (15)	Down's syndrome (13)
If your child has a rare condition (18)	Multi-sensory impairment (9)
Speech and language difficulties (14)	Visual impairment (8)
When your child has no diagnosis (16)	Deafness (11)

Copies of these booklets can be obtained from:

DfES Publications
PO Box 5050, Sherwood Park,
Annesley, Nottingham NG15 0DJ
Tel: 0845 602 2260 Fax: 0845 603 3360
Textphone: 0845 605 5560 Email: dfes@prolog.uk.com

Please quote the appropriate reference number.

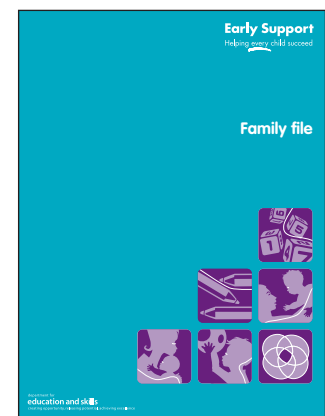
Information for parents If your child has a rare condition

Early Support has also produced a **Family Pack**, which supports families through the first years of their children's lives. The Pack contains background information about the services you may need, the help you are entitled to and a **Family File** designed to help co-ordinate any support being provided for your family. They are resources that other families have said would make a difference. If you and your child are receiving regular support from a professional or range of professionals, please feel free to ask them about the **Early Support Family Pack**, which may help and which is available free of charge.

Early Support would like to thank all the parents and families involved in the production of these resources.

Early Support would also like to thank **Contact a family** for their help in writing, consulting upon and producing this resource.

Contact a family provides support and information to families who care for children with any disability or specific health condition. Contact a Family provides information about disabilities, puts families in touch with other families where there is not a national support group, assists parents to develop their own support groups and provides a voice to raise awareness and campaign for families. For more information write to them at 209–211 City Road, London EC1V 1JN. Telephone: 020 7608 8700. Helpline: 0808 808 3555. Minicom: 020 7608 8702. Fax: 020 7608 8701. Email: info@cafamily.org.uk The Contact a Family website contains all publications, also available in paper format, including the **Contact a Family Directory**. Website: www.cafamily.org.uk



contact a family
for families with disabled children



Copies of this booklet can be obtained from:
DfES Publications
PO Box 5050
Sherwood Park
Annesley
Nottingham NG15 0DJ
Tel: 0845 602 2260
Fax: 0845 603 3360
Textphone: 0845 605 5560
Email: dfes@prolog.uk.com

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www.earlysupport.org.uk

We acknowledge with thanks the contribution of the
following organisation in the production of this resource.

contact a family
for families with disabled children