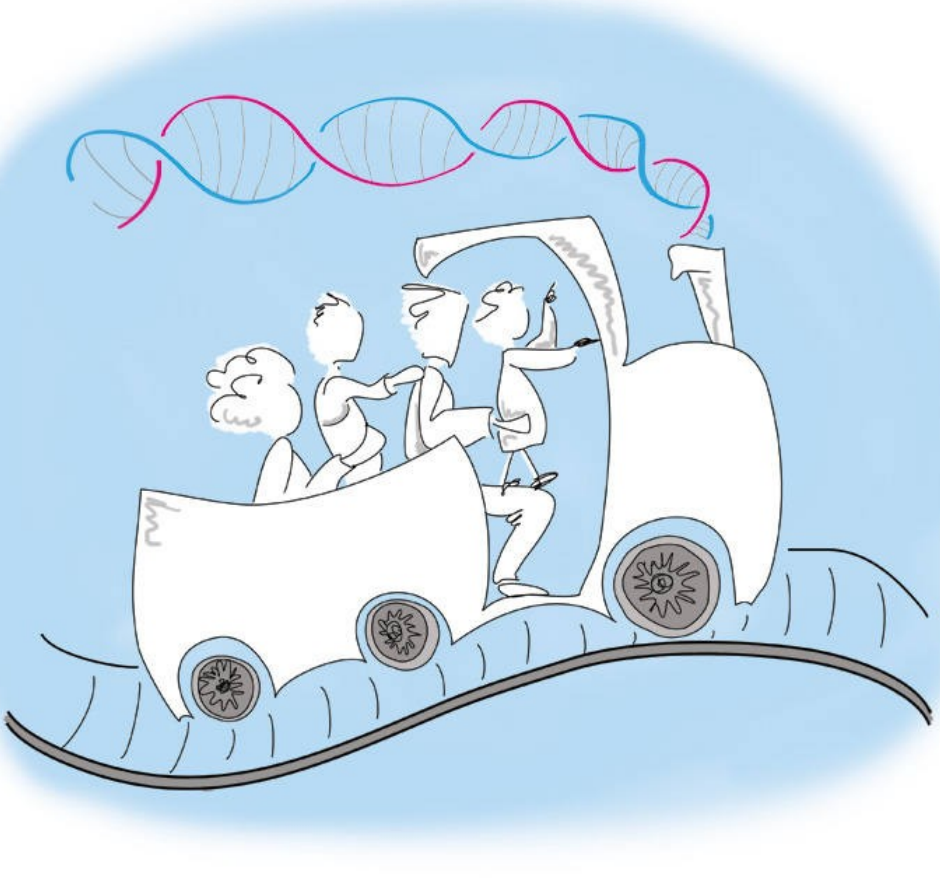
Living Without A Diagnosis



Information for Parents, Carers and Families

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Information For Parents

What is this booklet about?

There are some children who have learning difficulties or health problems, and no-one can explain the cause of these problems. If you are the parent of a child without a diagnosis, this information booklet has been written for you. It is designed to help answer some of the questions you may have. We also give you some ideas of helpful things you might do as a parent and talk about some of the experiences other parents have had. Unfortunately, it won’t be able to give you a diagnosis for your child.

“We have got no diagnosis, she is just Lisa, she is just unique. But to be honest with you, we get so much enjoyment out of her it totally outweighs any problems.”

How common is it not to have a diagnosis?

Even though most people do not realise it, having an ‘undiagnosed condition’ is actually quite common. For example, it is thought that about half (50%) of children with learning difficulties have no definite diagnosis. Even without a diagnosis, children are still entitled to receive healthcare, education, benefits and services that are appropriate to their particular needs. Not having a diagnosis should not stop a child from reaching their full potential.

Why are some conditions difficult to diagnose?

There are a number of reasons why making a diagnosis is not easy:

- Sometimes children have a number of different problems that do not all fit into one specific recognised condition.

- Many conditions have similar features and health problems, which makes it difficult to be accurate about a diagnosis.

- Certain conditions are so rare that it can be difficult for doctors to identify the condition.

- The same condition may affect children in different ways, which can add to the problem of making a diagnosis.

- Some features of the condition may not appear until later on in the child's life. This may cause a delay in getting a diagnosis, or in some cases a change of diagnosis.

(taken from Contact a Family, ***About Diagnosis***)

Doctors are now able to diagnose more conditions than ever before due to advances in our knowledge, and improvements in testing techniques and medical equipment. Some of these conditions will be genetic, (caused by mistakes in the "blueprint" of information we get from our parents), others will be the result of problems at birth or infection during pregnancy or in the first few years of life. However, because of improvements in science, there may be an expectation that doctors can always find a diagnosis. If they can't, it can be extremely disappointing and confusing for parents.

