When your child has additional needs

A guide to finding information and support for families

When your child has additional needs

Information for families

UK
Introduction

Finding out that your child has additional needs can bring about a whole array of emotions. We know from listening to parents that, regardless of the type of disability, health condition or additional need of their child, the common need is for information, support and advice.

Whatever stage you are at on the journey with your child, Contact a Family is here to help. This booklet gives some basic information on a range of topics which may be useful to you and your family. It will also point you in the direction of more in-depth help and support should you need it.

If you want to talk through any of the issues with someone, remember our helpline is available with trained parent advisers who will listen, understand and point you in the right direction. Call our freephone helpline on 0808 808 3555.

Information in this guide
The information in this guide was up-to-date at the time of going to print in January 2013. Information about services and benefits outlined in this guide are subject to change. Please call our freephone helpline to get the latest information.
What do you need to know about?

This guide will give you a basic introduction to a variety of subjects and services that you need to know about. Use this guide to get a brief overview of what is involved or what you may be entitled to, whether your child has a diagnosis or not.

Throughout this guide we list organisations that can provide further help and advice. You will find that services and the law vary between England, Wales, Scotland and Northern Ireland. Use the Contact a Family website www.cafamily.org.uk to look up which of our services are available in your area.

Freephone helpline: 0808 808 3555
www.cafamily.org.uk
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For many families the early years can be dominated by trying to find out more about their child’s condition and finding the right sort of help for their child. For some parents this may be prompted by concerns raised by their health visitor, or their child’s nursery, or a niggling concern about their child’s development from very early days. Certain identifying features may not appear until your child is older and this may mean that you find out more at a later stage. Whatever the case, many families will see their child go through lots of stages of assessment and maybe some other investigations.

If you are still at the stage of looking for an assessment of your child’s needs – talk to your child’s GP, health visitor, or another health professional involved with your child.

The assessment process can take a long time for various reasons. In some cases, it’s almost impossible for health professionals to single out a cause for a child’s condition. This does not mean you can’t get support. You should still be able to access services to help with any aspect of your child’s needs.

Contact a family produces the guide About Diagnosis. It covers a range of topics, including what support there is for parents when their child is diagnosed, understanding behaviour, genetic conditions and rare disorders.

Making sure your child gets enough sleep, eats well and becomes toilet trained can be more of a challenge if your child has a disability. We have free parent guides on these subjects available from our freephone helpline:
• Feeding and eating
• Helping your child’s sleep
• Toilet/potty training

Early Support has been developed in England and Wales to improve the way disabled children and young people and their families are supported. Early Support is a way of working where the different professionals involved coordinate their work to best meet the needs of the disabled child and their family. A key worker acts as a single point of contact for the family and helps by providing coordination and support where families need it.

It has been developed for children aged 0–5 years but in England is being extended to children aged 0–19 years.

Even if you are not offered Early Support, you might find the parent information on the websites useful. This includes information about a range of conditions and disabilities as well as practical tips on managing sleep and behaviour.

Early Support – England
www.ncb.org.uk/early-support

Early Support – Wales
Tel: 029 2034 2434 (ask to speak to an early support administrator)
www.earlysupportwales.org.uk

National Portage Association
Tel: 0121 244 1807
www.portage.org.uk

Provides a home-visiting educational service for pre-school children with additional support needs, and their families.

All of Contact a Family’s parent guides and leaflets are available to download at www.cafamily.org.uk, or parents can get a copy by calling our freephone helpline on 0808 808 3555.

Rare conditions

It’s estimated that up to four million children and adults are affected by rare conditions in the UK. Learning that your child has any condition can trigger a range of feelings such as loss, confusion and isolation. When a condition is rare you and your family may experience the added challenges of finding expert help, getting clear information and advice, and treatment options which may vary depending on where you live.

Contact a Family can help you to find information on rare conditions. We can put you in touch with other families with similar experiences who have children affected by the same condition as your child through extensive UK contacts and growing communities worldwide.

Freephone helpline: 0808 808 3555
www.cafamily.org.uk
We have information on support groups for many rare conditions, and you could link with other families through our internet based linking scheme [www.makingcontact.org](http://www.makingcontact.org).

