



THE HELPFUL GUIDE  
FOR FAMILIES WITH  
DISABLED CHILDREN

contact

*"It has given us confidence to ask for support and to know our rights and for our child."*

**Parent carer**

*"Best guide I have come across in 10 years."*

**Parent carer**

*"Great resource, info in one place that can be shared easily with family and friends."*

**Parent carer**

## WELCOME!



If you're reading this book then it's almost certainly because you care for a disabled child, or a child with additional needs. You might have a diagnosis for your child or you could be waiting for one. Maybe you've been living with your child's condition for some time but are now looking for extra support, or you're not sure, but you think your child may need extra help and support. Perhaps you feel like you are on an emotional roller coaster and simply don't know which way to turn next.

If this sounds familiar then you've come to the right place. Whatever stage you are at, Contact is here to help – you are definitely not alone!

Contact will guide you through what can be a confusing system of support. We'll support you to find the best way to help your child. We can help you make sense of any jargon and job titles you'll come across. We can also make sure you and your family have all the information and help you need to enjoy family life.

Accepting your child is disabled or has additional needs can take time. Feeling anxious about how you can make sure your child reaches their full potential, angry that you're somehow to blame and confused by the amount of information out there, are all very common reactions. While this probably isn't a road you expected to be travelling along, you are not alone. Now you've found us, Contact will be with you each step of the way.

*"Don't forget to ask for help and don't worry what others think – you are amazing so don't forget it!"*  
**Parent carer**

In this book you'll find lots of information about the things you might want to know as the parent of a disabled child or a child who has additional needs. It will also point you to more in-depth help and advice on our website: **contact.org.uk**

There's lots to take in so it might be worth looking at the sections you're most interested in now and come back to it over time. So keep

hold of this book and use it in a way that's most useful to you.

And because there's so much new jargon to get your head around we've put a list of some of the most common words you're likely to come across in a glossary at the back of this book. Look out for highlighted words and if you're unsure what they mean, check the glossary to find out.

*"The work Contact does is wonderful. There's no single person from official authorities to help families through the maze of support and tell us what we need to know. Contact covers that niche and helped us get on our feet and enjoy being a family."*  
**Parent carer**

### THE WORDS WE USE

We use the term 'disabled children' to include children with any type of additional need, special educational need, health condition or developmental delay.

*"Know their rights (and yours) – knowledge really is power. Contact can help with this."*  
**Parent carer**



Freephone helpline 0808 808 3555  
contact.org.uk

## IF YOU DO ONE THING... ADVICE FROM MUMS & DADS



We asked other mums and dads what's the one piece of advice they'd share if they met you for the first time and here's what they said. We couldn't have put it better ourselves!

**“Join a support group** either online or one you can attend locally. Being part of a group will help you feel less alone to cope with the stress that having a disabled child can sometimes bring.”

**“Get organised.** Having a child with a disability can mean a lot of paperwork, so get folders for different things like Disability Living Allowance, medical stuff and information from school for example and keep it all in date order.”

**“Trust your instincts.”**

**“Look after yourself.** Make time for yourself whenever you can – even if it's a bath in the middle of the day.”



**“Write down something positive** about your child and remind yourself about it when you're having a bad day.”

**“Make sure you claim Disability Living Allowance (DLA) for your child.** It's there to help with any extra costs of being disabled.”



Freephone helpline 0808 808 3555  
[contact.org.uk](https://www.contact.org.uk)



Contact is the charity for families with disabled children. We understand that life with a disabled child brings unique challenges and we exist to help families like yours feel valued, supported, confident and informed. We can provide you with trusted support and information in lots of ways – through our website and free helpline, parent guides and factsheets, workshops and other resources. And we also bring families together in local groups and online, to support each other by sharing experiences and advice.

## OUR HELPLINE

Talk to our parent advisers about any concerns you have about raising your disabled child – from money, benefits and your child’s education, to getting the right support. Call our free helpline on **0808 808 3555**. You can also email **helpline@contact.org.uk** or contact us on Facebook, Twitter and Livechat.

*“Contact shares our passion for our disabled children. They want our children to reach their full potential just like we do.”*  
**Parent carer**

## OUR LISTENING EAR SERVICE

Our free Listening Ear phone service is here for you if you’re struggling emotionally and just need someone to talk. **contact.org.uk/listening-ear**

*“I needed someone just to listen – and that’s exactly what I got.”*  
**Parent carer**


## OUR WEBSITE, GUIDES & FACTSHEETS

**contact.org.uk** is packed with up-to-date help for you and your family, including medical information on hundreds of health conditions and disabilities.

You can download our guides and factsheets on issues like education, benefits, and family life. And our Chatbot tool and Live Chat service can help you find the information you need.

## BRINGING FAMILIES TOGETHER

Other parents who know what you’re going through can be a great support. We can help you connect with other families like yours through our vibrant online communities.

 **Freephone helpline 0808 808 3555**  
**contact.org.uk**

*“Contact gave us the feeling that we were not alone. It was the first time that we felt there was a network of support and help out there.”*  
**Parent carer**









## WORKSHOPS, EVENTS & LOCAL SUPPORT




We provide a wide range of free parent workshops, information sessions, webinars and family events throughout the year. We’ll also help you get in touch with local parent support groups when you are ready. And if in the future you want to get involved in making a difference to local services, we can put you in touch with your local **Parent Carer Forum**.

We can also tell you about other charities or support groups that can help.



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 Freephone helpline 0808 808 3555  
www.contact.org.uk



YOU AS A PARENT CARER



As a parent, it's natural that your first instinct will be to think about your child and how to get the right support for them. But it's so important to think about yourself too.



### Top tips

- **Plan your time.** Trying to cram in too much will end up making you feel stressed when you do not achieve everything.
- **Make time to regularly do something for yourself.** Just ten minutes every day or an hour or two every week can really help.
- **Just say no.** Know your limits and stick to them.
- **Avoid people who stress you out.** If you know a particular person touches all your hot buttons, limit the amount of time you spend with them.
- **Take control of your environment.** If trips to the shops are really difficult, can you shop online instead?
- **Be positive.** Try to focus on the five things that worked today, not the one that didn't.

*"You can't pour from an empty cup... look after yourself as well."*

**Parent carer**

## WORKING

For many parents of disabled children it's very difficult to think about paid employment, particularly if your child needs a lot of care. For some parents, their caring responsibilities are such that work is not an option. However, with support, many parents do manage to juggle their caring responsibilities with employment.

## TAKING TIME OFF

If you're working you may sometimes be able to take time off. You can also ask your employer if you can change your working hours so you can care for your child too. You've got a few different options:

- **Flexible working – most employees can request flexible working from day one of their employment but different rules apply in Northern Ireland.**
- **Parental leave – you might be able to take time off work to look after your children.**
- **Carers Leave and time off for dependents – carers in England, Wales and Scotland have a right to one week's unpaid carers leave each year. All carers also can take time off work if one of your children has an emergency.**

More information about working and childcare is on page 74-77.

*"I was working full time but it was way too much. My employer was brilliant and allowed me to change my contract to term time only."*  
**Parent carer**



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contact.org.uk



## FINANCIAL HELP IF YOUR CHILD IS DISABLED

**Disability Living Allowance (DLA)** is the main benefit for disabled children up to the age of 16. It's there to help meet the extra costs you might have as a result of your child's disability. DLA is made up of two parts or 'components'. The care component is paid if your child needs extra care or supervision. The mobility component is paid if your child has problems getting around.

You can claim DLA even if your child doesn't have a diagnosis – it's enough that they have some form of disability.

It isn't means tested either so it doesn't matter what your income or savings are. Instead, you need to show that your child needs more care than other children of

the same age who are not disabled. If your child is 16 or over they will usually need to claim **Personal Independence Payment**.

In Scotland, DLA and Personal Independence Payment have been replaced by similar benefits called **Child Disability Payment** and **Adult Disability Payment**.



