

Information for parents

When your child has no diagnosis



About this publication

This is a guide 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 in co-operation with families and this edition is an updated version based on the original information for parents booklet 'When your child has no diagnosis', adapted by kind permission of **Early Support**, a UK government initiative. It was originally developed by **Early Support** in partnership with **Contact a Family**, in response to requests from families, professional agencies and voluntary organisations for better standard information. Families were consulted about the content and the text 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. This updated version of the publication was adjusted by the Early Support Wales team and **Contact a Family Wales** using feedback from parents and practitioners and in response to changes in the Welsh context.

To find out more about **Early Support** and to download copies of other **Early Support** materials, visit www.earlysupportwales.org.uk

Where a word or phrase appears in **colour**, like this, it means either that it is a technical term that is explained in the text around it.

If the name of an organisation appears in **colour**, it means that you can find their contact details at the back of the book.



Introduction

'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)

There are many reasons why children are born with disabilities and/or health needs. These include:

- difficulties during the pregnancy, including infections in the mother
- prematurity
- environmental problems
- genetic disorders
- **asphyxia**, a lack of oxygen, or trauma during or shortly after birth.

If you would like more information about genetic disorders then please refer to part 7 of **Contact a Family**'s 'About Diagnosis' information pack for parents. This is a pack of useful leaflets giving information on various aspects of diagnosis. You can obtain a pack by getting in touch with **Contact a Family** using the contact details at the back of this booklet.

Why do parents feel a diagnosis is important?

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 disorder might progress.

Many parents describe the feeling of frustration when their child is referred from one specialist to another, desperately seeking a diagnosis. Without a diagnosis you may feel unsure about where to get information and support. Finding ways around the 'system' can be confusing and parents often worry that their child will miss out on appropriate services because they don't have a diagnosis.



Why are some disorders so hard to diagnose?

In many cases it is almost impossible for a paediatrician to single out a specific cause, and a child may have a number of problems that do not fit into any one disorder. Sometimes parents who have a child with an apparently obvious disorder can discover that the cause is quite different from what they believed it to be.

There are a number of reasons why making a diagnosis is difficult:

- Doctors are now seeing a large number of children with **rare conditions**, which may only affect a small number of children. It's harder for doctors to diagnose a condition they've never seen before, and where there are very few studies that would make it possible to compare the features of your child's difficulties with other cases.
- Many disorders have quite similar features and symptoms, which can make it difficult to be accurate about a diagnosis.
- Some children will have a number of problems that do not fit into one specific disorder.
- There are substantial variations in the degree to which a child might be affected by a disorder, which might add to the problem of making a diagnosis.
- Certain identifying features may not appear until your child is older; this may result in a late diagnosis or even a change in diagnosis.
- For many disorders we still do not know the cause, and even when children are in the care of the best medical experts, a diagnosis is not made.

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. However, sometimes everything that can be done has been done and you are still left with no diagnosis.

New syndromes are being identified

Another factor that contributes to the difficulty of diagnosis is the large number of syndromes that are being identified. Parents who have been told previously that their child simply has developmental delay may be presented with a different number of syndromes suggested as possible diagnoses. This can raise hopes of a precise diagnosis, but it can still take some time to find the right specialist.

'I'm tired of having to explain to people that my child isn't naughty but has an unnamed condition' (Mother)

Does it matter whether you get a diagnosis or not?

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 are different. 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 disorder.
- 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. Find out more about this in the [Early Support background information booklet on Financial help](#).
- 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.



The Equality Act 2010 protects young children without a diagnosis who require care and additional support. You should be able to receive exactly the same support for your child as a child with a diagnosis. Legal jargon and technical language in documents that outline your rights can be confusing. If you have any questions about your child's entitlement to care and support, please ring the **Contact a Family** helpline (contact details at the back of this booklet).

'I decided it was time to accept that my daughter is unique. Now I'm not as 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)

A diagnosis may not be needed for treatment

It is not always essential to know the cause of a disability or condition to treat its symptoms. Many aspects of a disorder with or without a diagnosis can be treated to a high standard and individuals lead a good quality of life.

'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)

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.



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 disorder. 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 organisation if you are looking for information and help.

Contact a Family Wales

Contact a Family provides support, advice and information for families with disabled children, no matter what their disorder or disability. **Contact a Family** provides advice about financial and practical help as well as information on medical disorders 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.

Information for parents
When your child has no diagnosis

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

Contact a Family Cymru

33-35 Cathedral Road
Cardiff
CF11 9HB

Helpline: 0808 808 3555

Tel: 029 2039 6624

Web: www.cafamily.org.uk

Email: wales.office@cafamily.org.uk

Syndromes without a name (SWAN UK)

The UK 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.

Tel: 020 7704 3141

Email: SWAN@geneticalliance.org.uk

Web: www.undiagnosed.org.uk

Twitter: twitter.com/SWAN_UK

Facebook: www.facebook.com/SWANchildrenUK

About Early Support

Early Support in Wales is the Welsh Government's mechanism for achieving better co-ordinated, family-focused services for young disabled children and their families across Wales.

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** and associated training opportunities and to view or download other resources produced by the programme, visit www.earlysupportwales.org.uk

This information resource 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 and related conditions
- Behaviour
- Cerebral palsy
- Deafness
- Down Syndrome
- If your child has a rare condition
- Learning Disabilities
- Multisensory impairment
- Neurological disorders
- Sleep
- Speech, language and communication needs
- Visual impairment

Other Early Support information about services is available separately. To download any of the **Early Support** materials mentioned here, see www.earlysupportwales.org.uk

Contact a Family provides support, advice and information for families with disabled children, no matter what their disorder or disability. **Contact a Family** provides advice about financial and practical help as well as information on medical disorders 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 Cymru
33-35 Cathedral Road
Cardiff
CF11 9HB

Helpline: 0808 808 3555
Tel: 029 2039 6624

Web: www.cafamily.org.uk
Email: wales.office@cafamily.org.uk

Copies of this resource can be
downloaded from
www.earlysupportwales.org.uk

© Crown copyright 2013

Please quote ref: ESW/31/03/13

Extracts from this document may be
reproduced for non-commercial
education or training purposes on
condition that the source is
acknowledged.

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

contact a family
for families with disabled children



Llywodraeth Cymru
Welsh Government