You can also find us on Facebook [www.facebook.com/contactafamily](http://www.facebook.com/contactafamily) or sign up to receive the rare disorders e-newsletter every two months from our website.

Contact a Family has online medical information, which has information on more than 400 conditions with details of support groups, if there is one. We also have an internal database of a substantial number of specific conditions and rare disorders in addition to those listed online.

For information about a specific condition or to find a support group please call our helpline on Tel: 0808 808 3555.

**Finding reliable medical information**

Many families spend a lot of time looking for information and may search the internet to find out more. However, information available on the internet is not always reliable. There is a short guide on the Medical Information section of our website, [www.cafamily.org.uk](http://www.cafamily.org.uk) which can help you judge if a website provides relevant, quality information.

Great Ormond Street Hospital produces ‘jargon-free’ guides for families on a wide range of treatments and tests. These are available from [www.gosh.nhs.uk](http://www.gosh.nhs.uk)

We also produce the following information guides that you may find useful:

- **Concerned about your child – UK**
- **The NHS and caring for a disabled child – Wales**
- **The NHS and caring for a disabled child – England**

Approved information on your child’s condition is available by calling 0808 808 3555 or by visiting [www.cafamily.org.uk](http://www.cafamily.org.uk) and selecting the Medical Information section.
Many parents say the best help and advice comes from other parents. You may be able to join a local support group to share your experiences, get hints and tips, and support. This can be a great way of finding out what is happening near where you live and getting tips from other parents about dealing with local services.

There are also some national support groups which are specifically for the rarer conditions. These can also help you find information about your child’s condition and network with other parents so you can share information relevant to your own family. Our freephone helpline can let you know where your local or national support groups are in the UK.

If there is no support group for your child’s condition and you want to start one up, Contact a Family can provide information and support to help you do this.

**Linking up with parents in the UK and abroad**

If your child has a condition that is very rare and there is no support group, we can try to link you to another family either through our one-to-one family linking service or through our web-based linking service MakingContact.org, at www.makingcontact.org

“Not knowing too much about the condition, we had great comfort from contacting a support group, who not only provided us with information but also compassion.”

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk
Understanding your child’s behaviour

Some disabled children may display behaviour that challenges us. It can be very difficult for parents especially if their child has difficulties in communication.

Many parents may turn to professionals for advice and may well receive support in looking at why their child behaves in certain ways and work out strategies to help them.

Getting help
If you have concerns about your child’s behaviour and development, and you don’t know where to start looking for help, please ring our freephone helpline for advice. Ask for our parent guide Understanding your child’s behaviour as well as talking to one of our advisors.

If your child has a specific condition, the support group can usually offer tips and strategies to prevent or manage behaviour that is proving to be a problem.

Our freephone helpline can put you in touch with a support group for your child’s condition. Our website also lists national support groups in the medical information section.

You may also need to seek help from professionals involved with your child. Depending on the age of your child, you could talk to your health visitor, GP, someone in their early years’ education setting, or staff at their school.

It is important to address issues around your child’s behaviour as early as possible. For detailed information, hints and tips see our guide above or call our freephone helpline.

If your child has a severe learning disability and/or exhibits behaviour that is severely challenging, the Challenging Behaviour Foundation provides practical information and support for parents.

Challenging Behaviour Foundation
Family Support Line: 0845 602 7885
www.challengingbehaviour.org.uk

Health services

Advice
Your GP, or family doctor, is your first point of contact for medical advice and referrals for investigations. However, you can talk over any issue and receive basic medical advice from the National Health Service (NHS).
NHS Direct/111 – England and Wales
Tel: 0845 46 47
www.nhsdirect.nhs.uk
www.nhsdirect.wales.nhs.uk

NHS Direct operates in some areas and 111, which will gradually replace it, operates in others.

NHS 24 – Scotland
Tel: 08454 24 24 24
www.nhs24.com

nidirect - Northern Ireland
www.nidirect.gov.uk/health-and-well-being

Health benefits
Detailed information about health services is available from our freephone helpline. There are a range of health benefits your child may be entitled to:

• the cost of prescriptions (except in Northern Ireland and Wales where prescriptions are free)
• buying glasses
• help with the cost of travelling to hospital
• some dental care.

