

When your child has additional needs


A guide to finding information and support for families in England, Northern Ireland, Scotland and Wales



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 their child has, most parents want information, support and advice.

Whatever stage you are at 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. We also point you in the direction of more in-depth help and support.

 If you want to talk through any issue, call our freephone helpline on **0808 808 3555**

 Parents can call our our freephone helpline and ask for a copy of any of our guides: **0808 808 3555**

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! Information in this guide

The information in this guide is up to date at the time of going to print in January 2015. Information about services and benefits outlined in this guide are, however, subject to change. Please call our freephone helpline to get the latest information.




The early years and diagnosis

Some children are diagnosed by hospital staff prenatally or shortly after birth. For many families, though, their child's early years may be dominated by trying to find a diagnosis and the right sort of support for their child.

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. This may lead to your child going through lots of assessments by different professionals trying to find the cause.

If you are 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.

 Our guide *Concerned about your child* can help you identify the right specialist to talk to about your child's development.

Living without a diagnosis

If your child doesn't have a diagnosis, you should still be able to access services to help with any aspect of your child's needs. Families can find it takes some time to get a diagnosis, especially if their child has a rare condition.

 See our guides which parents in this situation may find helpful:

- *Developmental delay*
- *Living with a rare condition*
- *Living without a diagnosis*

Early years

Getting your child to sleep, coping with eating difficulties and toilet training are all important areas for parents with children under five. This may be more so if your child has additional needs.

 We have guides on these subjects available from our freephone helpline:

- *Feeding and eating*
- *Toilet/potty training*
- *Helping your child's sleep*

Early Support in England and Wales

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 different professionals coordinate their work to meet your disabled child and family's needs. Originally developed for children aged 0–5 years, Early Support is being extended to children aged 0–19 years in England.

Even if you are not offered Early Support, you might find the information for parents on their website useful. This includes information about a range of conditions and disabilities as well as practical tips on managing sleep and behaviour. The 'Can Do' cards have practical suggestions of things you can do to support your child's development: <http://tinyurl.com/bzwsunh>

> Early Support – England

councilfordisabledchildren.org.uk/earllysupport

> Early Support – Wales

029 2034 2434

www.earlysupportwales.org.uk

Pre-school home support or 'portage'

Pre-school home support, or portage, is a home-visiting education service for pre-school children who have additional support needs and their families. A teacher or home visitor works alongside you in the home, offering practical help and ideas to help your child with their play, communication, relationships and learning development. This service varies from area to area and is often only provided to children with more complex needs.

> National Portage Association (England and Wales)

The National Portage Association has information for parents. You can also search for your nearest home-visiting educational service for pre-school children with additional support needs.

0121 244 1807

www.portage.org.uk

> Scotland Family Information Service

The Scotland Family Information Service for parents and carers of children and young people has information on the pre-school home visiting service and the visiting teaching and support service (VTSS).

www.scottishfamilies.gov.uk

> Northern Ireland

NI Direct has information on home visiting support services – and contacting your local Education and Library Board.

www.nidirect.gov.uk



Rare conditions

It is 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, your family may find it difficult to find expert help, information and advice. 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. You can read our short guide to finding reliable information on the internet:

www.cafamily.org.uk/medical-information

Our website has a 'medical information' section, with details on more than 400 conditions and support groups. We also hold details of more than two thousand rare conditions in addition to those listed online.

Please call our freephone helpline for information on rare conditions and parent support groups. If your child has a rare condition and there is no support group, we can try to link you to another family through our family-linking service.

0808 808 3555

You can also use our web-based linking service to get in touch with other families affected by the same condition:

www.makingcontact.org.uk

Great Ormond Street Hospital produces 'jargon-free' guides for families on a wide range of treatments and tests:

www.gosh.nhs.uk

 You may also find our guide *Living with a rare condition* useful.

“ I have learnt more about my child's condition in the past week from Contact a Family than I have from anyone else in the last fifteen years. ”

Support groups



Many parents tell us that the best support and advice comes from other parents. There may be a local support group where you and other parent carers can share experiences and support each other. Local support groups are a great way to find out what is happening in your area and get tips from other parents about local services.

There are also hundreds of national support groups for rare conditions. These can 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.