It is worth remembering that, even if your child does not have a diagnosis now, advances in medical knowledge and testing techniques mean that there may be an explanation for your child's problems in the future

Living without a diagnosis: the experience of other parents

"If you have a diagnosis you're on some sort of track. Without a diagnosis it feels like you're lost in a swamp."

To help us write this booklet, we spoke to a number of parents of children who have no diagnosis. Hearing other people's stories can be very helpful. They also show you that you are not alone! We have included many of their experiences, some of which may be of interest to you. Parents also gave some suggestions of useful things you can do as a parent, and these have also been included in this booklet.

The emotional impact

Finding out a child is not developing as expected was, as expected, a very worrying and anxious time for some parents. Parents described feeling alone, angry and sad, particularly because their child was not the 'problem-free' child for whom they had hoped.

Waiting for the results of tests was also stressful, and it was disappointing and frustrating when the results did not give any definite answers. Some women said that when they first found out there was a problem they were worried that it may have been their fault, or something they had caused whilst they were pregnant. However, the reality is that these things are rarely anyone's fault. In most cases these things just happen, and there is no way that the parents could have changed the outcome.

Some parents said that not having a diagnosis made them feel out of control of the situation. They were unsure whether they would ever get a diagnosis and they didn't know what the future would hold for either them or their child. Without a 'name' for their child's problems, they were unable to search for information. This was very frustrating.

“I don’t know what is going to happen to him in the future and that is the worst thing I think, the ‘not knowing’.”

“ I think parents need to know that it is OK to feel resentful, angry and negative at times”

Parents often used the term ‘emotional rollercoaster’ to describe the day-to-day experience of looking after a child with a disability. At times it can be isolating, difficult and frustrating, but there was also an overwhelming sense of love and admiration that parents had for their child.

“She’s so lovable. She makes me smile, she makes me glow. I just love her to bits.”

Advice from parents

- Try to enjoy your child. It is easy to focus on all their problems and forget to enjoy watching them grow up.

- Once you accept your child for who they are, your life becomes easier.

- Talk to other parents in a similar position, such as members of the SWAN (Syndromes without a Name) support group, as they are likely to understand what you are going through.

- Don’t compare your child to other children of the same age, or how your other children were at that age, as this can be upsetting. Every child is different.

- Try not to focus on the milestones your child has not reached. Focus on those that they have.

- Try not to worry too much about the future. Try to focus instead on dealing with each day at a time.

- Raising a child with a disability can be hard work, both physically and emotionally. Don't be afraid to ask for help, and take help when it is offered.

- Having someone you can really talk to and who is not emotionally involved (such as a counsellor or health visitor) can be a great help, even if they don't have all the answers.

- For peace of mind, try to be as organised as you can. You might want to put certain procedures in place, for example organising your will.

- It's easy to forget to look after yourself when you are looking after a child with a disability. Take time out every once in a while; go out with friends; look after your health.

"People kept saying to me 'just enjoy him because they grow up so quickly', and I do feel that we didn't enjoy him as much because of all the anxieties that we had about what was going to happen. If it was to happen over again I'd definitely say try and put that to the back of your mind and just enjoy who he is."

"As much as you think you are coping, take a step back and say, well, perhaps I need help with this or that. Don't be afraid to ask for help. It doesn't make you any less of a parent."

How important is a diagnosis?

Whilst all the parents that we spoke to said that they would like a diagnosis, over time parents had found that getting a 'name' was not as important as it had been at first. For most parents, the priority was ensuring that the day-to-day issues related to their child's condition were met. Many said that, even with a diagnosis, they would still have to explain what the diagnosis meant, particularly to people who did not work in genetics or medicine. For many parents, getting a diagnosis was just something that 'would be nice to know'.

“Even if we had a diagnosis, he’s still Charlie to me. It’s not going to change him, not going to change him in the slightest.”

At Genetic Alliance UK, (a patient organisation supporting individuals and families affected by genetic disorders), we speak to patients and families every day who are living with both diagnosed and undiagnosed conditions. We find that they all face similar challenges accessing services and raising a child with a disability. Sometimes, even with a diagnosis, it can still be difficult to know what the future holds.

“He’s inspiring sometimes as to how loving and gorgeous he is to other children his own age. He’s so affectionate. There are just things to do with his syndrome that make him special. He’s just a gorgeous little boy.”