### FIND OUT MORE

*Help and advice on applying for these benefits in England, Northern Ireland and Wales, plus tips to answer all the questions:*

[contact.org.uk/benefits](https://www.contact.org.uk/benefits)

*In Scotland visit:*

[contact.org.uk/benefits-scotland](https://www.contact.org.uk/benefits-scotland)

*"Most new parents still don't realise they can claim Disability Living Allowance for their child or Carer's Allowance for themselves. Some feel they shouldn't, others think their child won't qualify. Some parents don't feel ready for that step, but it can make such a huge difference to families."  
Parent carer*



Freephone helpline 0808 808 3555  
[contact.org.uk](https://www.contact.org.uk)



## CARER'S ALLOWANCE (CA)

This is the main benefit for carers. You may be entitled to it if your child receives the care component of **Disability Living Allowance** at the middle or highest rate or the daily living component of **Personal Independence Payment** at either rate. You can't get CA if your earnings are too high but it doesn't matter what savings you have. Only your earnings are counted – it doesn't matter if your partner has earnings. In Scotland Carer's Allowance has been replaced with a similar benefit called **Carer Support Payment**.



### FIND OUT MORE

*Visit our website for more information:*

[contact.org.uk/carers-allowance](https://www.contact.org.uk/carers-allowance)

## CARER'S ASSESSMENTS

If you are caring for a disabled child, you might have needs of your own. You can ask for a carer's assessment as well as an assessment for your child. A carer's assessment focuses on you as a parent. Following a carer's assessment, local authorities may be able to provide services or financial support to help you in your caring role, and/or emotional support and short breaks. See page 36-41.



### FIND OUT MORE

*Download our free Carer's assessments - help for parent carers in England factsheet:*

[contact.org.uk/carers-assessments](https://www.contact.org.uk/carers-assessments)



COMMON CONCERNS  
ABOUT YOUR CHILD



Children usually learn important skills as they develop, like making eye contact, taking their first steps or saying their first words. These developmental milestones normally happen at around the same age for each child, although each child is different so a missed milestone does not necessarily mean there is a problem.

We know it can be worrying if your child seems to be slow to develop in any way, and if you have concerns, the first step should be to talk to your family doctor (GP), **health visitor** or nurse about your concerns. They might suggest your child sees a **paediatrician** or a specialist. It's never too early to ask for help. Getting help early can make a real difference.

Your child's **Personal Child Health Record** can help you decide whether your child is slow in their development. Try to keep it up-to-date and take it with you when you see your doctor or health visitor.

*"Asking for help isn't a sign of failure, it's a way forward to support your child, increase your knowledge and feel in control."*  
**Parent carer**



Freephone helpline 0808 808 3555  
contact.org.uk



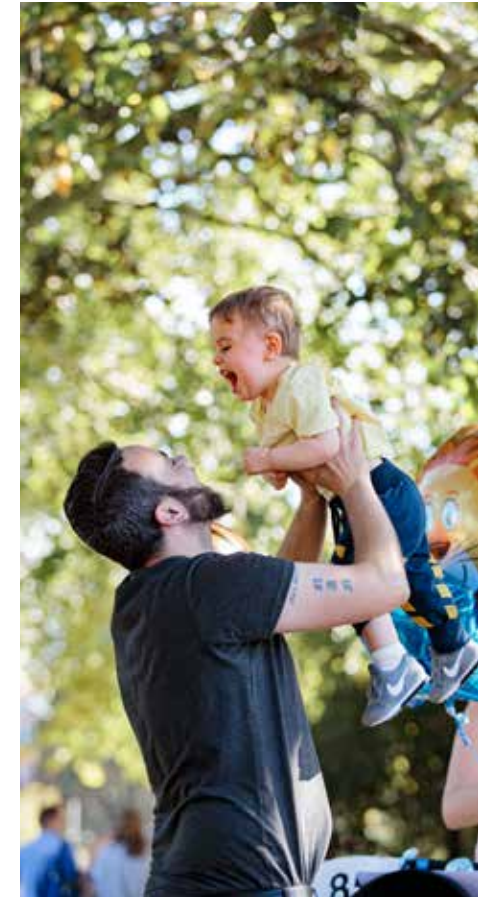
## SPEECH AND COMMUNICATION

Is your child slow to understand simple words, uses few words, or has difficulty making certain sounds compared with other children of their age?

A doctor or health visitor might refer you to:

- An **audiologist** who can advise on aids to improve hearing.
- A **speech and language therapist** to help your child develop communication skills.

*"I quickly noticed that Mark had problems with his speech. He didn't talk at all apart from saying 'mummy' and he also found it difficult to interact with others. I felt isolated and confused. I wasn't sure what to do or where to turn. Things started to improve when regular sessions for Mark were organised with a speech and language therapist at home."*  
**Parent carer**



### FIND OUT MORE

Our website has more information, including support groups who can help with speech and communication issues:

[contact.org.uk/speech-language](https://contact.org.uk/speech-language)



Does your child have difficulty swallowing, eating, drinking or are they reluctant to eat?

Your **health visitor** can give you advice, including information about breast feeding, bottle feeding and weaning onto solid food.

A doctor or **health visitor** may refer you to:

- **A speech and language therapist to help if there are physical problems with swallowing.**
- **A dietician who can provide advice on food, diet and nutrition.**
- **A clinical psychologist who can offer support and advice on encouraging your child to eat.**

If your child is under five and your child has problems with feeding and eating or speech and communication, a doctor or health visitor might suggest:

- **A pre-school home visiting or portage service which helps children with early communication and pre-school learning skills.**
- **A nursery or play school/group with trained people to help your child develop social skills.**

*“Our main challenge for our son now is managing his food intake. He is hungry all the time and this can make him manipulative. We control his food intake and reduce temptation by sitting down as a family at mealtimes.”*  
**Parent carer**



### FIND OUT MORE

Tips on making mealtimes easier website and our free guide, **Feeding and eating:**

[contact.org.uk/feeding-and-eating](https://contact.org.uk/feeding-and-eating)

## TEETH

Does your child have difficulty cleaning their teeth or do they find visiting the dentist difficult?

A doctor, health visitor or local dentist might suggest you take your child to see a **community dentist** who is trained to work with children and has special equipment for working with children with disabilities. You may also be able to find them on your local NHS website.

## MOVEMENT AND COORDINATION

Does your child have difficulty sitting up, walking, handling objects, or using certain parts of their body compared with other children of their age?

A doctor or health visitor might refer you to:

- **A physiotherapist to help with movement.**
- **An occupational therapist to help your child with everyday tasks and equipment.**



### FIND OUT MORE

Read about these and other common issues affecting children:

[contact.org.uk/common-concerns](https://contact.org.uk/common-concerns)



Freephone helpline 0808 808 3555  
[contact.org.uk](https://contact.org.uk)

## COMMON CONCERNS

### POTTY/TOILET TRAINING

Is your child slow in developing control of their bladder or bowel?

Your **health visitor** can give you advice and might refer you to:

- A **continence adviser** to give you advice and practical help if your child is incontinent.
- A **paediatrician** to check for medical reasons why your child might be finding this difficult.
- A **clinical psychologist** to give advice on how to encourage your child to use the toilet.

If your child requires nappies over the age of three, the National Health Service (NHS) can sometimes help by providing nappies and incontinence equipment. Your **health visitor** or GP can tell you more.

*“Although our children may have very different conditions, many of the problems are shared - sleeping, toileting, behaviour, with schools and yes with provision of services.”*  
**Parent carer**



#### FIND OUT MORE

Further advice and our guide for parents **Potty/toilet training** is available free from our helpline, or to download:

[contact.org.uk/toilet-training](https://contact.org.uk/toilet-training)



Freephone helpline 0808 808 3555  
[contact.org.uk](https://contact.org.uk)

## COMMON CONCERNS

### DIFFICULTIES LEARNING OR POOR ATTENTION SKILLS



Does your child have problems remembering information or responding to requests?

A doctor or **health visitor** might refer you to:

- A **nursery or play school/group for children under five** with people trained to help your child learn new skills.
- A **pre-school home visiting service** to help your child with early communication and learning skills before they start school.
- A **Special Educational Needs Coordinator (SENCO)**: a teacher responsible for coordinating any extra support a child needs in England and Northern Ireland. In Wales they are called an **Additional Learning Needs Co-ordinator (ALNCO)**. In Scotland this is called an **Additional Support for Learning teacher (ASL)**.
- An **educational psychologist** who might observe your child and advise on which teaching or behaviour programmes will help your child.



#### FIND OUT MORE

Our not-for-profit Fledglings shop helps families by supplying products and equipment to help with everyday challenges.

[fledglings.org.uk](https://fledglings.org.uk)





Does your child take a long time going to sleep or wake up frequently during the night?