“ Not knowing too much about the condition at first, we had great comfort from contacting a support group. They not only gave us lots of useful with information but also lots of emotional support and compassion. ”

! If there is no local support group or group for your child's condition and you would like to start one, our Group Action Pack guides provide information to help you. If you run group, sign up to our Local Group Network:. Find out more on our website:

www.cafamily.org.uk/supportgroups

Understanding your child's behaviour

Some disabled children may display behaviour that challenges us, particularly if they have difficulty communicating. There are often complex reasons behind a child's behaviour – it is rarely anyone's 'fault'. It's likely that all behaviours are a way of your child trying to tell you something. The challenge is to work out what your child is trying to tell you through their actions, and to help them find more acceptable ways to communicate.

Getting help

It is important to address issues around your child's behaviour as early as possible. If you have concerns about their behaviour and you don't know where to start looking for help, call our freephone helpline.

 You can also ask for our guide *Understanding your child's behaviour* for more detailed information and tips.

If your child has a specific condition, charities, support groups and other parents can usually offer tips and strategies to help you with your child's behaviour. Our freephone helpline can give you details of support groups for your child's condition. The 'Medical Information' section of our website also lists national support groups.

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

> Challenging Behaviour Foundation

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

Family Support Line: 0845 602 7885

www.challengingbehaviour.org.uk

Health services

Medical advice


Your GP, or family doctor, is your first point of contact for medical advice and referrals for investigations.



Health benefits

There are a range of health benefits you may be entitled to:

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

 Call our freephone helpline for more detailed information about health benefits you and your family may be entitled to.

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 and organise any therapies or services which might prove helpful.

Multi-disciplinary teams

These are teams of professionals with different expertise who work together to assess and support your child. The team may include, for example, a paediatrician, physiotherapist, and a speech and language therapist.

Agencies which usually work as multi-disciplinary teams include:

- child development team/centre
- child and adolescent mental health services (CAMHS)
- community learning disabilities teams (CLDT).

 Our leaflet *Concerned about your child* has details of the various health professionals who might be involved and how they might help your child.

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 psychologists, psychiatrists, nurses 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. This means 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.

Helping you to find your way around health

Below are details of websites to help you find out more about health services, including contact details for local services depending on which country you live in:

> England

www.nhs.uk

> Scotland

www.nhs24.com

> Northern Ireland

www.hscni.net

> Wales

www.nhsdirect.wales.nhs.uk

In an emergency – phone 999 and ask for an ambulance.

Out of hours, when your GP is closed and you need medical advice, then call **111**

- In Northern Ireland contact your GP out of hours service. You can find details at www.gpoutofhours.hscni.net

> AdviceGuide

AdviceGuide has information about your rights to health services and how to make a complaint:

www.adviceguide.org.uk

“ Try to enjoy your child. It is easy to focus on all their problems and forget to enjoy them for who they are and watching them grow up. ”

Unsure or unhappy about what is happening with your child's health?

If you are 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.

> The Patients Association

Offers advice on problems and campaigns to improve healthcare:

0845 608 4455

www.patients-association.org.uk



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 free guides on benefits and 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 backdated.

Please note: 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.

Introduction of new Universal Credit

Universal Credit is a benefit for working-age people, paid both to those who are out of work and to those in employment. Universal Credit will eventually 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.

At the time of writing, Universal Credit only applies in certain pilot areas, most of which are in the North West of England. Initially, the pilot areas focused solely on claims by single job seekers and couples without children. However, in November 2014 it was announced that Universal Credit would be extended to some families living in six jobcentre areas in the Wirral and Warrington. This will not apply to families who have a child on DLA/PIP or who is registered as blind or severely visually impaired. No details have yet been provided for when Universal Credit is likely to apply to families with disabled children in the pilot areas. Universal Credit is not expected to start applying to families with children outside of pilot areas until 2016. The timetable for Universal Credit's introduction in Northern Ireland has yet to be confirmed.

The timetable for Universal Credit's introduction is subject to frequent changes, so call our freephone helpline for up-to-date information.

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.

 See our guide *Claiming Disability Living Allowance for children* for more.

Personal Independence Payment (PIP)

DLA for adults aged 16–64 is gradually being replaced by a new benefit called the Personal Independence Payment (PIP). However, DLA will be retained for children aged under 16.

Like DLA, PIP is not means tested and it has both a mobility component and a daily living component that looks at care needs. However, PIP has different disability tests from DLA. PIP has already replaced new claims by adults for DLA (at the time of writing this does not apply in Northern Ireland). In some

parts of the UK, known as 'reassessment areas', some existing adult DLA claimants are also being moved onto PIP. This includes DLA claimants who are turning 16 and those aged 16 or above who have a change in their care or mobility needs. A postcode map of all the current reassessment areas is available on the gov.uk website.