Doctors and specialists

Going to lots of hospital appointments and seeing different specialists was a frustrating and time-consuming experience for some parents. Often, a number of different specialists were involved in their child’s care, and children were often referred from one specialist to another as the search for a diagnosis continued.

One issue that parents found particularly frustrating was the frequency with which they have to repeat their child’s ‘life story’, including a history of all the symptoms, tests and the specialists they had seen. It can be even more frustrating when you don’t have a diagnosis because you do not have a ‘label’ that summarises all your child’s problems. Whilst repeating this information every time you see a new specialist is understandably frustrating, in most cases it is necessary because there will be very specific things the specialist is

interested in finding out that relate to his or her particular speciality.

“If you are able to go in and say, ‘He’s got so and so disease’ then they go ‘Okay that is fine’, but you can’t. You have to go back from birth when you were first told, and explain the whole thing.”

If you feel like you are continually having to repeat your story and you need additional support, you can ask someone working with your child to complete a Common Assessment Framework (CAF). This will identify your child’s needs and what needs to be done to meet these. After a CAF has been completed there will usually be a multi-agency meeting so all the professionals involved can ensure they are working effectively together.

Parents also found that sometimes communication between different specialists was not as up to date as it should be. Many had taken an active role in keeping their GP and other specialists such as their paediatrician and geneticist up to date with any tests done, results given or specialists seen.

“I carry all the letters I’ve received from the paediatric consultant and geneticist to every appointment, and sometimes those letters haven’t yet been put on file. Sometimes I have to pull out the letter and show it to them.”

Some parents found that the lack of information, particularly about their child’s future development, was very frustrating. However, it’s worth remembering that it is also frustrating for your specialist. They too will want to find a diagnosis for your child’s condition. Yet even without a diagnosis, specialists will still be able to offer treatment and support that is tailored to your child’s needs.

Remember that you are ultimately the expert in your child’s condition. If there are developments in your child’s condition, or if new milestones are reached, you should keep a record of these to discuss with the specialist at your next appointment.

Advice from parents

- Take a notebook to all your appointments so you can make a note of anything you think is important. If there is a word you don't understand, ask the doctor to write it down for you so you can come back to it later or discuss it with other professionals.

- Make sure you receive copies of all the letters sent by different specialists, to ensure you are kept up to date.

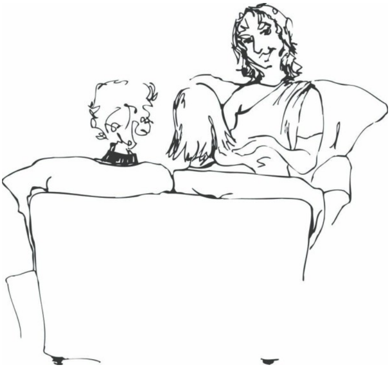
- Take responsibility for ensuring that all the different specialists, including your GP and healthcare worker, are kept up to date of any appointments and developments.

- Keep a paper trail. Keep copies of all letters, appointments, test results, etc. in a folder.

- Keep a record of your child’s progress. Keep a diary; take photos and videos if possible. As well as being a useful record to show to doctors, it can also be comforting to look back and see the progress your child has made.

- Create a ‘passport’ for your child. This can be a series of flashcards that explain things such as what your child can and cannot do, what they like/dislike, any health problems they have etc. These can be taken to appointments and are a quick way of passing on information about your child.

- If you feel that you need to see a specialist, or if you think you may have somehow got ‘lost in the system’, don’t be afraid to phone and find out. Ask to speak to the doctor’s secretary to find out what is happening with your child’s appointment.



- Whenever you think of a question that you want to ask the specialist, write it down immediately so you don't forget it. A number of parents, for example, kept a note-pad handy on their fridge, to jot down their questions.

- Don't be afraid to ask your specialist questions that are concerning you, however silly or insignificant you think they may seem.

- Take someone else with you to your appointments as a 'second pair of ears'. This person can take notes of the discussion you have with the specialist. These can be a great help later on when you try to remember what was said.

- If possible, try to stick with the same professionals so you don't have to keep repeating your child's life story.

Other services and professionals

Many parents found that their health visitor was a good source of information and support. A health visitor is a qualified and registered nurse or midwife with a specialist qualification in Community Health who visits families with children up to the age of five, at their home. Parents found that their health visitor:

- Provided useful information about their child's growth and development.

- Organised referrals, if necessary, to specialists such as community paediatricians and speech and language therapists.

- Provided information about local services such as special needs nurseries, and had knowledge about issues such as disability benefit.