A child that does not sleep creates exhausted parents but solutions can sometimes be found:

- **A health visitor can suggest strategies to promote a good sleep pattern and we can send you a parent guide on this topic.**
- **Your doctor might refer you to a paediatrician or psychiatrist who can assess your child's needs and suggest various treatments or behaviour plans to help your child's sleep.**

*"You might need to go back to basic sleep techniques again and again. Don't get disillusioned. It will be worth it!"*  
**Parent carer**

### Top tips for improving sleep

- **Keep a diary.** Is there a pattern to your child's sleep? Do they wake at the same time or sleep particularly badly on particular days or after certain activities?
- **Establish a routine.** For example, bath, pyjamas, story, bed.
- **Avoid TV and computers or hand held devices** like Xbox, PlayStation for example an hour before bed – they stimulate the brain.
- **Speak to other parents.** Have they tried something that has worked well that you can try?
- **Look at your child's bedroom.** It's important that the bedroom is restful and promotes sleep. Check the position of the bed, is there a pattern on the curtains that your child can see monsters in, are the colours calming? Are there any noises/shadows/too light/ too dark/too cold/too hot etc?
- **Try to make sure your child does not go to bed hungry.** If they're hungry at bedtime try getting them to eat more for their evening meal. Remember some drinks or snacks high in caffeine, sugar, or fat may have a negative impact on your child's sleep.



### FIND OUT MORE

Information and advice, including a free guide for parents, **Helping your child's sleep:**

[contact.org.uk/sleep](https://contact.org.uk/sleep)



Freephone helpline 0808 808 3555  
[contact.org.uk](https://contact.org.uk)



Behaviour issues are common to all children, from tantrums in the early years to the sulks of the teenage years. It can be helpful to know that all behaviour is a form of communication – the challenge for us, as parents, is to find out what our child is trying to tell us through their behaviour.

It's normal to feel frustrated, but it's worth remembering that difficult behaviour can often be resolved using simple strategies. It is important to tackle issues early on, and help is available. Our guide to **Understanding your child's behaviour** is written with parents and experts, and has strategies you can put in place, tips on how to understand and communicate better with your child, how to identify 'triggers', plus people and organisations who can support you and your family.



### FIND OUT MORE

Read our comprehensive guide **Understanding your child's behaviour**:

[contact.org.uk/behaviour](https://contact.org.uk/behaviour)

*"Finding out the triggers for my son's difficult behaviour meant we could avoid them – it's made life so much easier for all of us."*  
**Parent carer**

### Top tips for managing your child's behaviour

- **Rule out any medical or dental problems** which may be causing your child's behaviour. Your child may be in pain but not have any other way of telling you.
- **Keep a diary.** Is there a pattern to your child's behaviour? What happens before the behaviour and what do they get as a result?
- **Help your child to develop ways to communicate** their needs and emotions in a positive way which best suits your child's ability.
- **Talk to someone you trust** about behaviours you find difficult. It can help when you can talk through things with someone else; this could be a friend, another parent or a professional.
- **Be patient and persevere.** Remember if you are introducing new responses to behaviour that initially things may get worse before they get better! It may take your child some time to learn a different response. Keep in mind the benefits the change in behaviour will have.

### MORE HELP WITH COMMON CONCERNS ABOUT YOUR CHILD'S DEVELOPMENT

Find more information on common concerns on our website as well as which professionals may be able to help.



### FIND OUT MORE

Read about these and other common issues affecting children:

[contact.org.uk/common-concerns](https://contact.org.uk/common-concerns)

### TRY ONE OF CONTACT'S WORKSHOPS

We run a range of parent workshops about issues like sleeping and dealing with behaviour that challenges. You can find more details on upcoming workshops on our website.



Freephone helpline 0808 808 3555  
[contact.org.uk](https://contact.org.uk)





## GETTING A DIAGNOSIS

Whether you are searching for a diagnosis or already have one, Contact can help. We have information about how to get a diagnosis, which professionals to approach, living without a diagnosis and getting a diagnosis of a **rare condition**.

*“Try to enjoy your child. It is easy to focus on all their problems and forget to enjoy watching them grow up.”*  
**Parent carer**

### *Top tips on getting a diagnosis*

- **It's never too early to ask for advice.** If you have worries about your child, talk to your family doctor (GP), **health visitor** or nurse. They might suggest your child sees a **paediatrician** or other specialists highlighted in the Common Concerns section of this book, pages 18-29, who will try to work out why your child is finding things hard.
- **Make a list** of all the things that worry you about your child. You can show this to professionals when you see them.
- **Keep a record of your child's progress.** Take photos and keep a diary.
- **Write down any questions** you want to ask before you have an appointment.
- **Keep copies of all the letters** and results you get in a folder.

## FINDING RELIABLE MEDICAL INFORMATION

You can find lots of information online about medical conditions. But remember, not all online information is accurate and trustworthy.

Contact's website is a source of up-to-date and validated medical information on over 400 disabilities and health conditions. Our A to Z list of conditions includes details about the causes, symptoms and diagnosis, as well as the support available.

*“Be careful with the internet, there's so much out there and it's so easy to get poor information and frighten yourself.”*  
**Parent carer**

## RARE CONDITIONS

You may have been told by a doctor that your child has a **rare condition**. If so, you are not alone – there are around 3.5 million children and adults living with a rare condition in the UK.

If your child's condition is not on our website, you can contact our rare conditions information officer who has information on more than 2,000 rare conditions, along with details of available support groups



### FIND OUT MORE

Read more about getting a diagnosis for your child on our website:

[contact.org.uk/getting-a-diagnosis](https://contact.org.uk/getting-a-diagnosis)



**Freephone helpline 0808 808 3555**  
[contact.org.uk](https://contact.org.uk)



### FIND OUT MORE

Reliable medical information, plus support groups and more:

[contact.org.uk/health-medical](https://contact.org.uk/health-medical)



### FIND OUT MORE

Read our information on Living with a rare condition:

[contact.org.uk/rare-conditions](https://contact.org.uk/rare-conditions)



## LIVING WITHOUT A DIAGNOSIS

There are many disabled children living without a diagnosis. If your child has an undiagnosed condition you may worry that you might not be able to get any help or support – but this is not the case. Every child is different, and your child is entitled to get support for their individual needs, regardless of whether they have a diagnosis.

You are entitled to have a social services assessment of your child's needs and your needs as a parent carer. More information about this on page 36.

You may also be entitled to receive benefits such as **Disability Living Allowance, (Child Disability Payment in Scotland)** depending on the level of support or care that your child needs. Find more information on this on pages 16-17.

*"I felt that getting a name for our daughter's condition would help us when explaining to others what was wrong, but in the end it didn't matter. All the professionals involved needed to know was what the immediate difficulties were, so the right care could be arranged."*

**Parent carer**



### FIND OUT MORE

Support if you don't have a diagnosis for your child, including our free guide to **Living without a diagnosis:**

[contact.org.uk/undiagnosed](https://contact.org.uk/undiagnosed)



Freephone helpline 0808 808 3555  
[contact.org.uk](https://contact.org.uk)

## PARENT SUPPORT

Many parents say that other parents are the best source of advice and insight into their child's condition. Support groups can:

- **Help you find specialists to help you get a diagnosis if your child has lots of symptoms of a particular condition**
- **Give you information about your child's condition.**

*"I wait in the car until the doctor is ready to see my daughter – the receptionist rings me and we walk straight in."*

**Parent carer**



### FIND OUT MORE

Find your local and national support groups:

[contact.org.uk/parent-support-groups](https://contact.org.uk/parent-support-groups)

## ATTENDING APPOINTMENTS

If your child has an appointment to see a GP or a specialist, it can sometimes be difficult for them. They might be worried about going to new places or meeting new people. Here are some tips:

### Top tips on attending appointments

- **Try to get appointments early in the day**, as there is usually less of a wait.
- **If your child doesn't like to be in crowds of people**, ask if there is a quieter room you can wait in.
- **Try to get appointments with the same person** every time, so you don't have to repeat your story.
- **Before a doctor sees your child**, tell them what your child doesn't feel comfortable with.



### FIND OUT MORE

More tips on making appointments easier:

[contact.org.uk/appointment-tips](https://contact.org.uk/appointment-tips)



  
YOUR CHILD'S RIGHTS  
TO PRACTICAL HELP



Some disabled children and their parents will need practical support both inside the home and outside it. Local authorities have a legal responsibility to help families with disabled children. Social care is a term that generally describes all forms of personal care and other practical assistance for children, young people and adults, for example aids, equipment, adaptations and short breaks. Note that where we refer to the local authority social services department, this also includes the **Health and Social Care Services** in Scotland and the **Health and Social Services Trust** in Northern Ireland.

