



About diagnosis: How we can help

If your child has difficulties with any of these:

- Learning
- Hearing
- Physical disability
- Behaviour
- Speech
- Sight
- Medical condition

Part 1



30 years of
strengthening
families with
disabled children

You may be reading this guide because your child or a child in your family has recently been diagnosed with a disability or long-term condition. Or perhaps something about your child's development or behaviour has caused you to worry that they may have an unidentified condition or disability. Or it may be that your child is having tests right now.



In some cases a child may become disabled as a result of a life event, such as a sudden illness or accident. In many cases you may notice over time that your child has additional needs as they miss milestones in their development or start to show difficulties in certain areas. It is natural to want to know the cause of your child's additional needs and get a specific diagnosis. However, it may be some time before you are given a name for your child's condition – and this time can mean a period of uncertainty for you and your family. For a few families, getting a name for a condition – a diagnosis – might never happen.

Whatever your situation, it will be helpful to talk to the health professionals involved in your child's care. This guide has been written to help you get support at this time and, as important as it may be to get a diagnosis there may be a lot of help you can access now. For more information around diagnosis see our other guides listed on the back page.

Get in touch with Contact a Family

Contact a Family provides information and support to families with disabled children, whatever their child's disability or medical condition. We have local, national and regional offices and family support workers throughout the UK. Contact a Family is a registered charity and we run a free confidential helpline for parents on Tel: 0808 808 3555.

You can telephone the Contact a Family helpline for advice and information on any aspect of caring for your disabled child, including:

■ Education

We can help you find out if you can get extra help to support your child at school.

■ Medical information

We can usually provide information about your child's condition and help you make contact with support groups who can also help.

■ Behaviour

If your child's behaviour is causing you concern we can provide information to help you understand and control their behaviour.

■ Equipment in your home

We can tell you how to get help with equipment and get work done to your house to make it easier to look after your child.

■ Transport

We can help you find out what is available to help you and your child get around.

■ Short breaks or help caring for your child

We can put you in touch with local services who might be able to provide someone to look after your child for a few hours or perhaps overnight so you can have a rest.

■ Holidays and leisure

We can give you information about local places where you can take your child to have fun and enjoy yourselves. We can also tell you how to get help finding and paying for holidays.

■ Want to study or go to work?

We can provide information to help you find suitable childcare if you want to get a job, or training to help you find work. We can also tell you about your employment rights if you decide to go back to work.

■ Finance

We can tell you about financial help that you may be entitled to.

■ Debt

If you are struggling to pay your bills we can put you in touch with organisations who can help.

■ Contact with other families

We can help you make contact with other parents whose child has the same condition or make contact with other parents living close to you who face similar problems.

Other guides in this series

- 1 How we can help
- 2 Support for parents
- 3 What is developmental delay?
- 4 Understanding behaviour
- 5 Getting a diagnosis
- 6 What if we don't get a diagnosis?
- 7 What is a genetic condition?
- 8 Rare disorders
- 9 Sources of medical information
- 10 Concerned about your child
- 11 Practical and financial help

Getting in contact with us

Free helpline: **0808 808 3555**
Open Mon–Fri, 10am–4pm;
Mon, 5.30–7.30pm

www.cafamily.org.uk
www.makingcontact.org

Contact a Family Head Office:
209-211 City Road, London EC1V 1JN

Tel 020 7608 8700
Fax 020 7608 8701
Textphone 0808 808 3556
Email info@cafamily.org.uk

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Although great care has been taken in the compilation and preparation of this guide to ensure accuracy, Contact a Family cannot take any responsibility for any errors or omissions. The photographs in this guide do not relate to any personal accounts.



Other information available

- Special educational needs (England/Scotland/Wales/NI)
- Understanding your child's behaviour (UK)
- Aids, equipment and adaptations (UK)
- Disabled children's services (England & Wales/Scotland)
- Holidays, play and leisure (UK)
- Working (UK)
- Finding and paying for childcare (England & Wales)
- Benefits, tax credits and other financial help (UK)
- Dealing with debt (England & Wales/Scotland/NI)

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