- Provided emotional support, particularly to parents who were concerned or anxious about their child, or were finding it difficult to cope.

"In my case the health visitor has been a very good 'rock' in this whole process. I think also that is part of her job, to support us as a family and me as a mother."

There were a number of other professionals with whom families had come into contact and found helpful. These included:

- The **social worker** – can provide an assessment of your child's needs, which can lead to support and services for you and your child, and advise you about financial benefits to which you may be entitled.

- The **housing officer** – works for a housing association or local council. Your housing officer may be able to provide you with information about housing benefits and entitlements, including home adaptations and facilities.

- **Children's centre / nursery / play group staff** – help with activities to encourage your child's development and have useful information about local schools in the area.

- The **key worker** – a health professional or social worker who supports families and co-ordinates services, often for children with complex needs. These services can be involved from birth.

- The **occupational therapist** – can advise on equipment for daily living and managing more easily within the home.

- The **speech and language therapist** – assesses and treats speech, language and communication problems to enable people to communicate to the best of their ability. They may also work with people who have eating and swallowing problems.

- The **clinical or educational psychologist** – can assess whether a child has learning difficulties.

- The **physiotherapist** – advises and helps with exercises to improve mobility and coordination.

Certain professionals, such as the speech and language therapist or physiotherapist, will offer you advice and put programmes into place that will help with your child’s development. Attending appointments and seeing professionals is only one aspect of your child’s care. As your child’s main carer, it will be up to you to make sure you follow their advice on a day-to-day basis.

Some of the parents we spoke to found they had to be persistent in order to access services or get appointments. Other parents said that it was a ‘battle’ just to find out about the help and services that were available. Some parents said that they had to learn to be ‘pushy’. Unfortunately, this is often the reality of caring for a child with a disability, particularly when they have a number of health-related or developmental problems. However, the professional team around you (such as your health visitor or social worker, paediatrician or geneticist) should help you to navigate your way through the system and ensure you receive an effective service.

Parent support groups and charities may also be able to provide you with information and support. In addition, all councils now have a Family Information Service that provides information, advice and guidance to parents and carers on childcare and early years services in the local area. Their contact details are listed in the Contacts section at the end of this leaflet.

Another issue parents frequently raised was the amount of paperwork that needed to be completed to access certain services or benefits, and the amount of time this took. Some parents said that their housing officer or social worker helped them to complete these forms. Others had found voluntary organisations (such as the Citizens Advice Bureau) that were willing to help with this work. If you are having trouble filling out these forms, try to find someone who can take the time to help you.

Advice from parents

- Don't be afraid to chase things up and be persistent.
- Be aware of all the services and benefits that are available to you. Ask the professional team around you to provide you with this information.
- Find out about the local services in your area such as special needs nurseries, short break (respite) services or local parent support groups.
- Other organisations such as patient support groups, charities, the Citizens Advice Bureau (CAB) and other parents are also a good source of information.
- If you feel you can't cope with the number of appointments you have to attend, you can always speak to one of your specialists or your key worker about pushing back some of your appointment dates. It is very important for you and your child not to feel overwhelmed.
- Not having a 'name' for your

child's condition can make it difficult when filling out forms. You find you end up writing 'undiagnosed condition'. Having a letter from your consultant that explains what this means can be helpful.

"My health visitor came round with all the forms and she said, 'this is disability benefit, I'm sure you can claim this'. And she gave me these claim packs and I thought, 'well I'll just fill them out and see'. And then all of a sudden I got this letter through saying, 'you're entitled to full disability benefit', so that wasn't a problem. I mean I didn't even know about disability benefit until the health visitor brought the form round."

Education

Getting the right school for their child was one of the most important issues for parents. There were a number of things that parents had to think about when deciding which school was best for their child. These included the educational needs of the child, and whether mainstream schools in the area were able to cater for their child's educational or physical needs. Some children were in local mainstream schools, some were in schools for children with special needs, and some were in a 'dual placement' system which meant that for some of the week the child was educated at a mainstream school and for some of the week in a school specifically for children with special needs.

A number of parents commented that choosing a school was an anxious time. For some parents, the reality that their child needed extra assistance in class, or was best placed in a school for children with special needs, was hard to come to terms with. However, many parents whose children had started school made positive comments about the attention and support their child received.

"When we went to the school we said, 'we have got no diagnosis, she is just Leah, she is just unique'. They said, 'fine,

this is what we have, this is what we can do for her', so they were absolutely brilliant and they still are brilliant."