Getting the right practical help early on can help your child's development so it's good to explore what's available to them as soon as you can.

The laws are different depending on the nation you live in but generally your local authority should:

- **Let you know about useful services**
- **Assess the needs of your child and you as their carer**
- **Offer a range of services to meet these needs.**

You also have the right to challenge decisions you disagree with.



Freephone helpline 0808 808 3555  
[contact.org.uk](https://www.contact.org.uk)

## HOW TO GET HELP

Speak to your local authority to find out what services are offered. In England local authorities should publish information about services and support, including aids and equipment on their website as part of their **local offer**.

To understand you and your child's needs, your local authority will carry out an assessment which could lead to you getting practical support.

During an assessment an **occupational therapist** or **social worker** will usually visit your home to talk with you about your child for example how they sleep, their eating habits and how they communicate. They'll also ask if you have any other children to look after.

Most local authorities have departments called 'children with disabilities teams' (or similar). They are responsible for arranging this support, and you'll need to get in touch with them to ask for an assessment.

Once social services have carried out an assessment, they'll decide if and what services you need. If they think you need help, they will draw up a **care plan (care and support plan** in Wales).

### *Top tips for getting ready for an assessment*

- **Be prepared.** Think about what you want to talk about beforehand.
- **Keep copies of the letters** you write and receive about your child.
- **Make notes** when you have meetings with social services to help you remember what you've talked about.
- **Have someone with you.** If you have a partner, make sure you are both there. Or ask a friend or someone from your local support group.



### FIND OUT MORE

*Information on accessing services, including our guide to **Services and support from your local authority - England:***

[contact.org.uk/accessing-services](https://www.contact.org.uk/accessing-services)



## PAYING FOR SERVICES

Local authorities can charge for services – they'll each have their own charging policy and it's usually parents' income and savings that are taken into account. You shouldn't be asked to pay more than you can afford. When your child reaches age 16 their own ability to pay is taken into account, not yours.

## DIRECT PAYMENTS AND PERSONAL BUDGETS

You may be able to have more control over the way your services are provided using **Direct Payments** (UK) or asking for a **Personal Budget** (England, NI, Scotland).

Local authorities can give payments instead of services, to allow disabled people and carers to buy services including, for example, for your child to go to a local club or play scheme. **Direct Payments** are for parents and their disabled children who would like to manage their own social care needs.

Some families can also get an individual or **Personal Budget** to arrange services. This is an amount allocated by social services after an assessment, which is usually based on a points system. In Scotland this is known as **Self-Directed Support**.



### FIND OUT MORE

Practical help from social services including our guide **Services and support from your local authority - England:**

[contact.org.uk/social-care](https://www.contact.org.uk/social-care)



### FIND OUT MORE

Information about **Direct Payments and Personal Budgets:**

[contact.org.uk/personal-budgets](https://www.contact.org.uk/personal-budgets)

## SHORT BREAKS

At some stage you might benefit from a break from your caring responsibilities. A short break is an opportunity to recharge batteries and spend time with others. It also allows your child to have fun and make friends. Short breaks can include care at or away from home, overnight or residential breaks.

Local authorities have a duty to provide short break services and make clear how families can access these. To find out if you are eligible for a short break speak to your local authority or contact your local Family Information Service.

*"It's hard to quantify just how important short breaks are to us. They are, to use an overused phrase, a lifeline."*  
**Parent carer**



### FIND OUT MORE

More information on short breaks, including a free fact sheet for parents in England:

[contact.org.uk/short-breaks](https://www.contact.org.uk/short-breaks)

## AIDS AND EQUIPMENT

Caring for a disabled child may be made easier with the use of certain aids and equipment, and adaptations to your home. To find out what aids and equipment you might be entitled to, you can contact a professional such as a social worker, GP, district nurse, physiotherapist or school nurse.

An occupational therapist or social worker will usually visit you in your home to discuss the situation further and carry out an assessment. You may be entitled to a grant to cover the costs of any work you need carried out on your home to make it easier to care for your child.



### FIND OUT MORE

Our information on aids, equipment and adaptations explains your rights:

[contact.org.uk/aids-adaptations](https://www.contact.org.uk/aids-adaptations)

You can also visit our partner Fledglings shop to find practical solutions:

[fledglings.org.uk](https://www.fledglings.org.uk)



  
EDUCATION & LEARNING

Some children and young people need more support than others to get as much as they can from education.

They might need extra help because they have difficulty with reading, understanding or talking. They might also find it hard to manage their emotions or are having problems developing physical skills.

A child who needs a lot of extra help with their learning has **special educational needs (SEN)** or **additional support needs (ASN)** in Scotland or **additional learning needs (ALN)** in Wales. Schools, nurseries and colleges have to support children and young people who have additional needs and to treat them fairly.

Schools must also support children with health conditions, including support to manage medications, personal care and to catch up after a period of absence.

*“We have found that being positive, politely persistent, gritting our teeth and not falling out with the teachers has worked best in getting the support our daughter needs.”*

**Parent carer**





## WHO CAN HELP?

If you think your child has difficulty with learning, talk to a professional who knows your child well. Depending on how old your child is, you could talk to your **health visitor**, someone at their nursery, play group or pre-school, or their teacher if they already go to school.

Most schools have a teacher responsible for additional support. In England and Northern Ireland they are called a **Special Educational Needs Coordinator (SENCO)**. In Wales they are called an **Additional Learning Needs Co-ordinator (ALNCO)**. In Scotland they are called the **Additional Support for Learning teacher (ASL)**.

Tell the person you talk to what your concerns are. Give them examples, and ask what support your child could have.

*“My son finds school life challenging sometimes, but the teachers understand his difficulties and he is making good progress with the extra help he is getting.”*

**Parent carer**



## FIND OUT MORE

*In-depth information about help in education:*

[contact.org.uk/education](https://contact.org.uk/education)

## WHAT HELP CAN A SCHOOL OFFER YOU?

Most children who need extra help with their learning will go to a local mainstream school. There is lots of support a school can put in place to help your child. For example, a teacher or teaching assistant could give them individual help, or help in a small group. A visiting specialist teacher or professional like a **speech and language therapist** could help them too.

If your child needs more support, then you, the school or someone else can ask for a formal assessment. This could lead to a legal document that outlines all your child’s educational needs and the extra help they will get.

If your child has complex needs, you might find that they learn best in a special school with extra facilities. Your child could benefit from specialist teachers and therapists, or special equipment.

### *Top tips for working with your child’s school*

- **Get to know key staff.** It’s important to build a good relationship from the beginning with your child’s class teacher and if the school has one, the SENCO or Learning Support Teacher.
- **Share information.** You are an expert on your child and you will have useful information – for example, what upsets your child and what works best to help him or her calm down? Make sure the school has any reports from professional assessments or information about your child’s medical condition.
- **Deal with problems quickly.** Many problems can be dealt with informally by speaking to the teacher face to face when you pick up your child. If the problem is a bigger one you can ask for an appointment.
- **Write things down.** Your own observations are important – for example you might notice changes in your child’s behaviour after a difficult day at school. If you have a meeting, note the date and any action you or the school have agreed to take.

Our website and free helpline can help you with these and other areas of school life such as:

- **Extra support in school**
- **Attendance**
- **Exclusions**
- **School transport.**



**Free helpline 0808 808 3555**  
[contact.org.uk](https://contact.org.uk)

# Help us reach more families like yours

*Kind donations enable Contact to support the families who rely on our life-changing free services. Here are a few ways you could help us.*



## Hold a fundraiser

Invite friends for a coffee and cake event, hold a dress down or fancy dress day at work, or get involved in our annual dinosaur-themed fundraising day – whatever you choose, our fundraising team can offer help.

## Take on a challenge

Whether you prefer to run, walk, swim, climb, bounce, or crawl through mud, we have challenge event places to suit everyone!



## Play our lottery

For just £1 a week you could win four great prizes including our £10,000 jackpot! Find out more at: [lottery.contact.org.uk](http://lottery.contact.org.uk)



## Donate

If you're able, please consider making a donation or become a regular giver to Contact. You could also give in memory or celebration, or leave us a gift in your Will.