Community Dental Services (CDS)
The CDS provides treatment to patients who find it difficult to access dental care, including disabled children. To find out how to access your CDS contact them directly or:

• in England – ask your local GP practice or child development team
• in Northern Ireland – ask your Health and Social Care Trust
• in Scotland and Wales – ask your Local Health Board.

Assessments and support
Your child might be referred to a child development centre or unit where health professionals will carry out an assessment
of your child and organise any therapies or services which might prove helpful.

What are multi-disciplinary teams? These are teams of professionals with different expertise that might take part in carrying out an assessment of your child. For example a paediatrician, physiotherapist, and speech and language therapist.

Contact a Family can provide more detailed information about the different health professionals who might get involved and how they might help your child – see our parent guide Concerned about your child.

Agencies which usually work as multi-disciplinary teams include:

- Child Development Teams
- Child and Adolescent Mental Health Services (CAMHS)
- Community Learning Disabilities Teams (CLDT).

Child Development Team/Centre (CDC) This is a health-care team specialising in working with children when there are concerns about their development. Many different professionals can work in this type of team, including paediatricians, physiotherapists, occupational therapists, psychologists, speech and language therapists, and child and adolescent psychiatrists.

Child and Adolescent Mental Health Services (CAMHS) CAMHS teams promote the mental health and psychological wellbeing of children and young people. They include professionals that work in a number of different organisations such as health, education and social services. The professionals can include occupational therapists, clinical psychologists, psychiatrists, and social workers. There may be a CAMHS Learning Disability team in your area. These teams specialise in meeting the psychological and emotional needs of children and young people with a learning disability.

Community Learning Disabilities Team (CLDT) Some CLDTs promote a lifespan service. They can help plan and arrange care and support for people with learning
disabilities and their carers across the age ranges. The teams are made up of staff from health and social care and can include social workers, community nurses, psychiatrists, psychologists and a range of therapists.

Unsure or unhappy about what is happening regarding your child?
If you’re unsure about the role of any health professional, or the purpose of any treatment or test, ask the person who referred you to explain.

You can always discuss any concerns you have about any of your child’s support or treatment with your GP.

If you need a referral from your child’s GP or hospital specialist for other health services, try to be patient but persistent.

You are entitled to change your GP if you are not happy with the service you are getting.

Benefits and other financial help

The benefits and tax credit systems are extremely complicated. Many people don’t even realise they are entitled to claim. Our helpline has specialist advisers who can make sure you are receiving the correct benefits and tax credits. Information about benefits and tax credits is subject to change and we provide only brief details here. For up-to-date information, please call our freephone helpline.

If you’re not sure if you’re entitled to a benefit, it is worth completing a claim form to find out. Some benefits cannot be back dated.

The Patients Association
Tel: 0845 608 4455
www.patients-association.org.uk

Offers advice on problems and campaigns on improvements to healthcare.
Please note:

Non-permanent residents
If you or your partner are subject to immigration control, or don’t have full residency rights there may be special rules and you should seek further advice before making a claim. This is because in some cases the immigration rules mean you aren’t allowed to get a benefit and if you do make a claim it could affect your rights to remain in the country. Our helpline advisors can give basic advice on immigration issues if this is a concern for you.

From October 2013 – Introduction of a new Universal Credit
The Universal Credit will be a benefit for working age people, paid both to people who are out of work and to those in employment. It will replace most of the current means tested benefits for people of working age – that is, Income Support, income-based Jobseeker’s Allowance, income-related Employment and Support Allowance, Child Tax Credit, Working Tax Credit and Housing Benefit. It is expected to be introduced for new claims from October 2013, (April 2014 in Northern Ireland) with claimants on existing means tested benefits being moved onto the new credit at some point between 2014 and 2017.

