

Information for parents

When your child has no diagnosis





'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 nor 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 which can cause disability in a child. Difficulties during the pregnancy can be relevant, or prematurity, or a genetic condition, or trauma during the birth itself. In some cases it's impossible for paediatricians 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 have 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 make it hard to be very 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 still you will be 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, because they are not able to understand **why** they can't walk or see or whatever. However, for many practical purposes, it does not make any difference whether you have a diagnosis or not, for the following reasons:

- Treatment, therapy or teaching will be tailored to your child's needs, not to the name of their condition.
- You are 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 are 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 am 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 is 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 is 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 locally 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.

The Contact a Family website includes an online *directory of rare conditions and syndromes affecting children*.

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

Web: www.cafamily.org.uk

Alternatively, you could contact **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: undiagnosed@clara.co.uk

Web: www.undiagnosed@clara.net

The **Early Support Pilot Programme (ESPP)** is a Government 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. ESPP promotes service development in partnership with health, education and social services, service users and organisations in the voluntary sector. For more information, visit www.espp.org.uk

ESPP 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.

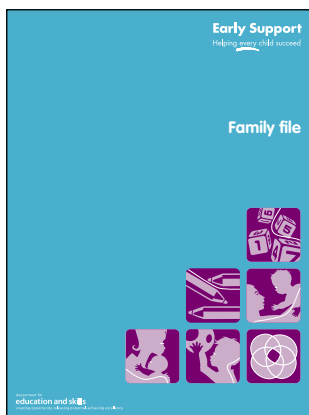
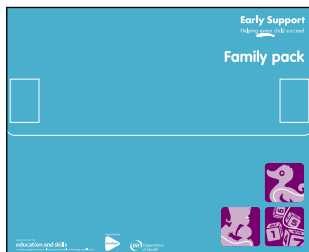
This booklet is one in a series produced by ESPP in response to requests from parents and voluntary organisations for better information for parents. ESPP has produced booklets about a number of disabilities or known conditions and expects to develop more as the programme progresses. The following titles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



ESPP 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.

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

ESPP would also like to thank the **Council for Disabled Children** for their help in writing, consulting upon and producing this resource.

The **Council for Disabled Children** promotes collaborative work and partnership between voluntary and non-voluntary agencies, parents and children, and provides a national forum for the discussion, development and dissemination of a wide range of policy and practice issues relating to service provision and support for children and young people with disabilities and special educational needs.

COUNCIL FOR
DISABLED
CHILDREN

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

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following organisation in the production of this resource.

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