 For details of the reassessment areas where PIP is being rolled out, or for details about PIP's introduction in Northern Ireland, call our freephone helpline.

 See our guide Personal Independence Payment for more information.

Employment Support Allowance (ESA)

ESA is a benefit for people aged 16 or over whose capacity for work is limited by their health problems.

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 or PIP) will stop. Call our freephone helpline for more information.

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 £102 a week (£110 per week from April 2015) after taking off childcare costs and certain 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). 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 will be higher if you have a dependent child who is getting DLA, PIP, or is registered blind. Make sure you tell the Tax Credits office if your child is awarded DLA or PIP, or if their award is increased to the highest rate of the DLA care component, or higher rate of the PIP daily living component.

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 either 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.

> **Tax credits helpline: 0345 300 3900**

> **Textphone: 0345 300 3909**

 Call our freephone helpline for individual advice and our *Tax credits* guide

Other benefits you may be able to claim

Income Support and income-based Jobseeker's Allowance

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 to help with their rent.

Council Tax discount

A 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 is also a council tax disability reduction where someone in your property uses a wheelchair indoors or needs an additional room for reasons connected with their disability. In addition, every area also has a scheme providing help with council tax bills for those on low incomes.

! There are other benefits that you may be able to claim depending on your circumstances. Call our freephone helpline 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 with the day-to-day care of a child or young person under 18, who has a severe disability, or serious illness. Grants may be given, for example, for laundry equipment, transport expenses, clothing, holidays, or recreational items.

> Family Fund

08449 744 099

www.familyfund.org.uk

> Turn2us

Turn2us is a website where you can search for grant giving charities:

www.turn2us.org.uk

! You can also call our freephone helpline for a grants list for families.

“ We wouldn't have had a holiday at all if we had not got a grant from the Family Fund. ”

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 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.

Parental leave

If you have a disabled child or young children, you should have the right to unpaid leave to look after them. You are allowed 18 weeks leave for each child. Normally this must be used before your child's fifth birthday but if a child gets DLA or PIP you can take this leave up until their eighteenth 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. This should not be confused with the new 'shared parental leave' rules which the government has introduced in the first year of a child's birth or adoption. This allows some mums with a baby born (or adopted) after 5 April 2015 to end maternity leave early and instead share some of the leave with the child's father or her partner.

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 child minder 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 have 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 more information.



“ Working is possible, but you need support from your employer, suitable childcare and some luck. Finding the right childcare was not easy for us. ”

> Working Families

Detailed advice about employment issues:

Helpline: 0300 012 0312

www.workingfamilies.org.uk

Childcare

Many parents report that finding suitable childcare is one of the main barriers to working. For information on finding appropriate childcare in England, Northern Ireland, Scotland, and Wales, contact your local family information service. Details of your 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 once it has been introduced). From Autumn 2015, the government will introduce a new tax free childcare scheme for working families who do not get help with childcare via tax credits or Universal Credit.

It is also sometimes possible to get direct payments to pay for childcare, following a social services assessment (see more about direct payments on page 22). Call our freephone helpline for more detailed advice on working and childcare.

Practical help

It is not always easy to know where to start when you're looking for help for yourself and your child. Most areas in the UK have local voluntary organisations for disabled people and families with disabled children. There may also be a local carers' centre, where people can talk you through what help and services are available and how things work in your area.



Our 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. We can also let you know about local carers' centres, and other voluntary organisations.

i To find out about 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 guide about 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. 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, for example, your well-being, (including health and safety issues), and your needs in terms of 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 (see page 30)
- 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, but they should provide the support you and your family are 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.

Can you arrange your own help?

Local authorities, or health trusts in Northern Ireland, can make payments instead of providing 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.

However, families should be aware that the outcome of the assessment and the amount of money allocated may not be enough to meet their child's actual need.

i For more information about your rights and local services for you or your child, call our freephone helpline.



“ Getting the personal budget for our son meant we could be more flexible. For example, we used it to pay for a play scheme in Cornwall for him when we went on our first holiday in years. ”

Aids, equipment and adaptations

Caring for a disabled child can sometimes be made easier with the use of certain aids, equipment and/or adaptations. Having the right equipment can also help a child to communicate and become more independent as they grow up.

Some items, such as mobility aids or special beds are expensive and the range available is vast.

 Our guide *Aids, equipment and adaptations* has information on how to obtain equipment from statutory sources. It has information on where to get equipment for play and leisure, second-hand equipment, financial help and VAT relief and help adapting your home.