Main benefits if you have a disabled child

Disability Living Allowance (DLA)
DLA is the main benefit for disabled children. A claim can be made for each disabled child in your family. There are two parts to DLA – a care component and a mobility component. DLA is not means tested so it does not depend on your income. Your child may be entitled to one, or both, of these components:

- if a child needs extra care or supervision compared to other children of the same age they may qualify for the care component
- if a child needs help getting around they may qualify for the mobility component. The higher rate of the mobility component can give access to the Motability Scheme to help hire, or buy, a car.

For more information about DLA, see our guide to claiming *Disability Living Allowance for children*, available from our helpline or our website.

DLA for adults aged 16–64 is to be replaced by a new benefit called the Personal Independence Payment (PIP). This process will start from April 2013. However, DLA will be retained for children aged under 16.
Employment Support Allowance (ESA)
ESA is a benefit for people over 16 whose capacity for work is limited by their health problems. It was introduced in October 2008 and replaced most new claims for both Incapacity Benefit and Income Support on the basis of incapacity.

There are two types of ESA – contributory ESA and income-related ESA. Some people will receive both types of payment – others may only get one or the other. However, unless they have worked and paid national insurance contributions in the past, most young disabled people will only be eligible for income-related ESA. If your son or daughter claims ESA, any tax credits or benefits you get for them (other than DLA) will stop.

A benefit for carers

Carer’s Allowance (CA)
If your child gets the middle or highest rate of DLA care component (or either rate of the daily living component of Personal Independence Payment), you or your partner may also be able to claim CA as their carer.

In order to qualify for CA you must be:

- caring for your child for at least 35 hours per week
- over 16 years of age
- not in full-time education
- if you work you must earn no more than an earnings threshold. This is currently £100 a week (after taking off certain childcare costs and other expenses).

Money for having children

Child Benefit
You may receive this if you are responsible for a child under 16. Or if your child remains in non-advanced education, or unwaged training, up to the age of 19 (sometimes 20). From January 2013, Child Benefit is withdrawn from households where a parent earns more than £50,000.

Child Tax Credit
This can be claimed by anyone with a dependent child. The amount you get is based on your family circumstances and your annual income (but not your savings). Your award may be higher if you have a child who is getting DLA or is registered blind. Make sure you tell the Tax Credits office if your child is awarded DLA, or if their DLA award increased to the highest rate for personal care.

Benefits for working

Working Tax Credit
This is extra money for families with children where someone is working the required number of hours. This is 16 hours a week if you are a lone parent, or a couple where one of you works and the other is entitled to Carer’s Allowance, or is incapacitated. Most other couples are expected to work at least 24 hours per week. The amount you get will depend on your circumstances and annual income, but not savings.

Freephone helpline: 0808 808 3555
www.cafamily.org.uk
Other benefits you may be able to get

Income Support and income-based Jobseeker’s Allowance are two means tested benefits for people who are not working, or working less than 16 hours per week. However, some carers can claim Income Support even if they work more hours than this. Income Support can only be claimed by certain groups who are not expected to look for work – such as lone parents with a child under five, or some full time carers.

Housing Benefit
Also called a rent rebate in Northern Ireland, or a Local Housing Allowance for those who rent privately. People on a low income and with savings under £16,000 (or over if in receipt of the guarantee element of Pension Credit) can apply for Housing Benefit, Local Housing Allowance or a rent rebate to help with their rent.

Council Tax Benefit is help for Council Tax payers on a low income. In April 2013 the government intends to replace the current national scheme of Council Tax Benefit with local schemes that will vary from area to area.

Council Tax Discount is when your Council tax bill is reduced by 25 per cent (50 per cent in some cases) if there are less than two adults in your household. Children and certain adults (including some carers) can be ignored.

There are other benefits that you may be able to claim depending on your circumstances. Call our freephone helpline on 0808 808 3555 for advice.

Other sources of financial help

You may also be entitled to financial help from other sources, for example grants from different funds and trusts.

A grant from the Family Fund
This may be available to some families with a low income who are receiving certain benefits or tax credits. Grants may be paid for specific items to help relieve the stress arising from the day-to-day care of a child or young person under 18, who has a severe disability or serious illness. For example laundry equipment, transport expenses, help with driving lessons, clothing, holidays or recreational items.

