

## Support and help for parents and carers

### Support networks

When parents find out that their child has a disability, they usually experience a number of emotions. These may include shock, sadness, worry, anger and confusion. It is important to acknowledge that all these feelings are normal.

For most parents it takes time to accept that their child, and they themselves, may have to face problems they had not envisaged.

It is frequently the unknown, and the feeling of not having control, that parents find most difficult to cope with.



For many parents, seeking support from someone who has been through a similar experience can help enormously. By seeking this kind of support, you should be given some idea of the problems you may have to face, ideas on how to tackle them and a truly understanding support system.

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Part of coming to terms with this situation is accepting that your child may have a different life from the one you imagined. The goals your child will achieve may be different, but nevertheless they will often be very satisfying.

Young Epilepsy National Services can provide information about epilepsy support groups and organisations specifically related to a variety of syndromes. They can be contacted on their helpline 01342 831 342 (Mon-Fri, 9-1) or by email [enquiry@ncype.org.uk](mailto:enquiry@ncype.org.uk)

Contact a Family will put families in touch with other families and local parent support groups. They can be contacted on 0808 808 3555 or online at [www.cafamily.org.uk](http://www.cafamily.org.uk).

Face2face offers a one-to-one befriending service for parents of disabled children. They can be contacted on 0844 800 9189 or online at [www.face2facenetwork.org.uk](http://www.face2facenetwork.org.uk).

Special Needs Kids is a website for parents and carers of special needs children. They provide information about support groups and links to organisations offering advice and information. They can be contacted on [www.special-needs-kids.co.uk](http://www.special-needs-kids.co.uk).

Cerebra offer information and support for parents and carers on any subject relating to caring for a disabled child with brain

related conditions. They can be contacted on their helpline: 0800 328 1159 or you can visit [www.cerebra.org.uk](http://www.cerebra.org.uk).

Sense offers support for deaf/blind people and their families.

Further information can be found at [www.sense.org.uk](http://www.sense.org.uk), or they can be contacted on 0845 127 0060.

## Coping with stress

Having a child with a chronic illness or disability is bound to cause increased stress on parents, siblings and family life in general.

Within a short period of time you will have had to learn an enormous amount about your child's condition and special needs. You will have become the expert and your instinct on what is best for your child cannot be overestimated.

It is likely that you will face many situations where you have to fight for what you believe is right for your child and many parents report that this is the most stressful and exhausting part of having a child with special needs.

Some of the signs of stress are:

- Difficulty in sleeping
- Feelings of anger, fear, helplessness
- Headaches
- Muscular tension, especially of neck and back

How you cope with stress is very important. If it is not managed properly it may lead to health problems in the future.



Try to keep a balance and give time to nurture the other important relationships that you have in your life. This may not be easy, but you need to keep well, both mentally and physically. If you are well, you will be better able to look after your child.

When you feel stressed:

- Take at least 15-20 minutes on your own in a place with no distractions to sit quietly and breathe deeply
- Seek support by surrounding yourself with friends and family whom you trust and who will give you a break when you need it
- Whatever your child's disability, it is very important that you do not convince yourself that you are the only person that can care for them
- Caring for a child with disabilities can be mentally and physically exhausting and all parents need a regular break. If possible, organise respite care on a regular basis
- Take some time for yourself, perhaps think about doing yoga or meditation classes to learn how to relax the body.
- Talk about your situation with someone who has been through a similar experience

- Try and get plenty of sleep and eat a healthy diet
- If possible take up some physical exercise on a regular basis
- Listen to soothing music
- If you feel you need help, seek help from your doctor
- If possible keep a positive frame of mind



## Depression

If you have some of the signs of stress mentioned above and/or some of the following, you may be suffering from depression:

- Persistent feelings of being intensely sad
- A feeling that everything is hopeless
- Despair for the future

Some of the suggestions for coping with stress may help you, but it is important that you visit your GP. Your doctor can advise you on the best course of action – possibly counselling, medication or both.

