

## Information for parents When your child has no diagnosis



## About this publication

This booklet is for parents with young children with additional support needs where no diagnosis has been made and there is no obvious cause for the difficulties that a child experiences.

It was developed by the [Early Support](#) programme in partnership with [Contact a Family](#) in response to requests from families, professional agencies and voluntary organisations for better, standard information and it reflects what parents who have 'been there before' say they would have liked to have known in the early days of finding out about their child's situation.

To find out more about [Early Support](#) visit [www.earlysupport.org.uk](http://www.earlysupport.org.uk)



*'All the time you keep hoping that the doctors can say what is wrong and that there is something they can do and your child will suddenly catch up and be able to do all the things that other children do.'*

(Mother)

It's natural that parents want to know the cause of a disability in their child or an identified need for support. Without a clear diagnosis, it can feel like you're in limbo, not knowing what's happening to your child or what the future holds. It can also feel frightening if you don't know how a condition might progress.

It can be very frustrating when a child is referred backwards and forwards between different specialists for more tests and there is still no clear answer to the question, 'What's happening and why?'

## Why is it so hard to get a diagnosis?

There are many things that can cause disability in a child. Difficulties during a pregnancy, prematurity, genetic conditions or trauma during birth itself can all be relevant. In some cases it's impossible to single out a specific cause – especially where children have a range of health problems that do not fit easily into any known **syndrome**. A **syndrome** is a characteristic pattern, or group of symptoms, which often appear in combination with one another.

Some children have a **rare disorder**, which may only affect a handful of other children across the country, or perhaps none at all. It's harder for doctors to diagnose a condition they've never seen before, and where there are very few studies which would make it possible to compare the features of your child's difficulties with other cases. Many conditions have quite similar features and symptoms, which can also make it hard to be specific about your child's particular condition.

Some features may not appear until your child is older, when it will become more obvious that they are affected by a particular syndrome or disorder. More and more syndromes are being discovered each year, so it may be that a diagnosis will be achieved for your child in the future, even if it does not seem to be possible now.

If you feel strongly that all avenues to getting a diagnosis have not been explored, you should certainly discuss this with your child's doctor and request a second opinion. But sometimes everything that can be done has been done and you are still left with no diagnosis.



## Does it matter whether you get a diagnosis or not?

*'I felt that getting a name for our daughter's condition would help us when explaining to others what was wrong, but in the end it didn't really matter. All the professionals involved needed to know was what the immediate difficulties were, so the right care could be arranged.'*

(Mother)

Not having a diagnosis may matter very much to you as a parent and it may matter to your child as they get older, so they can understand **why** they can't walk or see or have an impairment. However, for many practical purposes, it doesn't make any difference whether you have a diagnosis or not. This is because:

- Treatment, therapy or teaching should be tailored to your child's needs, not to the name of their condition.
- You're entitled to have a social services assessment of your child's needs and of your needs as a parent or carer, whether your child has a named diagnosis or not.
- You're entitled to receive benefits such as Disability Living Allowance on the basis of the difficulties that your child has and the support they need. Entitlement does not depend on being able to name the disorder your child has.
- Your child is entitled to have extra or different support to help them at school, if they need it. This does not depend on knowing the cause of their learning difficulties.

Some families are never able to achieve a diagnosis for their child, but as the years go on, some begin to feel that it's not as important to them as it once was.

*'I decided it was time to accept that my daughter is unique. Now I'm not so fixated on the idea of a diagnosis as a solution, I can get on with my life. We just have to deal with each new issue in the best way we can.'*

(Mother)

## Where to get support, if you don't know why your child needs help

*'We use a local group for special needs families, which is excellent.'*

(Father)

Many areas in the UK have a local parents' support group where families of children with all kinds of disabilities come together for mutual support and contact. It might be helpful to find out if there's one near you. Even if you had a diagnosis, it's unlikely that another child in the group would have the same condition. However, a lot of the issues you face on a day-to-day basis will be familiar to other parents and they often have practical advice to share. Local groups have the advantage of meeting regularly and locally, which can be important in providing a support network, if you need one. Another advantage is that other members can pass on information about support and services that are available in your area and that they have already used.