Your health or social worker, or staff at your child's pre-school or nursery, should be able to offer you advice about the options in your area. In addition, you may want to go and look at different local schools and speak to the staff to find out which would be most appropriate for your child's needs. Most schools nowadays have a Special Educational Needs Co-ordinator (SENCO) who should also be able to offer you advice.

Special Educational Needs assessments

A number of the parents we spoke to in England had gone through the process of applying for an assessment of special educational needs from their local education authority (LEA). This was because it was felt that the local nursery or mainstream school was unable to meet their child's educational needs.

An assessment is carried out by the LEA to find out about a child's difficulties and agree upon the extra help they need. As a parent you have the right to request this directly from the LEA. Those children with the greatest learning difficulties receive a statement of special educational needs (usually just called a Statement). A Statement describes the special educational help a child must be given by law. Applying for an assessment can be a long and difficult process, particularly when you do not have a diagnosis. However, the professional team around you will be able to help you.

England, Wales and Northern Ireland each have their own Code of Practice for Special Educational Needs. Links to additional information about educational support is provided in the Education section at the end of this booklet.

In Scotland the system is slightly different and children with complex needs require a co-ordinated support plan (CSP). Professionals and parents are entitled to ask the education authority for a CSP, and once requested the education authority have 4 weeks to decide whether or not to prepare a plan.

If you feel that your child’s educational needs are not being met, speak to your child’s teacher or special educational needs co-ordinator (SENCO). You may also find it helpful to talk to local and national voluntary organisations (see the Education section at the end of this booklet) or your local Parent Partnership Service.

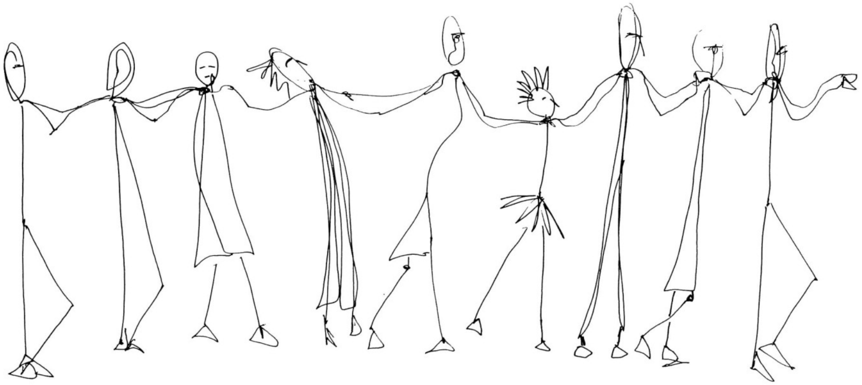
Parent Partnership Services

Parent Partnership Services are local organisations that offer free information, advice and support to parents and carers of children and young people with special educational needs. They can also offer support in preparing for and attending meetings, help in filling in forms and writing letters, and in resolving disagreements with your child’s school and the local authority.

For further information about your local Parent Partnership Service (National Parent Partnership Network), see the Education contact details provided at the end of this booklet.

Advice from parents

- Visit the nurseries and schools in your area and speak to the teachers, before making a decision about which is



best for your child.

- Order a copy of the SEN Code of Practice. Its free to download from the Department for Education (the link is in the Education section at the end of this booklet).

- Applying for a statutory assessment can be a long and complicated process. If you are going to apply, it's a good idea to know as much as possible about the process beforehand.

Family

Raising a child with a disability can cause a strain on relationships. Some of the parents we spoke to said they argued more as a result of the stress and worry of looking after a child with a disability.

"I think you have to stop and say, 'I need to take time out for myself and my relationship'. I think in that we've suffered because we didn't have time for each other."

Parents can have different ideas about what's best for their child. Often it is the mother who attends all of the appointments, and the father can feel uninvolved. Many couples emphasised the importance of being supportive of each other and communicating about issues such as what happened at an appointment, so that both parents feel involved in their child's care. It's also important to accept help, - either from friends, family or short break (respite) services, so that you and your partner can have time together, even though it can be quite daunting at first to let someone else look after your child.

"We felt really guilty sending the girls somewhere so we could have a break. But you need to accept all the help and support you can get in order to keep on top of things."

Since 2011, local authorities have a general duty to provide a range of short breaks to parents of children with special needs in their area. Access to these services vary, so speak to a professional involved with your child's care to see if this service is available to you.

For single parents the experience can be very lonely. Many parents turned to family members and friends for support.

"I think my dad took on the dominant, father role. He used to come round a lot and help me cope."