## Spread the word

Nominate us as Charity of the Year at your work, school or local supermarket. Or simply spread the word about Contact by telling your friends and family about us!

For more information about the different ways you could help Contact support more families with disabled children, please visit: [contact.org.uk/fundraising](http://contact.org.uk/fundraising)



THE TEENAGE YEARS  
& PREPARING FOR  
ADULT LIFE



The teenage years are a time of change. Your child is starting the journey to becoming an adult. During this time, young people will experience new things, and gain new rights and responsibilities. They will start to explore what they want to happen in the future, like becoming more independent, getting a job, making new friends and having a relationship.

It is important to start planning as early as possible to support a young person in their transition to adult life. Planning should involve the young person, their parents and anyone else who is important to the young person.

*“Think about what they like doing, what they’d like to do, not where they will go. Think about getting a life, not a service. It’s hard to imagine when your child isn’t at school anymore, that there is a life outside educational institutions.”*

**Parent carer**



Freephone helpline 0808 808 3555  
contact.org.uk

## EDUCATION

If your child gets support through school, health or social services, the transition process should begin when they reach 13 to 14-years-old. Planning should start early and involve you as parents. Once your child turns 16, they are classed as a young person with the right to make decisions about their support, including how they want to be educated.

Your child can leave school at the end of the school year when they turn 16 but this does not mean the end of education. Other educational options include:

- **Stay on at their school or in another school**
- **Go to a further education college (mainstream or specialist)**
- **Do an apprenticeship**
- **Do a programme of training and work experience.**



### FIND OUT MORE

Read more about education beyond 16 on our website:

[contact.org.uk/education-beyond-16](https://contact.org.uk/education-beyond-16)

## TRANSITION FROM CHILD TO ADULT SERVICES

Transition to adulthood will involve finding out your child’s views about what they want and working with them, and any professionals in their care, to put this into place.

The local authority must carry out an assessment before they transfer your child to adult care services to determine what their needs will be. This will give you an idea of the help that you and your child can expect when they move into adult care and support. You may be able to get a **personal budget** or **direct payments** to meet some of their needs (see page 40).



### FIND OUT MORE

Moving into adult services including help with personal budgets and direct payments and making decisions:

[contact.org.uk/preparing-for-adult-life](https://contact.org.uk/preparing-for-adult-life)



*“Another part of transition is about gaining independence, work and life experience. Our daughter did four days work experience in year 10 in the office of a local charity. She had a brilliant time.”*  
**Parent carer**



Freephone helpline 0808 808 3555  
contact.org.uk

## CHANGES TO FINANCIAL SUPPORT

Once your child turns 16, you will find that there are changes to the benefits a young person can claim. It's really important to seek advice to find out how the changes are going to affect your family income. Call our freephone helpline for further advice.

Find out more in our Money and Financial help section, pages 68-73.

## THINKING ABOUT PUBERTY

As a parent it isn't easy to know how and when to get ready for the changes that puberty brings, or how and when to talk about sex and relationships with your child. You may find it easier to start by talking to your child's school about their sex and relationship education (SRE) programme. You and the school both play a vital role.



### FIND OUT MORE

Read more about growing up and puberty on our website including our guides to **Growing up, sex and relationships:**

[contact.org.uk/puberty-growing-up](https://contact.org.uk/puberty-growing-up)

## WORK & TRAINING

An aspiration for most young people is to have a job. For a young disabled person this may mean extra support to achieve this.

Planning for employment should start early in school, exploring what a child wants to do and what they need to learn to achieve these goals. This could include training to develop communication, social and life skills to prepare for work. It could also include the opportunity to access meaningful work experiences.

There are a number of training schemes, organisations and supported employment schemes that can help a young person prepare for and find a job. Contact our helpline for details.



### FIND OUT MORE

Information on getting a job and training:

[contact.org.uk/getting-a-job](https://contact.org.uk/getting-a-job)



## MAKING FRIENDS & COMMUNITY SUPPORT

Making friends and going out and having fun is something many young people say they want. Developing the skills needed to do this, as well as accessing facilities in the community and knowing how to keep safe are all important parts to living as independently as possible.

Some young people will need support to achieve this and may be eligible for a **personal budget or direct payment** to help with this (see page 40)

*“Laura is 16, she needs help and supervision with personal care. She is becoming more independent in that she can make a sandwich or dress herself but it’s all done with supervision. The opportunity to go away from home to a residential specialist college was a positive stepping stone to moving on for both of us.”*  
**Parent carer**

## HOUSING

It may seem too early to think about how and where a young person may want to live in the future. But exploring the different ways people live and different housing and support options now will help when, or if, the time comes to plan for this. Keep up-to-date with any changes to housing/support that may happen along the way.

For a young person this may mean taking small steps, for example making choices about how they want their room, helping with shopping, and learning how to cook. When a young person is thinking of where they want to live and who they want to live with, they may also be learning how to budget, and the life skills needed to live independently.

## OTHER IMPORTANT TOPICS TO THINK ABOUT

Transition to adulthood will look different for every child, but may also include some of the following:

- **learning communication skills or creating a communication passport**
- **developing skills for living in semi-supported or independent accommodation, for example cooking, cleaning, personal care**
- **money – knowing coinage, opening a bank account, budgeting awareness, benefits**
- **maintaining a healthy lifestyle – nutrition, exercise, making and keeping friends**
- **transport and travel training to enable independence**
- **learning how to be safe at home or outdoors**
- **parental responsibility and making decisions beyond 16.**



## FIND OUT MORE

Information on all these topics is at:

[contact.org.uk/preparing-for-adult-life](https://contact.org.uk/preparing-for-adult-life)

If you live in Scotland visit:

[talkingabouttomorrow.org.uk](https://talkingabouttomorrow.org.uk)



Freephone helpline 0808 808 3555  
[contact.org.uk](https://contact.org.uk)



CONNECTING WITH  
OTHER PARENTS



Parents often tell us that the best support comes from talking to other mums and dads of disabled children. When you are ready, we can help you get in touch with others who understand what you're going through for advice and support. After all, you're the experts in caring for your child.

The different ways we can help you connect with others:

- **Family events**
- **Parent workshops**
- **Online support – our online communities**
- **Finding local parent support groups**
- **In England, we can put you in touch with your local *Parent Carer Forum*.**



*"It's great to meet others in the same situation. It's easier to talk to people who can understand your struggles."*  
**Parent carer**

*"You need support from people who 'get it' – only parents who are in the same situation can really understand."*  
**Parent carer**

*"Some of the best advice I have received has been from fellow parents, who have been very honest with me."*  
**Parent carer**

## ONLINE SUPPORT

Our online communities are a safe place where UK parent carers can connect with other families to talk about anything to do with caring for their disabled child.

You can chat about your child's condition with other parents or dive into a discussion and share your experiences on everything from health care to holidays. You can also get information and advice from us here.

You can also talk to a member of the advice team on our Live Chat service.



### FIND OUT MORE

All our online support, including our closed (private) Facebook group for parents:

[contact.org.uk/online-communities](https://www.contact.org.uk/online-communities)

## FAMILY EVENTS AND PARENT WORKSHOPS

We run workshops and information sessions for parents in parts of the UK on topics including early years, understanding your child's behaviour, sleep and managing stress.

We also organise family days so parents can make new friends and socialise.



### FIND OUT MORE

Search our website for workshops and family days out:

[contact.org.uk/workshops](https://www.contact.org.uk/workshops)



**Freephone helpline 0808 808 3555**  
[contact.org.uk](https://www.contact.org.uk)



### LOCAL SUPPORT GROUPS

We can help you find local support groups, which are usually run by parents of disabled children. There are also support groups for specific and rare conditions. We have details of groups across the country where you can meet other parents face-to-face, as well as online support groups.

Support groups can help you:

- **Get information about managing your child's condition**
- **Share experiences**
- **Make friends and socialise**
- **Find emotional and moral support**
- **Take part in activities like family days out.**

### CONTACT CAN HELP IF YOU RUN A SUPPORT GROUP

We offer lots of help, advice and resources for people who are running support groups for other families or if you are looking to set one up yourself. Contact began as a parent support group, so we know just how to help!