Family Fund
Tel: 08449 744 099
www.familyfund.org.uk

Turn2us is a website where you can search for grant giving charities
www.turn2us.org.uk

You can also call our helpline on 0808 808 3555 for a grants list for families.
Working and childcare

Working parents have the right to take time off work in certain circumstances. They are also entitled to ask for a change to their working week to help juggle work and caring for their child.

Flexible working
If you have a child aged under 17 (or under 18 if they get Disability Living Allowance) and have worked for your employer for at least 26 weeks, you normally have the right to request flexible working. This could be asking for a change to the number of hours you work, or the times you work. Employers must consider any request seriously, but they can refuse if they provide a good business reason. Employees looking after disabled adults aged 18 or over also have this right. The government intends to extend it to all employees from 2014.

Parental leave
If you have disabled child or young children you should have the right to unpaid leave to look after them. You are normally allowed 13 weeks leave for each child aged under five. But if a child gets DLA you can take 18 weeks leave up until their 18th birthday. Usually you can only take a maximum of four weeks leave for any one child in a year. Your employer can let you take a longer period of leave if they wish. From March 2013 the government plans to extend parental leave for non disabled children from 13 weeks to 18 weeks. Further changes, including a new type of flexible parental leave allowing parents to choose how they will share the care of their child in the first year after birth are planned for 2015.

Time off for dependents
Most employees have a right to take a short period of time off to deal with an emergency involving a dependent. This right only applies to emergencies, for example, a childminder falling ill, and only covers the time required to make alternative care arrangements.

Both dependents leave and parental leave is normally unpaid. But check your contract of employment in case your employer has agreed to a more generous policy.

If you are pregnant, or you or your partner having recently had a baby or adopted you may also have a right to maternity, paternity or adoption leave that includes some statutory payments. Contact our freephone helpline for further information.

Detailed advice about employment issues is available from:

Working Families
Helpline: 0300 012 0312
www.workingfamilies.org.uk

Freephone helpline: 0808 808 3555
www.cafamily.org.uk

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Childcare
Many parents report that finding suitable childcare is one of the main barriers to working. For information on finding appropriate childcare contact your local Family Information Service (FIS).

Details of your FIS can be found at http://findyourfis.daycaretrust.org.uk/kb5/findyourfis/home.page

Many parents also say that childcare is too expensive. Depending on your circumstances there may be help available with these costs. For example if you are a working family you may be able to get help towards certain childcare costs via Working Tax Credits (or the new Universal Credit from October 2013). It is also sometimes possible to get direct payments to pay for childcare following a social services assessment. Contact our freephone helpline for further information.

Practical help

It’s not always easy to know where to start when you’re looking for help for yourself and your child. Most areas in the UK now have local voluntary organisations for disabled people and families with disabled children and independent carers’ centres where people can talk you through what help and services are available and how things work in your area.

Our team of helpline parent advisers can put you in touch with parent support groups for the condition affecting your child, advise you about rights and entitlements and offer a listening ear.

They can also advise about your local carers’ centre or other voluntary organisations. To find support in your area, call our freephone helpline.

Duties of social services
Note that where we refer to the local authority social services department, this also includes the Social Work Department in Scotland and the Health and Social Services Trust in Northern Ireland.

There is UK-wide legislation covering services and support for disabled children and their families. The devolved nations (Scotland, Northern Ireland and Wales)
and England also have nation-specific laws. If you live in England or Scotland call our helpline for a copy of our free parent guide *Disabled Children’s Services*. Our helpline can also provide information if you live in Wales or Northern Ireland.

Every local authority must protect and promote the welfare of children in need in its area. To this end you have a right to have your child’s and family’s needs assessed by social services, as well as your own needs as a carer. A carer’s assessment focuses on you as a parent and your needs, like your well-being, including health and safety issues, and important commitments like relationships, education and employment.

**What extra help can you get?**

Assessments for you or your child are important because they can lead to a number of services being provided, like practical help in the home and short breaks.

Duties of children’s services to disabled children and their families include:

- assessing the needs of disabled children and their carers
- providing a range of services to meet these needs.