Parents who had more than one child often described feeling guilty for being unable to provide the same amount of attention to all their children. They worried that siblings would feel they were not as loved as their brother or sister. Growing up with a brother or sister who has some kind of disability and who needs more attention, can be very hard for children. However, some parents were surprised at how affectionate and supportive siblings could be.

"She just likes to be involved, she wants to help him. She is perfectly aware of the fact his eyes don't work properly and that he needs extra help, and all she is concerned with is, is he okay, and making sure nobody is mean to him."

There may be specific support projects in your area for siblings of disabled children. These are worth looking into.

Advice from parents

- Explain the situation to siblings, taking into account their age and maturity level.

- It is important to try to take time out once in a while to spend with other siblings.

- It is a good idea to find a term such as 'developmental delay', or 'SWAN

child' (**s**yndrome **w**ithout **a** **n**ame) that describes your child's condition. This can be helpful when explaining your child's disability to other people (such as friends and other parents). Ask your healthcare specialists to help you come up with a term that best describes your child's disability.

"That's hard, sharing yourself, that is really hard. But I will say always make time for your other children, because otherwise that can have a bad knock on effect."

Future children

Many parents of children with undiagnosed conditions want to have more children, but feel concerned that a future child may have the same health and developmental problems as their affected child. If parents feel that they would like to try for another baby, it would be important for their undiagnosed child to be seen for a review by a geneticist. As genetic testing has improved a great deal in recent years, there may be new tests that could throw more light on the cause of the child's problems. For example, there have been many recent advances in testing for chromosome abnormalities on a blood sample. If such an abnormality is discovered in an undiagnosed child, it can not only provide an explanation for the child's problems but can also give information about the possibility that the same problems may occur in a future child. It may also be possible to offer the parents the option of a specialised test in a future pregnancy.

Even if a child has seen a geneticist for an up-to-date review, they may still remain undiagnosed. If this is the case, often the best a geneticist can do is give the parents what is called an "*empirical*" risk. This means that the geneticist relies on his or her experience and medical reports of other undiagnosed children with a similar set of problems in order to give an *estimation* of the recurrence risk for a future child. Empirical risks are really a "best guess", but a guess made with a great deal of thoughtful medical experience.

If you are thinking of having another child, and it has been a year or more since your undiagnosed child saw a geneticist for an assessment, then it is often worth getting your GP or paediatrician to refer your child to a geneticist for re-assessment and an up-to-date opinion.

Information and support

It’s natural to want to find out as much information as possible about your child’s disability. Parents used a number of different methods to find information. Some looked on the internet, others used chat forums to speak to other parents, and some contacted patient support groups.

Even without a confirmed diagnosis, you may still be able to find a lot of useful information from patient support groups and other parents who have a child with similar symptoms, particularly about the day-to-day issues of caring for your child. There are a number of parent groups that can help put you in touch with other families. The support group for parents of children without a diagnosis, SWAN UK, has recently been re-established. Their contact details are listed at the end of this booklet. There may also be other charities and support services in your area that can provide short breaks (formerly known as respite), help you fill out forms, and provide other forms of support and information for you and your child.

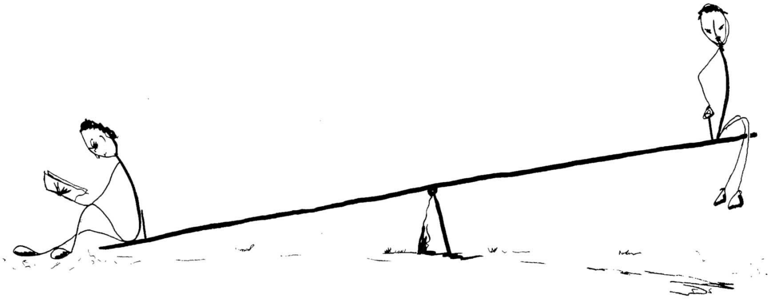
“If you go to these parent chat rooms, all the trivial things that are actually quite big things as a parent, you can resolve quite happily and quite easily because other people have been through it, or are in the same boat as you. It is nice to know that you are not the only one, it is not a stupid question and you don’t actually have to go to the doctor to ask.”

Whilst the internet can be a great source of advice and information, some parents found that it was easy to scare themselves by looking online. In addition, not all the ‘medical’ information found on the internet has been verified by medical professionals and may not be correct. This is something you should be aware of.

"There is a certain level of 'ignorance is bliss'. I do regret trawling the internet to find out about the things that she had listed down as possible syndromes. It just meant eight to ten months of complete worry."