#### FIND OUT MORE

*Our helpline can put you in touch with your local support group.*

*Our website also has information about how we support local groups:*

[contact.org.uk/parent-support-groups](https://contact.org.uk/parent-support-groups)



*"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 information but also lots of emotional support and compassion."  
Parent carer*

### PARENT CARER FORUMS

In England there are **Parent Carer Forums** in each local authority area. A forum is a group of parents of disabled children who work with professionals to improve local disabled children's services. It is a way that parents can meet others in a similar situation as well as make a difference for lots of families in their area. If in the future you want to get involved in developing local services we can put you in touch with your local forum.



#### FIND OUT MORE

*See more about Parent Carer Forums:*

[contact.org.uk/parent-carer-participation](https://contact.org.uk/parent-carer-participation)



**Freephone helpline 0808 808 3555**  
[contact.org.uk](https://contact.org.uk)





## FAMILY, FRIENDS & RELATIONSHIPS

Relationships are so important. When they work well, they're a vital source of support and protection against life's stresses and strains. Of course all relationships go through periods of change and challenges and, as a parent caring for a disabled child, you might also have to cope with new emotional, social, physical and financial pressures. Some people find these experiences bring them closer together and make their relationship stronger. Others can find themselves overwhelmed by the experience and struggle to stay together.

At Contact, we're here for everyone who is involved in caring for a disabled child. You might be in a relationship with a spouse or partner or maybe you're a single parent, grandparent or another member of the family. Perhaps you look more to your friends or colleagues for support. We have information and ideas that can help you look after your relationships and make sure they are working well.

### *Some practical tips*

- **Express your feelings.** Tell your family, partner or friends how you feel and don't keep things bottled up.
- **Take time to build and develop your connections** with the people around you.
- **Make time to regularly do something for yourself.** Just ten minutes every day or an hour or two every week can really help.

*"We were also helped by getting the right support and services in place for our son, as this made our parenting role easier and enabled us to spend time working on our relationship."*  
**Parent carer**



**Freephone helpline 0808 808 3555**  
[contact.org.uk](http://contact.org.uk)

## SUPPORTING BROTHERS AND SISTERS

Sometimes it can feel like the brother or sister of a disabled child has to grow up very quickly. Giving siblings the chance to talk things over can help them deal with the difficulties that are bound to crop up occasionally. The good news is that any challenges rarely stop the relationship siblings have with their disabled brother or sister being one of the most important in their lives.



### FIND OUT MORE

*Information about relationships and coping with stress, plus support for family members including guides for **Siblings, Fathers and Grandparents:***

[contact.org.uk/family-life](http://contact.org.uk/family-life)

### *Top tips to help brothers and sisters*

- **Tell them that no-one is to blame** for their brother or sister's difficulties and talk about how to explain their difficulties with friends.
- **Make sure that your son or daughter's school knows** what is happening at home.
- **Try to spend some time** every day with each child on their own.
- **Acknowledge negative feelings** as well as positive ones.
- **Give a choice** about spending time with their brother or sister.
- **Allow brothers and sisters to speak their mind**, even if it's difficult.
- **Give siblings permission to enjoy** and live their own life and celebrate their achievements.
- **Get in touch with your local young carers' project** – supporting siblings and young carers to have fun and meet children in similar situations.





It costs more to raise a disabled child so getting financial help can make a real difference to you and your family. You may be able to claim certain benefits to help you with these extra costs. Some parents feel unsure about claiming benefits or think their child's condition won't count, but the support can be life changing so seek advice to ensure you don't miss out.

The system is complicated, and that's where Contact can help. Our helpline advisers can check that you're getting all the financial support you are entitled to.

The main benefits you could get for a disabled child are:

## DISABILITY LIVING ALLOWANCE (DLA)

**Disability Living Allowance** is the main benefit for disabled children under the age of 16. DLA isn't means-tested, so it's not dependent on earnings or savings. Instead you need to show that your child needs more care or needs more help getting around outdoors than children of the same age who are not disabled. You can find out more information about this important benefit on page 16 of this book. DLA in Scotland has been replaced by a similar benefit called **Child Disability Payment**.

*"My son has complex needs which affect his development, motor skills and behaviour. However, it never entered my head that he may be able to claim a benefit. After consulting the Contact website, I made a claim which has now been granted. This will make a big difference to us as a family. I only wonder that all the myriad social workers, doctors and other professionals we have seen over four years never mentioned it."*

**Parent carer**

*"DLA means my son gets the chance to do the same things other kids do."*

**Parent carer**



Freephone helpline 0808 808 3555  
contact.org.uk

## PERSONAL INDEPENDENCE PAYMENT (PIP)

**PIP** replaces DLA for adults. Your child will normally be asked to move from DLA to PIP at 16. There are two parts to it: the mobility component – paid if your child has problems getting around, and the daily living component – paid if they have difficulties meeting their own care needs. In Scotland PIP is being replaced by a similar benefit called **Adult Disability Payment**.

*"The money's made a lot of difference. It's eased the pressure on my husband. We were relying on him to do overtime to see us through but now he's able to spend more time with my daughter and little boy."*

**Parent carer**



## FIND OUT MORE

*Claiming DLA, PIP and Universal Credit, plus in-depth guides and factsheets to help you to make a successful claim:*

[contact.org.uk/benefits](https://www.contact.org.uk/benefits)

## UNIVERSAL CREDIT (UC)

**Universal Credit** is the main benefit to help people of working age with their day to day living costs. It has replaced tax credits and other means-tested benefits like income support and housing benefit.

Universal Credit is means-tested so whether you qualify and the amount you'll receive depends on your income, capital and other family circumstances.

If your income and savings are low enough you can get Universal Credit to top up your earnings or to support you if you're out of or unable to work. If you rent your home it can include help with your housing costs.

## OTHER HELP

If your child is awarded DLA or PIP or the Scottish equivalent you might be able to get other help too.

Depending on the type of disability benefit they get, you might get **Carer's Allowance (Carer Support Payment in Scotland)** – the main benefit for carers. See page 17 of this book for more details.

Getting a disability benefit for your child also means you qualify for an extra amount in your **Universal Credit**.



### FIND OUT MORE

Information about the benefits available, including our **Money Matters** guides – checklists of any financial help you may be able to claim:

[contact.org.uk/benefits](https://contact.org.uk/benefits)



Freephone helpline 0808 808 3555  
[contact.org.uk](https://contact.org.uk)

## MONEY AND WORK

Some working parents on low incomes get **Universal Credit** to top up their earnings. Universal Credit can include extra money to help you pay for childcare if you are working.

It is helpful to know that certain benefits, for example **Disability Living Allowance**, **Personal Independence Payment** and Child Benefit can still be paid if you move into work.

Other benefits like Universal Credit and **Carer's Allowance (Carer Support Payment in Scotland)** can be affected by your earnings but this will depend on how much your earnings are.

Contact's helpline Family Finance Team can help you work out how going back to work will affect your benefits.



### FIND OUT MORE

About your employment rights and money in work

[contact.org.uk/work-childcare](https://contact.org.uk/work-childcare)



## HELP WITH THE DAY-TO-DAY EXPENSES

Day-to-day costs can soon add up, especially if you've given up work to look after your child. You might be able to get help to pay for certain things:

- **Support with Council Tax (rate rebate in Northern Ireland) for those liable for council tax and on a low income. Help varies depending on your local scheme.**
- **Help with rent. If you rent your home you may be able to get help with your housing costs as part of a **Universal Credit** claim.**
- **A loan to help pay your mortgage interest if you qualify for **Universal Credit**.**
- **Help with household items and disability equipment. Some charities provide grants. Call our helpline or visit our website for a list of grant-giving organisations.**

## HELP AT SCHOOL

Your child might qualify for free school meals and for help with school uniform costs. This usually depends on what benefits you are on but in some parts of the UK all younger children qualify.



### FIND OUT MORE

Read more about help to pay Council Tax on our website:

[contact.org.uk/other-benefits](https://contact.org.uk/other-benefits)

Plus money advice, including help with dealing with debt:

[contact.org.uk/debt-help](https://contact.org.uk/debt-help)



  
WORK & CHILDCARE



If you're thinking about returning to work, we can help you find courses to update your skills and schemes to help you get back into work. We can also tell you about what your employer must do so you can juggle work and caring – see Page 15 for more information about this.

## CHILDCARE

Good quality childcare can benefit you and your child. Some parents have friends and family who can help with childcare. But if you are going back to work, you might want to get something more formal in place, like a childminder or after school club.

Some childcare settings provide specialist services for disabled children, however all childcare should welcome and include disabled children.