Counselling gives people a chance to discuss important issues and worries with someone - knowing that everything that has been discussed is strictly confidential.

Many parents find that this can help them to cope with issues that are causing them difficulty, which might not necessarily be just their child's disability.

If your doctor feels that you will benefit from counselling, this can be arranged on the National Health Service or you can have counselling sessions privately.

For information about counselling, and details of local qualified/registered counsellors and psychotherapists visit [www.counselling-directory.org.uk](http://www.counselling-directory.org.uk).

All members in the directory have to provide copies of their qualifications and insurance cover, or must be registered with a recognised professional body.

The Depression Alliance supports a national network of self-help groups and details can be found at [www.depressionalliance.org](http://www.depressionalliance.org).

Help, information and advice on depression can also be found at [www.mind.org.uk](http://www.mind.org.uk) or by ringing their Mind information line 0845 766 0163.

For emotional support and information you can contact [www.sane.org.uk](http://www.sane.org.uk) or call SANEline Tel: 08457 678000 or The Samaritans [www.samaritans.org.uk](http://www.samaritans.org.uk) Tel: 08457 909090.

## Respite Care

Sadly, not all parents get access to respite care because it is such a sought after service. Not only do you benefit enormously from having a break, it also encourages a sense of independence for your child with disabilities. It may also allow your child to take part in activities that are not usually available to them and

give them an opportunity to make new friends.

If you have other children, respite care will allow you to spend time doing some of the things that would not be possible with a disabled child.

Short Breaks Network provides family-based short breaks on a regular basis for disabled children and their families. The length of these breaks can vary from one evening a week to a weekend every month.

They can take place in the homes of trained carers and their families, in your child's own home, or in community settings. [www.shortbreaksnetwork.org.uk](http://www.shortbreaksnetwork.org.uk).

Mencap also provides a helpline with information about respite care for children with learning disabilities. Helpline: 0808 808 1111 or [www.mencap.org.uk/helpline](http://www.mencap.org.uk/helpline).

Special Needs Kids caters especially for parents of children with special needs. Their website lists the respite care centres that can be found in the UK. [www.special-needs-kids.co.uk](http://www.special-needs-kids.co.uk).

SNAP childcare provides experienced nannies, carers, mother's helps and childcare workers for babies and children with a range of additional needs. These needs include mild to severe learning difficulties, autism, challenging behaviour emotional difficulties, physical disabilities and complex medical needs. They also assist families across the UK in particularly difficult situations. Tel: 0207 729 2200 [www.snapchildcare.co.uk](http://www.snapchildcare.co.uk).

Crossroads Care is a national provider of support for carers and the people they care for. They employ over 5,000 trained professionals and can offer a break or

regular support. Tel: 08454 4500 350 or visit [www.crossroads.org.uk](http://www.crossroads.org.uk).

## Welfare benefits

You may be entitled to receive benefits if you have certain costs to meet. You can check whether you qualify to receive financial or other support by using various methods.

Welfare rights officers, also known as welfare benefit advisers or advice workers, will be able to provide you with information and advice about any benefits to which you are entitled. They should also be able to explain benefit rules and help you fill in the relevant forms to apply for benefits or tax credits. Your child's social services department should be able to give contact details for your local adviser.

The Benefit Enquiry line is run by the Department for Work and Pensions (DWP). They offer people with disabilities, their carers or representatives' confidential advice and information on benefits and how to claim them.

The service is also able to send out an extensive range of leaflets and claim packs; they are also able to provide help to complete certain disability-related claims over the phone. Helpline 0800 882 200 8.30am - 6.30pm Monday–Friday, 9am-1pm Saturday see: [www.direct.gov.uk](http://www.direct.gov.uk) and type in benefits.

The Online Benefit Adviser is an online questionnaire to help you find out which benefits and tax credits you may be entitled to receive. It will also direct you to a section where you can read the up-to-date benefits and financial support information. These can be reached at: [www.direct.gov.uk/en/Dio11/DoltOnline](http://www.direct.gov.uk/en/Dio11/DoltOnline).