Services for your disabled child may include:

- practical assistance in the home, like help with the personal care of your child, for example help with feeding and eating, bathing or using the toilet
- equipment for recreational needs, like a TV, radio or computer, leisure facilities (this could mean outings or a placement at a children’s setting)
- education facilities (this could mean home-based education or funding for the personal care needs of students so they can study)
- travel and other assistance, like travel to and from day provision
- home adaptations
- short breaks or residential care
- occupational, social, cultural or leisure activities
- home help
- advice, guidance or counselling.

**Who can provide help?**

Children’s services will not necessarily provide all this support, they should provide the support you and your family is assessed as needing where you meet the criteria. Children’s services/social work teams set eligibility criteria, or rules, for deciding who has a ‘need’ for services so they can prioritise their spending and make sure the people most in need get help. If your child’s assessed needs match the local eligibility criteria, the local authority has a duty to provide or arrange services to meet those needs.

If they don’t, the local authority has no actual obligation to provide or arrange services. However, they should still try to meet the need, for example by contacting a local charity or voluntary agency for help.

Some children’s services may also pay local voluntary organisations to provide support for your child and other family members, like siblings and other carers.

Freephone helpline: **0808 808 3555**

[www.cafamily.org.uk](http://www.cafamily.org.uk)
Can you arrange your own help?
Local authorities (health trusts in Northern Ireland) can make payments instead of services, to allow disabled people and carers to buy in the services they’ve been assessed as needing. These are called Direct Payments. Some families can also access ‘Individual’ or ‘Personal Budgets’ to arrange services. The budget is an amount allocated following an assessment which is usually based on a points-based system.

These methods are also known as Resource Allocation Systems (RAS). However, families should be aware that the outcome of the assessment and amount allocated may not be enough to meet actual need.

In England, the government has also said it will extend the use of Personal Budgets across a range of service areas, including special educational needs, support for children with disabilities and those with long-term health conditions.

For more information about your rights and services for you or your child, call our freephone helpline for a chat or a copy of our free guides:

- **Disabled Children’s Services**
- **Getting direct payments for your disabled child – England and Wales**
- **A parents’ guide to direct payments in Scotland**

**Abilitynet**
Helpline: 0800 269 545
www.abilitynet.org.uk

Advice and information, training and suppliers of computers and software for disabled children and adults, with centres around the UK.

**Disabled Living Foundation (DLF)**
**Living made easy for children**
Helpline: 0845 130 9177
www.livingmadeeasy.org.uk/children

Has a children’s website providing information about aids and equipment and funding for them.

**Whizz Kidz**
Tel: 020 7233 6600
www.whizz-kidz.org.uk

Provides customised mobility equipment not available on the NHS, wheelchair training and advice.
Some children may need more support than others to achieve their potential depending on their additional needs. If you’re concerned about your child’s learning, it’s helpful to know that schools and early years settings have legal obligations to support children who have difficulty in learning, and to treat disabled children fairly.

For more information about your rights and services for you or your child, call our freephone helpline for a chat or a copy of our free guides:

- Special educational needs – England
- Special educational needs – Wales
- Special educational needs – Northern Ireland
- Additional support for learning – Scotland

What are special educational needs?
Children with special educational needs (SEN) are children who have considerably greater difficulty learning than others of the same age. This includes children who, because of their disability, cannot use the same educational facilities as other children of a similar age.

There are various steps or stages of support a school can put in place to help your child. These include measures known as School Action and School Action Plus (Early Years Action/Action Plus for under fives). If your child requires more input than this then you, the school or other agencies can request a statutory assessment which may produce a statement of special educational needs, (or co-ordinated support plan in Scotland).
When your child has additional needs

Who to talk to if you are worried about your child’s education
If you’re concerned that your child has special educational needs, talk to a professional who knows your child. Depending on the age of your child, you could talk to your health visitor, someone at their early years setting, (for example nursery, play group, pre-school), or their school teacher.

Most schools have a teacher responsible for SEN – in England, Wales and Northern Ireland – they are called a Special Educational Needs Coordinator (SENCO).