## Voluntary organisations

Voluntary organisations are usually charities that provide help and advice. Find out if there are any that operate locally and what they can offer. Or contact the following national organisations if you are looking for information and help.

**Contact a Family**, the UK charity for families with disabled children, can tell you whether there is a local support group in your area. You can also talk things through with a parent adviser, order free factsheets and find out about the support and help that is available. 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 Helpline: [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)

Web: [www.cafamily.org.uk](http://www.cafamily.org.uk)

**Syndromes without a name (SWAN)**, the support group for families who have a child with an undiagnosed condition. SWAN has information, resources, a newsletter and a helpline, and they can put you in touch with other families where possible.

### **Syndromes Without a Name (SWAN)**

Tel: 01922 701 234

Email: [info@undiagnosed.org.uk](mailto:info@undiagnosed.org.uk)

Web: [www.undiagnosed.org.uk](http://www.undiagnosed.org.uk)

## Early Support

**Early Support** is the central government mechanism for achieving better co-ordinated, family-focused services for young disabled children and their families across England. It is developing at a time of significant change, as part of the re-structuring of children's services in response to *Every Child Matters* and alongside new integrated assessment, information and inspection frameworks for children's services.

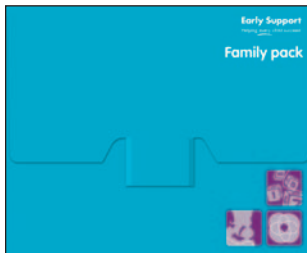
**Early Support** builds on existing good practice. It facilitates the achievement of objectives set by broader initiatives to integrate services, in partnership with families who use services and the many agencies that provide services for young children.

To find out more about **Early Support** programme, associated training opportunities and to view other materials produced by the programme, visit [www.earlysupport.org.uk](http://www.earlysupport.org.uk)

This booklet is one in a series produced in response to requests from families, professional agencies and voluntary organisations for better standard information about particular conditions or disabilities. The other titles in the series are:

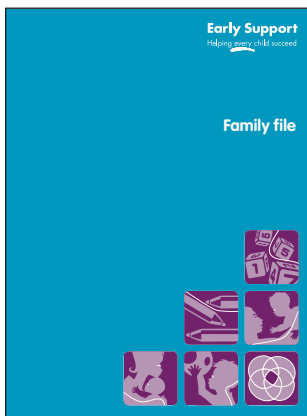
Autistic spectrum disorders (ASD)	(ES12)
Cerebral palsy	(ES10)
Deafness	(ES11)
Down syndrome	(ES13)
If your child has a rare condition	(ES18)
Learning disabilities	(ES15)
Multi-sensory impairment	(ES9)
Speech and language difficulties	(ES14)
Visual impairment	(ES8)





This is the second edition of the booklet, which up-dates information and incorporates comments from those who used the material in 2004-2006.

Other Early Support information about services is available separately, or as part of the [Early Support Family pack](#). The [Family pack](#) (ES1) helps families who come into contact with many different professionals to co-ordinate activity and share information about their child through the first few years of life, using a [Family file](#) (ES5).



To obtain copies of any of the [Early Support](#) materials mentioned here, ring 0845 602 2260 quoting the reference number for the publication.

**Early Support** would like to thank the many families and professionals that have been involved in development of these resources and to thank **Contact a Family** for their help in writing and more recently revising this booklet.

**Contact a Family** provides advice, information and support to families with a disabled child. **Contact a Family** provides advice about financial and practical help as well as information on medical conditions and disabilities. They also put families in touch with others through support groups and one to one linking, assist parents to develop their own support groups and provide a voice to raise awareness and campaign for families.

The **Contact a Family** website contains all publications, also available in paper format, including the *Contact a Family Directory*.

### **Contact a Family**

209–211 City Road  
London  
EC1V 1JN

Tel: 020 7608 8700

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Web: [www.cafamily.org.uk](http://www.cafamily.org.uk)

**contact a family**  
for families with disabled children

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DfES Publications  
PO Box 5050  
Sherwood Park  
Annesley  
Nottingham NG15 0DJ  
Tel: 0845 602 2260  
Fax: 0845 603 3360  
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[www.earlysupport.org.uk](http://www.earlysupport.org.uk)

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**contact** a family  
for families with disabled children

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