Who provides what?

The National Health Service is responsible for providing equipment to meet nursing or medical needs. Often, the local authority's children's services are responsible for providing equipment for daily living, and the non-medical needs of disabled children and young people.

Equipment needed to help your child's independence or meet any of their social care needs is usually the responsibility of the local authority (social work department in Scotland, or health and social services trust in Northern Ireland). This includes help with arranging adaptations to the home, or any additional facilities for your child's greater safety, comfort and convenience. It also includes aids and equipment to help with lifting and transferring your child, their personal care, eating, bathing and washing.

Equipment to help a child access the curriculum may be arranged by the school or the education department of children's services.

Some condition support groups and charities also offer or lend equipment and give grants for children who have certain conditions or long-term illness. Call our freephone helpline for information.

> Fledglings

Fledglings is a national charity selling products that improve the lives of disabled children and their families:

0845 458 1124 / 01799-541807

www.fledglings.org.uk

> Abilitynet

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

0800 269 545

www.abilitynet.org.uk

> Disabled Living Foundation (DLF)

Provides information about aids and equipment and funding for them:

0845 130 9177

www.livingmadeeasy.org.uk/children

> Whizz Kidz

Provides customised mobility equipment not available on the NHS, wheelchair training and advice.

020 7233 6600

www.whizz-kidz.org.uk

“ Finding the right equipment is a must. We bought a special cup so Sarah was able to drink by herself. This gave her more independence and confidence. ”

Education


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 early years settings, schools, and colleges have legal duties to support children who have difficulty in learning, and to treat disabled children fairly.

What are special educational needs (SEN)?

Children with special educational needs, (or additional support needs in Scotland), 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.

Most children with SEN will go to a local mainstream school. There are various steps or stages of support a mainstream school can put in place to help your child. Extra help can include individual or small group support from the teacher or a teaching assistant, and help from a visiting specialist teacher or professional such as a speech and language therapist. If your child requires more input than this, then you, the school or other agencies can request a formal assessment. This may produce a legal document describing all your child's educational needs and the extra help that will be given to meet those needs.

If your child has complex needs, they may learn best in a special school where there are additional facilities such as specialist teachers and therapists, or special equipment.

 For more information about your rights and services for you or your child, call our freephone Education Advice Service helpline for a chat.

Changes to special educational needs law in England began in September 2014. Proposals to change the education systems in Northern Ireland, Scotland and Wales are being planned.

For the latest information, please contact our freephone helpline.

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 them. 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 Education Advice Service

0808 808 3555

✉ helpline@cafamily.org.uk

> SNAP Cymru – Wales

0845 120 3730

www.snapcymru.org

> Enquire

The Scottish advice service for additional support for learning

0845 123 2303

www.enquire.org.uk

> Special Educational Needs Advice Centre (SENAC) – Northern Ireland

028 9079 5779

www.senac.co.uk

> Centre for Studies on Inclusive Education (CSIE)

Offers information about inclusive education and related issues.

0117 353 3150

www.csie.org.uk

Looking after yourself and your family

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.

All members of the family and friends are welcome to call our freephone helpline for information.

Your relationships


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.

> Relate

Relate offers information, advice and counselling, either face to face, by phone, email, or online.

0300 100 1234

www.relate.org.uk

 See our guide *Relationships and caring for a disabled child* for more information.



“ Family means the world to me. I wouldn't survive without the love, support and strength I get from my family. My mum has always been there to help with school runs when I need her to. ”



Siblings

You may want to help your non-disabled children understand more about their brother or sister and access their own support outside the family. Most siblings cope well with their childhood experiences and do best when parents, and other adults in their lives, accept their brother or sister's disability and clearly value them as an individual.

📖 Call our freephone helpline and ask for our *Siblings* guide.

> Sibs

Support for young and adult siblings:

01535 645 453

www.sibs.org.uk

> Carers Trust Youngcarers.net

Peer support for young carers, including siblings, listing local young carers projects.

www.youngcarers.net

Fathers

Some fathers feel excluded from vital information about their disabled children's lives, particularly if they don't live with the child. Work or other commitments also might mean a father can't always attend appointments.

📖 Our *Fathers* guide is available from our freephone helpline.

“ As a dad, there can be pressure to be the strong one, but I needed to stop that and deal with my emotions. I love my family and I do everything I can to make it work. ”

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.

> Grandparents Plus

Grandparents Plus promotes the role of kinship care and care by grandparents:

0300 123 7015

www.grandparentsplus.org.uk

Friends

If you don't have a large or 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 family.