Advice from parents

- Be careful of the information you read on the internet. It can be very easy to scare yourself.
- Parent support groups and chat forums can be good sources of information, particularly about the 'day-to-day' issues of caring for your child, with which your specialist may not be able to help you.
- Find out about local services in your area. Your council's Family Information Service can be a valuable source of information about local services.
- Having a computer and being able to access the internet can be very helpful. Being able to do your shopping on-line, for example, can make life much easier.



Charities, support groups and other useful information services

General

Contact a Family
UK-wide charity that provides support, advice and information for families with disabled children, no matter what their condition or disability. They also put families in contact with other families who are affected by the same or similar disabilities or medical conditions.
Free helpline: 0808 808 3555
Email: helpline@cafamiliy.org.uk   Web: www.cafamily.org.uk

Citizens Advice Bureau
Gives free, confidential information and advice to help people with their money, legal, consumer and other problems across the UK.   Web: www.adviceguide.org.uk

Carers UK
Offers information and advice to carers of children and adults with disabilities.
Tel: 020 7378 4999
Email: info@carersuk.org   Web: www.carersuk.org

Directgov
Government website providing easy access to government information and services. Has information about education, carer advice, benefits and financial support. Also has a link to local councils throughout the UK.   Web: www.direct.gov.uk

Every Child Matters
Programme set up by the Department for Children, School and Families which has a useful website providing information on early years and childcare, health and education for children. Particularly useful information can be found on the following pages:
Web: www.dcsf.gov.uk

www.dcsf.gov.uk/everychildmatters/earlyyears/

www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/AHDC/

www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/earlysupport/home/

www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/earlysupport/resources/esresources/

Every Disabled Child Matters
Campaign and lobbying organisation to get rights and justice for every disabled child.
Web: www.edcm.org.uk

Family Information Service
Provides information, advice and guidance to parents and carers on childcare and early years services in the local area.
Tel: 0207 953 4085   Web: www.nafis.co.uk

NHS Direct
Provides health information and advice.
Helpline: 0845 4647
Web: www.nhsdirect.nhs.uk

Support groups

Ableize
UK and Ireland information resource run by people with disabilities. Offers information on mobility, and provides information, support and advice.
Web: www.ableize.com

Afasic – speech, language & communication
UK charity helping children affected by speech, language and communication impairments, and their families.
Helpline: 0845 355 5577   Web: www.afasic.org.uk

Changing Faces

Charity supporting people who have disfigurement of the face or body from any cause.

Tel: 0845 4500 275 Web: www.changingfaces.org.uk

Genetic Alliance UK

Provides information about specific genetic conditions and contact details of support organisations across the UK.

Tel: 020 7704 3141
Email: mail@geneticalliance.org.uk
Web: www.geneticalliance.org.uk

Kith and Kids

Kith and Kids' overall aim is to empower families living with disability to overcome their social isolation and access the services they need.

Tel: 020 8801 7432
Email: projects@kithandkids.org.uk
Web: www.kithandkids.org.uk

Mencap

UK charity supporting people with learning disabilities.

Helpline: 0808 808 1111
Email: help@mencap.org.uk Web: www.mencap.org.uk

National Autistic Society

Information and support for people with autism and their families.

Helpline: 0845 070 4004 Web: www.nas.org.uk

SIBS

UK charity for people who grow up with a disabled brother or sister.

Tel: 01535 645453 Web:www.sibs.org.uk

SWAN (Syndromes Without A Name) UK

Organisation offering support and information to families with children who have undiagnosed genetic conditions. They also enable families to contact other families through their blog, Facebook and a quarterly newsletter.

Tel: 020 7704 3141 ext.110

Email: SWAN@geneticalliance.org.uk
Web: www.swanuk.wordpress.com
Facebook: www.facebook.com/SWANchildrenUK

United Response
Supports people with learning disabilities, mental health needs and physical disabilities to live in the community, across England and in Wales.
Tel: 020 8246 5200
Email: info@unitedresponse.org.uk
Web: www.unitedresponse.org.uk

Unique
The Rare Chromosome Disorder Support Group.
Tel: 01883 330 766
Email: info@rarechromo.org
Web: www.rarechromo.org

Education

Advisory Centre for Education (ACE)
A national charity that provides advice and information to parents and carers on a wide range of school-based issues including special education needs.
General helpline: 0808 800 5793
Exclusion helpline: 0808 800 0327
Web: www.ace-ed.org.uk

Department for Education
Web: www.education.gov.uk

Link to SEN Code of Practice:
www.education.gov.uk/publications/standard/publicationDetail/Page1/DfES 0581 2001