## FINDING CHILDCARE

In England, Scotland and Wales, you can find information about childcare at your Family Information Service. In Northern Ireland look for Family Support. They can help you find out about the different types of childcare that are available, such as:

- **Childminders**
- **Nurseries**
- **After-school clubs**
- **Pre-schools**
- **Holiday play schemes.**

They might also be able to tell you about childcare providers who know how to care for children with medical needs too.

*“Being a mum with one child having complex needs, epilepsy and learning difficulties meant it was an uphill road. Still, it was one I was determined to pursue. Why should my chances be limited and why should I not have the same opportunities as others?”*

**Parent carer**



Freephone helpline 0808 808 3555  
www.contact.org.uk

## PAYING FOR CHILDCARE

Childcare can be expensive, but there are some schemes that might help you with the costs. All parts of the UK have schemes offering free childcare for children under the age of five, which families with disabled children can access.

If you are a working parent and you claim **Universal Credit** (see page 71) you may be able to get extra money towards the costs of any registered childcare that you pay for.

You may have heard of the **tax-free childcare scheme**. However, if you use this scheme you will lose any Universal Credit payments you get. Most people are better off getting Universal Credit, so make sure you get advice from our helpline.

Many families with disabled children report that childcare can be unsuitable and availability limited. If you are having problems getting suitable childcare, or are refused a childcare place, we have sample letters on our website to ask your local authority for help.

*“Getting a nursery place for my daughter when she was 3 made her transition to school much easier as she had friends that understood her disabilities. It also helped me get back to work sooner, before I lost my confidence about being out of the job market.”*  
**Parent carer**



## FIND OUT MORE

Information about finding and paying for childcare:

[contact.org.uk/finding-childcare](https://www.contact.org.uk/finding-childcare)



PLAY, LEISURE  
& HOLIDAYS



Play, leisure and holidays are a valuable part of every childhood. Access to good quality play and leisure opportunities can help children with additional needs develop social and physical skills, form friendships and become more confident. Unfortunately, some parents of disabled children tell us that they can sometimes experience barriers to accessing leisure and play opportunities and this can affect the whole family. Contact knows how important leisure, play and holidays are. That's why we have lots of information about:

- **Help to pay for leisure activities**
- **Arranging holidays for disabled children**
- **Organisations which provide grants for play and leisure**
- **The chance to go on short breaks (see page 41).**



*"Plan it with precision, patience and persistence, but make it happen! It is so worth it."*  
**Parent carer**

### *Tips for planning a day out:*

- **Work out what you can realistically manage** – what can your disabled child cope with, what can you afford?
- **Have a list of activities your kids enjoy** and include a rainy day alternative.
- **Accept** that your disabled child's expectations of a good time may not be the same as yours.
- **Even if money is limited**, or you don't have your own transport, you don't have to miss out. Learn to be a creative with the pennies and make the most of any free stuff.
- **Make sure you have an in-depth knowledge** of every public WC, friendly pub, café and discreet alley. It's also imperative to know how long it takes between each pit stop, either by bus or foot depending on time constraints and budget.

## PLAY AND LEISURE IN YOUR AREA

If you want to know more about leisure facilities and sports clubs in your area, our helpline can help. Or you could contact a local parent support group (see page 62) or **carers' centre** near you. Some of them run their own events.

You can also find information at:

- **Your local library**
- **Your local council website**
- **A local leisure or youth service for details of inclusive facilities**
- **Sports clubs.**

*"Socially we need somewhere for our daughter to go where she could be with other disabled youngsters. She gets fed up being around her family and enjoys the company of others, however when the school closes at the weekend, that's the end of it and she is bored."*  
**Parent carer**



Freephone helpline 0808 808 3555  
contact.org.uk



## DAYS OUT

Many tourist attractions offer discount schemes and queue jump passes for disabled people and their carers. Ask when you book.

## HELP PAYING FOR LEISURE ACTIVITIES

Local authorities can give payments instead of services, to allow families to pay for their child to go to a local club or play scheme.

**Direct payments** are for parents and their disabled children who would like to manage their own social care needs. Some families can also get individual or **Personal Budgets** to arrange services. You can find out more about **Personal Budgets** and **Direct Payments** on page 40.



### FIND OUT MORE

*Our website is packed with ideas and activities:*

[contact.org.uk/play-leisure](https://www.contact.org.uk/play-leisure)

## HOLIDAYS

Everyone needs a change of scene from time to time. There are many organisations which provide holidays and holiday accommodation for families with disabled children. Some charities could help you meet the costs of a holiday and our helpline has a list of those organisations that can help.

## OUT AND ABOUT

There is help for some disabled children to get about by car, including parking through the Blue Badge parking concession scheme and leasing a car through the Motability Scheme.

You may also be able to get help with the costs of train travel, like the Disabled Persons Rail Card. In some areas of the UK, disabled people and their carer can travel for free on buses.



### FIND OUT MORE

*More information about getting around:*

[www.contact.org.uk/transport](https://www.contact.org.uk/transport)





  
CAMPAIGNING  
TOGETHER



At Contact we believe disabled children and their families should have the same rights as everyone else. That's why we campaign to make things fairer. We work alongside families about the issues that matter most to them, to influence politicians and decision makers so they tackle the inequalities that many face.

We do this in lots of ways:

- **Online surveys and research reports highlighting particular issues for families**
- **Helping families speak to the press and social media campaigns**
- **Parliamentary meetings and events to help politicians understand what life is like for families.**

Our campaigns are trusted by families because they are built on what you tell us. We set up and run the Disabled Children's Partnership, a coalition of more than 100 organisations campaigning for improved health and social care for families with disabled children. Join us at [disabledchildrenspartnership.org.uk](http://disabledchildrenspartnership.org.uk)

*"Thank you very much for inviting me and my daughter to Parliament today. It was very emotional but I've gained so much from the experience. I've never had so many offers of help in such a short time and that's all thanks to you!"*

**Parent carer**



Freephone helpline 0808 808 3555  
[contact.org.uk](http://contact.org.uk)

### WHY NOT JOIN US?

When you are ready you might want to get involved with one of our campaigns. You can get involved as much or as little as you like – it's up to you.

If you're interested in learning more about running a campaign why not join our Change Maker programme. You'll join a fantastic team of like-minded parents wanting to make a real difference.

We'll give you opportunities to take action, speak out in the media and meet with decision makers in government. You'll have access to training and other support aimed at helping you boost your skills and be an even better campaigner.

Find out more at:

[contact.org.uk/campaigning](http://contact.org.uk/campaigning)

*"If it hadn't been for Contact pushing the government on this, we would have been pushed even further into poverty. I feel that a huge financial weight has just lifted from my shoulders and I'll be able to sleep better without the need to worry about the future as a family."*

**Parent carer**





  
SUPPORTING  
CONTACT

## SUPPORTING CONTACT

At Contact, families with disabled children are at the heart of our work and it is only through the generosity of our supporters that we can deliver our vital services. When the time feels right, please consider supporting Contact to help us reach more families who need us.

There are lots of way you could get involved – **fundraise, donate, campaign** or **volunteer**. Thank you for making a positive difference to families like yours and helping disabled children to thrive. Visit [contact.org.uk/fundraising](https://contact.org.uk/fundraising) or email [fundraising@contact.org.uk](mailto:fundraising@contact.org.uk).



### THE DINODAY CHALLENGE

Kids across the country will be completing fun challenges as part of Contact's annual DinoDay event in June. This fun, inclusive family event asks children to pick any challenge inspired by the number 19 and they'll receive a free t-shirt for taking part!

Ziggy (pictured) spent most of his life being tube-fed and he struggled to eat a wider range of foods. Ziggy's parents challenged him to try 19 new foods for DinoDay and his mum said:

*"He loved the challenge and did so well. He talked about it at school for weeks! We are so proud of him and grateful to Contact for the inspiration."*  
**Ziggy's mum Jackie**



FIND OUT MORE

Visit our website:  
[contact.org.uk/dinoday](https://contact.org.uk/dinoday)

contact  
**WEEKLY**  
**LOTTERY**



Just £1 a week could win you up to **£10,000** – and help us support families with disabled children  
**lottery.contact.org.uk**



**Additional Learning Needs Co-ordinator (ALNCO)** A teacher responsible for co-ordinating any extra help or support in education a child in Wales needs.