In Scotland, talk to your child’s teacher or someone in their early years setting. Tell them what your concerns are, giving examples, and ask what support can be put in place. Scotland has an existing approach called Getting it right for every child. Ask about this.

Getting independent help?
For information on help in your area, or for more detailed information about any aspect of your child’s education, it is a good idea to get independent advice.

Contact a Family
SEN National Advice Service
Tel: 0808 808 3555

SNAP Cymru – Wales
Tel: 0845 120 3730
www.snapcymru.org

Enquire: The Scottish advice service for additional support for learning – Scotland
Tel: 0845 123 2303
www.enquire.org.uk

Special Educational Needs Advice Centre (SENAC) – Northern Ireland
Tel: 028 9079 5779
www.senac.co.uk

Centre for Studies on Inclusive Education (CSIE)
Tel: 0117 353 3150
www.csie.org.uk

Offers information about inclusive education and related issues.
If a child has additional needs, other members of the family may need support and information, not just parents. Whether you have a large extended family, are a single parent, a sibling, or grandparent of a child with additional needs, there is support available.

**Your relationship**
As parents of a child or children with disabilities, you may face more significant emotional, social, physical and financial pressures. Some find that these pressures bring their family closer together, while others may struggle without the right support for their caring and other responsibilities. See our parent guide *Relationships and caring for a disabled child* for more information and advice.

You can also contact:

**Relate**
Tel: 0300 100 1234  
www.relate.org.uk

Relate offers advice, relationship counselling, sex therapy, workshops, mediation and support either face-to-face, by phone, email or online.

**Siblings**
Everyday family activities may be limited as parents try to the juggle the needs of all the children in the family and this can lead to more pressures at home.

We have a guide about the needs of *Siblings* with help and activities just for them, available from our freephone helpline or our website.

**Carers Trust Youngcarers.net**
www.youngcarers.net

Moderated online community for young
When your child has additional needs

carers, including siblings, which lists local young carers projects.

Sibs
Tel: 01535 645 453
www.sibs.org.uk

Support for young and adult siblings.

Fathers
Fathers can sometimes feel excluded from some of the vital information about their disabled children’s lives, particularly if they don’t live with the child. Work or other commitments might mean dads can’t always attend hospital appointments or meetings. We also have a Fathers parent guide available from our freephone helpline or our website.

Grandparents
Grandparents may need support too and may have concerns for both their grown-up children and their grandchildren. We’ve worked with grandparents to write our Grandparents guide available from our freephone helpline or our website.

Grandparents Plus
Helpline: 0300 123 7015
www.grandparentsplus.org.uk

Promotes the role of kinship care and care by grandparents at all levels.

Friends
If you don’t have a large and extended family, it’s important to have a support network. Parents say they get a lot of emotional and practical support from friends, neighbours, work colleagues, and others outside their immediate family. Making time for friends can give you a welcome break from your parenting roles and responsibilities. We can put you in touch with support groups which are a great way to meet new friends in a similar position as you.
All members of the family and friends, as well as parents, are welcome to call our freephone helpline for information.

As a busy parent of a disabled child, it’s important that you’re able to take a break and have some time for yourself.

It’s easier to look after your child if you’ve had some time to do the things that you can’t do when you’re looking after your child. This could be anything from going to the hairdressers, to the gym or simply taking time out to lie in the bath, or take a walk to the shops by yourself.

Lone parents
If you are a lone parent, you might find these organisations helpful.

**Gingerbread – England and Wales**
Helpline: 0808 802 0925
www.gingerbread.org.uk

**Gingerbread - Northern Ireland**
Helpline: 0808 808 8090
www.gingerbreadni.org

Advice, information and support for lone parents, including parents with disabled children.

**One Parent Families Scotland**
Helpline: 0808 801 0323
www.opfs.org.uk

Advice, information and support for lone parents in Scotland.

## Taking a break

Friends and family may help you informally, but sometimes you may need regular breaks (called short breaks) which allow you to spend time either with your other children or alone, so you can recharge your batteries, catch up on sleep, do vital jobs and spend time with your partner if you have one. Remember asking for help is not a sign of weakness or bad parenting! Spending time away from your disabled child can also help foster a sense of independence. This may be particularly helpful for your child as they grow up.