Independent Panel of Special Education Advice (IPSEA)
Provides free education advice and representation for parents of children with special educational needs and disabilities in

England and Wales.
Tel: 0800 0184016 Web: www.ipsea.org.uk

National Parent Partnership Network (NPPN)
Your local authority will have a parent partnership service. They offer free, confidential and impartial information, advice and support to parents and carers of children and young people with special educational needs (SEN). They can give you advice about statutory assessments, statements, SEN Code of Practice, your rights and responsibilities and who you can talk to about any concerns you may have about SEN.
Tel: 020 7843 6058
Email: nppn@ncb.org.uk Web: www.parentpartnership.org.uk

Portage
A home-visiting educational service for pre-school children with additional support needs and their families.
Tel: 0121 244 1807
Email: info@portage.ork.uk Web: www.portage.org.uk

Special Educational Needs and Disability Tribunal (SEND)
Parents whose children have special educational needs can appeal against decisions made by local education authorities in England about their children's education.
Tel: 0870 241 2555 Web: www.sendist.gov.uk

Special Education Needs Tribunal for Wales
The equivalent body in Wales. Tel: 01597 829 800
Web: www.wales.gov.uk/sentwsub/home/?lang=en

Additional Support Needs Tribunal for Scotland
The equivalent body in Scotland. Tel: 0845 120 2906
Web: www.asntscotland.gov.uk/asnts/141.html

Education Support for Northern Ireland
The equivalent body in Northern Ireland.
Tel: 028 3751 2383
Web: www.education-support.org.uk/parents/special-education/sendist

The Children's Legal Centre
Provides legal advice, information and representation for children and young people who are involved in a dispute with a school or local authority.
Free Child Law helpline: 08088 020 008
National Education helpline: 0845 345 4345
Email: clc@essex.ac.uk Web: www.childrenslegalcentre.com

Finance, benefits, equipment and holidays

3H Fund
A charity that makes it possible for disabled people and their carer or family to have memorable and fulfilling holidays.
Tel: 01892 860 219
Email: info@3hfund.org.uk Web: www.3hfund.org.uk

Caudwell Children
Provides direct donations for treatment, therapy and specialised equipment.
Tel: 0845 300 1348
Email: charity@caudwellchildren.com
Web: www.caudwellchildren.com

Children Today
Raise funds to provide special equipment for children and young people throughout the UK.
Tel: 01244 335622
Email: info@childrentoday.org.uk
Web: www.children-today.org.uk

Dream Makers

A national children’s charity sending sick and disabled children on dream holidays as well as providing equipment.
Tel: 0121 711 8982
Web: www.dreammakerschildrenscharity.com

Disability Alliance UK

Provides information on social security benefits and tax credits to disabled people, their families and carers.
Tel: 020 7247 8776 (not an advice line)
Email: office.da@dial.pipex.com Web: www.disabilityalliance.org

Disability Benefits Helpline

Offers advice on Disability Living Allowance and Attendance Allowance.
Helpline: 08457 123 456
E mail: DCPU.Customer-Services@dwp.gsi.gov.uk
Web:www.dwp.gov.uk/about-dwp/customer-delivery/disability-and-carers-service/

Family Fund

Helps families with severely disabled children by providing grants for things that make life easier and more enjoyable for the disabled child and their family, such as washing machines, computers and holidays.
Tel: 0845 130 4542
Email: info@familyfund.org.uk Web: www.familyfund.org.uk

Newlife Foundation for Disabled Children

Charity providing equipment to help individual children. Also provides a nurse service that offers support and advice.
Tel: 01543 468 999 Nurse service: 0800 902 0095
Email: info@newlifecharity.co.uk
Web: www.newlifecharity.co.uk

Pearson's Holiday Fund

Provides grants that financially assist disadvantaged children and young people (between 4 and 16 inclusive) in the UK to have holidays or take part in respite activities.
Email: general.secretary@pearsonsholidayfund.org
Web: www.pearsonsholidayfund.org

The Aidis Trust

Helps people with disabilities make the best use of information and communication technology by giving information, help and support on all aspects of disability computing.
Tel: 0207 426 2130
Email: info@aidis.org Web: www.aidis.org

Whizz Kidz

Charity giving disabled children the chance to lead more independent lives. Provides mobility equipment, advice and training.
Tel: 020 7233 6600
Web: www.whizz-kidz.org.uk

We are extremely grateful to all the parents who allowed us to interview them during the making of this leaflet.

This information was developed by Genetic Alliance UK, a national alliance of patient organisations which supports children, families and individuals affected by genetic disorders.

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Alliance
UK