**Additional Support for Learning (ASL)** is the extra or different help provided to learners who have additional support needs in Scotland. The preschool home-visiting teacher is responsible for this before children start school. Once children begin school either the child's teacher or the Additional Support Learning staff is responsible.

**Adult Disability Payment** This benefit replaces Personal Independence Payment for people aged 16 – pension credit qualifying age in Scotland. You can still receive payments of Child Benefit and other benefits you get for your child alongside it.

**Audiologist** Carries out hearing tests and can help a child with hearing aids if needed.

**Care plan** A written document outlining the services you have been assessed as needing by your local authority (LA). It should be agreed with you and your family and state what the LA plans to achieve by providing the services, what each person and agency is expected to do, how long the services are needed and the date of the next review.

**Carer's Centre** Most local authorities in the UK have a local carer's centre, usually a local charity giving information, support and advice to carers, including parents of disabled children. Look on your local authority website.

**Carer's Allowance** This is the main benefit for carers.

**Carer Support Payment** This is the main benefit for carers in Scotland.

**Child Disability Payment** The main benefit for disabled children in Scotland, to help meet any extra costs of being disabled.

**Children's Services** Department of the local authority in England and Wales legally responsible for assessing a disabled child and family's needs, and for providing services to meet those assessed needs.

**Clinical Psychologist** Offer advice on eating, toileting and behavioural difficulties. You may also find it helpful to talk to them about how your child's difficulties affect the family.

**Continence Adviser** Can give you advice and practical help if your child is incontinent.

**Community Dentist** Can provide advice on diet and planning for healthy teeth as well as dental services to children who find mainstream dental services difficult.

**Dietician** Can advise on food, diet and nutrition if a child is reluctant to eat, needs to be on a special diet or has difficulties chewing and/or swallowing.

**Direct Payments** If your local authority agrees that your child needs services, you can choose to get money to buy these services yourself instead of having them organised by the local authority. This money is given to you in the form of direct payments.

**Disability Living Allowance (DLA)** The main benefit for disabled children and is there to help meet any extra costs of being disabled.

**Educational Psychologist** Can assess a child's development and provide support and advice on learning and behaviour to you or your child's teachers.

**Family Doctor or GP** Will be the first person to ask for medical help and advice. They can ask for your child to be seen by another specialist.

**Health and Social Care Services** Department of the local authority in Scotland legally responsible for assessing a disabled child and family's needs, and for providing services to meet those assessed needs.

**Health and Social Care Trust** Department of the local authority in Northern Ireland legally responsible for assessing a disabled child and family's needs, and for providing services to meet those assessed needs.


**Health Visitor** A nurse who has extra training to work with families in the community. They can give practical advice on day to day matters like feeding, sleep, teething, development and behaviour. Some health visitors have specialist roles such as working with children with disabilities.

**Local Offer (England)** A wide range of information about all the support and facilities which families with disabled children can expect to find in their area, usually on your local authority website.

**Occupational Therapist** Pays attention to hand-eye coordination, perception and manipulative skills. They can advise and provide suitable aids to help with everyday activities such as feeding, dressing, toileting, bathing and play in younger children and writing skills in older children.

**Paediatrician** A doctor who specialises in looking after babies, children and young people. A paediatrician can coordinate and liaise with other agencies involved in the management, care and education of the child and family.

**Parent Carer Forum** A group of parents and carers of disabled children who work with local authorities, education settings, health providers and other providers to make sure the services they plan and deliver meet the needs of disabled children and families.

 **Freephone helpline 0808 808 3555**  
[contact.org.uk](https://www.contact.org.uk)



**Parent Support Group** Parent Support Groups generally offer: friendship; opportunities to socialise; information and advice; emotional and moral support; a listening ear; a regular meeting place; activities such as a crèche for siblings or family days out. Local groups vary in terms of the type of service they offer and can be open to parents and carers of children with any disability. Others are for parents whose children have the same condition.

**Personal Budget** Local authorities might offer families the option of a personal or individual budget (known as Self-Directed Support in Scotland and as Direct Payments in Wales). It's an allocated amount of money that the local authority considers sufficient to meet all of your child's eligible needs.

**Personal Child Health Record** This is given when your child is born. It can help you decide whether your child is slow in their development.

**Personal Independent Payments (PIP)** This benefit replaces Disability Living Allowance (DLA) for people aged 16 – pension credit qualifying age. You can still receive payments of Child Benefit and any other benefits you get for your child alongside PIP.

**Physiotherapist** Helps in the management and development of movement skills. There are a number of ways in which children can be helped. These may include exercises to strengthen weak muscles and games to

improve coordination and motor skills.

**Pre-school Home Visiting Service** Is sometimes available for children with delayed development. In England this is called Portage. A teacher or Portage home visitor works alongside parents in the home offering practical help and ideas to help with the development of play, communication, relationships and learning for young children.

**Portage Service** See Pre-school Home Visiting Service above.

**Psychiatrist** A doctor who specialises in problems that affect the ways a person thinks, feels or behaves. A child and adolescent psychiatrist specialises in working with children and young people. The psychiatrist might want to meet the whole family before deciding what help is appropriate. They can prescribe medication and might suggest a child be seen by a clinical psychologist.

**Rare Condition** You may have been told by a doctor that your child has a rare condition. A condition is considered rare if it affects fewer than five people in every 10,000. It's estimated that there are between 6,000 and 8,000 known rare conditions.

**Self-Directed Support** An allocated amount of money that the local authority considers sufficient to meet all of your child's eligible needs in Scotland. Parents can choose how much input or responsibility they wish to

have in directing their support.

**Short Breaks Services** Sometimes families who have disabled children and/or health conditions benefit from a break from their caring responsibilities. Local authorities now have duties to provide short break services and make clear how families can access these.

**Social Care** A term that generally describes all forms of personal care and other practical assistance for children, young people and adults who need extra support.

**Social Worker** Usually a 'gatekeeper' of services that local authorities must legally provide for families with disabled children. For example they will carry out an assessment of your family's needs, and tell you about and arrange any practical support that results from that assessment.

**Special Educational Needs (SEN)** A child who needs extra help to access education is said to have special educational needs (SEN). Some children may have SEN because of a medical condition or a disability. Other children may have SEN without a diagnosis or a disability.

**Special Educational Needs Co-ordinator (SENCO)** Co-ordinates support for children with special educational needs in England.

**Speech & Language Therapist** Helps children learn to communicate, either through speech or other methods. They can also help if there are problems with eating,

drinking and swallowing.

**Transition** A term used to describe the process of putting services and support in place to help a young disabled person reach their potential as they grow up from the teenage years into an adult.

**Universal Credit** A benefit for people of working age. It is paid to people who are out of work and in employment and replaces most of the current means tested benefits for people of working age.



Freephone helpline 0808 808 3555  
[contact.org.uk](https://www.contact.org.uk)

## Support a kinder future through your Will



Our charity, Contact is committed to being here for families with disabled children long into the future. And loving supporters, like you, can make that possible by remembering our charity in your Will.

### Write or update your Will free with us

We understand writing a Will is a deeply personal decision, and one that reflects how you want to care for the people and causes closest to your heart. We have a limited number of spaces for supporters to write or update their Will for free through our partnership with the National Free Wills Network. This simple offer gives you the opportunity to plan with confidence, using a participating solicitor local to you.

There is no obligation to leave a gift to Contact if you choose to use our free service. We hope you will consider remembering our charity in your Will – a gift of any size will give families the support and guidance they need for generations to come.

### When the time feels right, please contact us for more information.

Speak to Sophie on  
**020 7608 8733**  
**legacies@contact.org.uk**  
**contact.org.uk/legacies**



Please scan the QR code to receive your free information pack



## Life-changing toys, clothing & equipment for disabled children

Fledglings is Contact's partner online shop, supplying products and equipment to help with everyday challenges.

Their wide product range includes clothing & swimwear, sensory toys, learning resources, eating & drinking aids and bedtime & toilet training products.

[fledglings.org.uk](https://fledglings.org.uk)



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## GET IN CONTACT WITH US

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London N1 7EU

Telephone: 020 7608 8700

[info@contact.org.uk](mailto:info@contact.org.uk)

[contact.org.uk](http://contact.org.uk)

**Free helpline for parents and families:  
0808 808 3555 (Mon–Fri, 9.30am–5pm)**

Access to interpreters

[helpline@contact.org.uk](mailto:helpline@contact.org.uk)



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