Making time for friends can give you a welcome break from your parenting role and responsibilities. We can put you in touch with support groups which are a great way to meet new friends in a similar position to you.

As a busy parent of a disabled child, it's important that you're able to take a break. It's easier to look after your child if you also have some time to do things for yourself. This could be anything from going to the hairdressers, the gym or simply

taking time out to lie in the bath, or walking to the shops by yourself. See page 30 for more information on short breaks.



Lone parents

If you are a lone parent, you might find these organisations helpful:

> Gingerbread

Gingerbread offer advice, information and support for lone parents, including parents with disabled children.

England and Wales:

0808 802 0925

www.gingerbread.org.uk

Northern Ireland:

0808 808 8090

www.gingerbreadni.org

> One Parent Families Scotland

Advice, information and support for lone parents in Scotland.

0808 801 0323

www.opfs.org.uk

Taking a break

Friends and family may help you informally, but sometimes you may need regular breaks (called 'short breaks'). Short breaks 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 being a bad parent. Spending time away from your disabled child can also help foster a sense of independence in your child. This is particularly helpful for your child as they grow up.

To find out if you are eligible for short breaks, you need to ask for an assessment of your needs 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 advice as they may be able to support you in your request for help.

There may also be a short-break service where no assessment is necessary and you can make a self-referral. These services are sometimes called 'universal services' as these are available to all children.

Short breaks might include:

- out of school and weekend clubs
- access to play schemes
- holidays
- care in the home
- stays away from home (residential care) for disabled children and young people
- outings away from home.

i To find out how to get more formal breaks and help to finance them, call our freephone helpline for information about what may be on offer in your local area.

Play, leisure and recreation

All children need the chance to play. 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 may need help to learn to play. For example, play may be different for a child with a hearing or visual impairment, or 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.



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.

“ We took our five year old son to a disability hockey session. Finally, he can take part in something rather than watching from the sidelines. He loves it and has made new friends. ”

i To find out how to access play, leisure, cultural or sporting activities in your area, call our freephone helpline.

📖 Our free guide, *Holidays, play and leisure*, sets out your family's legal rights and has information on help you might get to pay for activities. Call our freephone helpline and ask us to send you a copy.



Growing up and the teenage years

Adolescence is a time of change for young people, and you will now be looking to the future with your son or daughter. Transition to adulthood will involve finding out your child's views about what they want and working with them, and any professionals involved in their care, to put this into place.

To find out what services and support are available, call our freephone helpline. You can also ask us for a free guide on preparing for adult life and transition.

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. We are revising our guide on *Growing up, sex and relationships* for parents of children and young people who have disabilities or additional needs. Call our freephone helpline and ask for a copy.

➤ **Transition Information Network (TIN) England and Wales**

TIN provides information about the transition process for disabled young people, parent carers and professionals:

www.transitioninfonetwork.org.uk

➤ **Education Support for Northern Ireland – Transition Service,**

The Transition Service provides information about the transition process for disabled young people, parent carers and professionals:

www.education-support.org.uk/parents/special-education/transition-service

➤ **Enquire (Scotland)**

Enquire is the Scottish advice service for additional support for learning, offering independent and impartial advice and information to parents, carers, practitioners, children and young people:

<http://enquire.org.uk>

➤ **Lead Scotland**

Lead Scotland (Specialists in Linking Education and Disability) aim to widen access to learning for disabled people and carers across Scotland:

www.lead.org.uk

Support Contact a Family

Help us continue to provide information, advice and support to all families with disabled children in the UK.

From cake sales, to running the London Marathon, or signing up to be a regular giver – there are many ways you can help. Find out more on our website, and get in touch with our fundraising team:

🌐 www.cafamily.org.uk/fundraising

☎ 020 7608 8786

✉ fundraising@cafamily.org.uk

And why not get involved in our campaign work across the UK?

🌐 www.cafamily.org.uk/takeaction



Written by Contact a Family.

contact a family
for families with disabled children

Get in contact with us

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 info@cafamily.org.uk


 www.cafamily.org.uk


 www.facebook.com/contactafamily

 www.twitter.com/contactafamily

 www.youtube.com/cafamily

Free helpline for parents and families:

 **0808 808 3555** (Mon–Fri, 9.30am–5pm)

 helpline@cafamily.org.uk (Access to over 170 languages)

Our free family linking service

 www.makingcontact.org



Charities Evaluation Services



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