To get short breaks, you will need to ask for an assessment of yours and your child’s needs from social services. If you’re concerned about approaching social services, you may find it helpful to contact a voluntary organisation for support and advice as they may be able to support you in your request for help.

Short breaks might include holidays, care in the home or outings away from home, or stays away from home (residential care) for disabled children and young people. To find out how to get more formal breaks and help to finance them call our freephone helpline for information in your area, and ask for our free guides *Disabled children’s services* and *Direct payments*.

Freephone helpline: 0808 808 3555
www.cafamily.org.uk
All children need the chance to play. Parents may find it helpful to know that governments in the UK recognise that disabled children need good-quality play and leisure opportunities throughout childhood to reach and maintain their highest development and wellbeing.

Your child might need help to learn to play. For example, play may be different for a child with a hearing or visual impairment, or one who has limited understanding or mobility. Sensory play and music therapy can be helpful to stimulate your child and help them express themselves. This can be tactile play, using sensory rooms, water and coloured light and soft music. The KIDS website has some good ideas for sensory play at home www.kids.org.uk

If your child has a disability or health condition, you’ll need to think about the type of play opportunities they may be interested in. These may range from wanting access on a regular basis to a playgroup, adventure playground, holiday play scheme, toy libraries, or leisure centres. Don’t forget public parks and local leisure facilities like swimming pools or school play schemes, clubs and sports activities.

They may have times set aside for children with disabilities, offer inclusive play or both.

Who to ask about services
To find out how to access play, leisure, cultural or sporting activities call our freephone helpline and ask for our free guide, Holidays, play and leisure. It sets out yours and you child’s legal rights and has information on financing activities. Our helpline advisors can also let you know what activities are in your area.
Growing up and the teenage years

Adolescence is a time of change for young people, and parents will now be looking at future provision for their son or daughter. Parents may be more involved in their young people’s future lives than they would be otherwise. Transition to adulthood is a process that involves the young person communicating about what they want, and for parents and professionals to work with the young person.

For more information on the process, what to think about and what’s involved, call our freephone helpline for our Preparing for adult life and transition guides.

As your child grows up you will need to think about how to help them understand the emotional and physical changes that happen in their teenage years.

For some young people with learning or development difficulties, this may be more complex.

Young people with disabilities have the same rights and needs as others to understand their bodies and have information about relationships to help them understand.

Freephone helpline: 0808 808 3555
www.cafamily.org.uk
Other sources of support

Carers UK
Tel: 0808 808 7777
www.carersuk.org

Provides an information and advice service for anyone with a caring role. They have offices in all four UK nations.

Education and Resources for Improving Childhood Continence (ERIC)
Helpline: 0845 370 8008
www.eric.org.uk
www.trusteric.org (for older children)

Provides advice and information on bedwetting, soiling and incontinence.

Rapid Effective Assistance for Children with Potentially Terminal Illness (REACT)
Tel: 020 8940 2575
www.reactcharity.org

Assists children with life-threatening illnesses, can help with getting specialist equipment, everyday items and family holidays.

Freephone helpline: 0808 808 3555
www.cafamily.org.uk
Social networking
Contact a Family is on Facebook and Twitter. Join us at:

Facebook
www.facebook.com/contactafamily

Twitter
www.twitter.com/contactafamily

Podcasts
You can download podcasts from our website at:
www.cafamily.org.uk

Videos
You can watch videos on our YouTube channel at:
www.youtube.com/cafamily
Getting in contact with us

Free helpline for parents and families
0808 808 3555
Open Mon–Fri, 9.30am–5pm
Access to over 170 languages

www.cafamily.org.uk
www.makingcontact.org

Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children.

• Understanding your child’s behaviour (UK)
• Aids, equipment and adaptations (UK)
• The tax credits guide (UK)
• A guide to dealing with bullying: for parents of disabled children (UK)
• Disabled children’s services
• Getting direct payments for your disabled child
• Benefits, tax credits and other financial help.

A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

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Registered Charity Number: 284912
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VAT Registration No. GB 749 3846 82

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Incorporating The Lady Hoare Trust

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