



Information for parents
ENGLAND | SCOTLAND
WALES | NORTHERN IRELAND

contact *For families
with disabled children*

HELP IN THE EARLY YEARS IF YOU ARE CONCERNED ABOUT YOUR CHILD

Finding out that your child has additional needs can bring about a whole array of emotions. We know that regardless of the type of disability, health condition or additional need their child has, parents want information, support and advice they can trust. Whatever stage you are at with your child, Contact is here to help. This factsheet 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.

GETTING A 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 a health visitor, nursery, or a nagging concern about a child's development from very early days. It may lead to your child going through 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. Look on our website, or contact our helpline and ask for a free copy to be sent to you:

0808 808 3555

helpline@contact.org.uk

www.contact.org.uk/concerned-about-your-child

LIVING WITHOUT A DIAGNOSIS

Families can find it takes some time to get a diagnosis, especially if their child has a rare condition. Your child is entitled to get the support for their needs whether they have a diagnosis or not.

Our free guides for parents, also on our website or available from our helpline, may be helpful if you're in this situation:

- ***Living without a diagnosis***
- ***Developmental delay***

Great Ormond Street Hospital also has jargon-free information for families on a wide range of hospital treatments and tests at:

www.gosh.nhs.uk

FINDING INFORMATION ABOUT YOUR CHILD'S CONDITION

Many families spend a lot of time looking for information and may search the Internet to find out more. However, information on the Internet is not always reliable. You can read our short guide to finding reliable medical information here:

www.contact.org.uk/finding-medical-information

Our website also has an A-Z of medical information about more than 400 different conditions. It is written by the health specialists in their field, alongside details of relevant support groups. You can search for your child's condition at:

www.contact.org.uk/medical-information

LIVING WITH A RARE CONDITION

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.

If your child has a rare condition and you can't find information about it on our website, we may still be able to help. Please call our freephone helpline.

You may also find our guide ***Living with a rare condition*** useful. Find it on our website or call our helpline for a copy:

www.contact.org.uk/rare-condition-guide

BEHAVIOUR

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 for parents on these topics:

- [*Feeding and eating*](#)
- [*Helping your child's sleep*](#)
- [*Toilet/potty training*](#)
- [*Understanding your child's behaviour*](#)

They are available free from our helpline or website:

www.contact.org.uk/concerned-about-your-child

FREE CHILDCARE IN THE EARLY YEARS

In England all three and four-year-olds are entitled to 15 hours of free childcare for 38 weeks of the year. Some two-year-olds are also eligible, for example any two-year-old who is in receipt of Disability Living Allowance (DLA) or who has a statement of special education needs, or an Education, Health and Care Plan. Some working families are entitled to an extra 15 hours of free childcare. A childcare setting can also get extra funding if a child receives DLA. Find out more at:

www.contact.org.uk/paying-for-childcare

DISABILITY LIVING ALLOWANCE

Disability Living Allowance (DLA) is the main benefit for children with a condition or disability. DLA helps to meet the extra costs that you might have as a result of your child's disability. You can claim DLA even if your child doesn't have a diagnosis. It isn't means-tested, which means that if your child is eligible, you can get no matter how much money or savings you have.

We have more information about DLA on our website, including a free in-depth guide that has helped other parents claim DLA. Or you can call our helpline for more information:

0808 808 3555

www.contact.org.uk/dla

TAKING A BREAK

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. A break may also allow your child to have a change of scene, try different experiences, have fun and make friends.

Local authorities have legal duties to provide breaks for carers and disabled children, called short breaks. They must make it clear how families with disabled children can access these. For more information see our factsheet [*Short breaks – how you and your family can benefit*](#) available from our website or helpline.

www.contact.org.uk/short-breaks

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 the grandparent of a child with additional needs, there is support available.

All members of the family and friends are welcome to contact our free helpline for information.

0808 808 3555

helpline@contact.org.uk

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. Our guide [*Siblings*](#) has information for parents on how to help siblings and where to go for support. You can find it on our website or call our helpline for a copy:

www.contact.org.uk/supporting-siblings

Fathers

Fathers may feel they have a dual role; they may need to offer support, but also provide the practical help when it is needed. Some fathers may feel excluded from vital information about their disabled children's lives, particularly if they don't live with the child. Dads might like to read our guide for [*Fathers*](#), available on our website or from our helpline:

www.contact.org.uk/fathers

Grandparents

Grandparents may need support too and may have concerns for both their grown-up children and their grandchildren. We have worked with grandparents to write our guide for [*Grandparents*](#), to support them and their families:

www.contact.org.uk/grandparents

Friends

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 also a great way to meet new friends in a similar position to you. Call our helpline or see:

www.contact.org.uk/support-groups

YOUR RELATIONSHIPS

As parents of a disabled child, 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.

Our guide *[Relationships and caring for a disabled child](#)* has information about looking after your relationship, managing conflict plus lots more relationships advice. It's available free from our helpline or to download:

www.contact.org.uk/relationships

You can also visit Family Life Plus, our relationship support site developed with charity One Plus One, where you can find information on handling stress, managing your time, parenting styles, dealing with in-laws and so on:

www.relationshipstool.contact.org.uk

LONE PARENTS

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

Gingerbread

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

England and Wales

Helpline 0808 802 0925

www.gingerbread.org.uk

One Parent Families Scotland

Advice, information and support for lone parents in Scotland.

Helpline 0808 801 0323

www.opfs.org.uk

SUPPORT GROUPS

Parents often 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. Support groups are also a great way to find out what is happening in your area and get tips from other parents about local services.

There are hundreds of national support groups for different conditions, including 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, or you can search for them in our A-Z medical directory:

www.contact.org.uk/medical-information

HOW CONTACT CAN HELP

If you have concerns about your child, whether that's missing developmental milestones, speech and communication, co-ordination, sleeping or behaviour, Contact can help. We have advice on many of these common concerns and can point you in the right direction of professionals to turn to for support.

OUR HELPLINE

Our helpline advisers can support you with any issue about raising your disabled child: medical information, early years, diagnosis, benefits, education and local support. You can call or email them your query:

0808 808 3555

helpline@contact.org.uk



FREEPHONE HELPLINE

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