



About diagnosis: Support for parents

Information which may help you when:

- Hearing the news
- Getting support
- Talking to professionals
- Contacting other parents

If you have recently found out your child may have a disability, this guide can help you make a start at getting the right support and good information.

A period of coming to terms with the news

"We were just told the name of her condition. There was no other information offered to us: no prognosis; no treatment; no nothing. We had just been told our child had a critical rare disorder and we didn't know what to ask. We walked out of that hospital feeling stunned and alone."

Parent



Almost all parents describe a time of getting used to a new child as part of the family. When a child has a disability or additional need, parents sometimes talk about a period of coming to terms with the news. Many feel shocked, upset, and anxious for the future. Some describe this time as similar to going through a period of loss and grief. If you have a partner, the two of you may be experiencing different emotions at different times and this might cause tension in your relationship. Most say that getting the right support and good information can help enormously, both at this time and as their child learns to cope with the challenges that living with a disability can bring.

"Our longing for a son who might run and play football with his dad and brother has changed into a joy that he swings his foot at a stray potato which has fallen from the basket, without falling over. Our high hopes for an early articulate reader transformed into delight that he uses his signs to tell us that its milk he wants."

Parent



Getting support

If you're struggling with your own feelings, talking them over with someone you trust is likely to help. This might be your partner, your own parents, another family member, a friend or a professional involved in your child's care. Or you may find it more helpful to talk to other families who also have a disabled child and have had similar experiences.

If you have a partner, the way you communicate with each other will be a strong factor in determining how you cope in the long term with your child's additional needs.

"Keeping talking to each other and not bottling up our feelings – being truthful about what we really think about our situation."

Parent

Support and understanding from other family members can be a lifeline for some parents during a difficult period like this. Any practical support they can provide can make it easier to manage things like attending medical appointments and assessments. Emotional support can help you feel understood and more able to cope.

"Having a supportive extended family nearby [helped]. When our child was younger we would only leave him with close family members who understood his needs."

Parent

We produce a number of guides for families: 'Relationships', 'Siblings', 'Grandparents' and 'Fathers' that you may find helpful at this time.

Contact with other parents

Some parents find it helpful to chat to others who have gone through similar experiences. Many medical conditions that affect children (including some very rare ones) have a national support group, usually run by parents of a child with the condition. They can be invaluable source of support and advice, especially when it feels as if nobody else understands what you're going through.

"It has been really useful talking to other dads who are in the same position as myself regarding disabled children."

Sometimes there won't be a support group for your child's specific condition, but there may be a local multi-disability group for parents of children with any kind of disability. Contact a Family may have a volunteer parent representative in your area, too. If you don't have a firm diagnosis yet, there may still be groups that can support you around some of the challenges your child is experiencing, for example a charity for people affected by restricted growth. You'll meet other parents who have experienced the same feelings of isolation that you have, and who understand the feelings that having a disabled child can bring.

"It really helps being able to speak to other families with the same disability or just a special need and compare notes on benefits, therapies, medical experts etc. We use a local group who are excellent."

Parent

Call our helpline for details of national and local support groups for families caring for a disabled child. If your child has a rare condition for which there is no existing network of parents, our helpline will try to link you on a one to one basis with other parents caring for a child with the same condition. If you have access to the internet you may wish to visit our internet based linking scheme at Web: <http://www.makingcontact.org>.



Professionals and local organisations

Sometimes support from family members and friends can make you feel under more pressure – you may feel they are looking to you for information or you worry about how they might react. Or you may feel more comfortable seeking support from outside the family.

“Some of our family has given us a lot of support but unfortunately it feels that some have turned their backs on us or cannot face what is happening.”

Parent

Local disability and carer organisations can be an excellent source of information and support. They can tell you about local services for children with additional needs, help you to apply for benefits, and put you in touch with statutory services around education and getting a break from caring. Many are also able to provide counselling services. For details of organisations in your area ring our freephone helpline.

“In the end, a local charity provided us with counselling and I’m sure that is the main reason we are still together as a family.”

Parent

Talking to health professionals

Many parents describe the news that their child has a condition or is disabled in some way as a huge shock. It may be that in hearing the news, you aren’t able to take in any other information given to you. This is a very common reaction. To help you the doctor or therapist will usually send you a copy of the letter written to your GP.

It is very natural to expect answers straight away, but answers might not be possible for now. Over time you may find the relationship you develop with health professionals involved in your child’s care is quite different to what you’ve been used to in the past.

If you have an appointment coming up, think in advance of any questions you want to ask. To help you remember you could write a list of questions and take this with you. You can also take someone with you if you need support.

Questions you might ask include:

- What happens next? Do I come back and see you?
- Do you have any written information?
- Can I check that I’ve understood what you said?

If, at a recent appointment, you left without asking all the questions you think you needed to, you can always ask for any follow up appointment to be brought forward.

For more information on questions you can ask at an appointment get a copy of the leaflet 'Questions to Ask' by visiting the Department of Health at Web: <http://www.tinyurl.com/5vlc4m>

The leaflet is available in a number of languages and a paper copy can be obtained from: DH Publications Orderline, PO Box 777, London SE1 6XH Telephone: 0300 123 1002 (8am – 6pm Mon to Fri)

Other guides in this series

- 1 How we can help
- 2 Support for parents
- 3 What is developmental delay?
- 4 Understanding behaviour
- 5 Getting a diagnosis
- 6 What if we don't get a diagnosis?
- 7 What is a genetic condition?
- 8 Rare disorders
- 9 Sources of medical information
- 10 Concerned about your child
- 11 Practical and financial help

Getting in contact with us

Free helpline: **0808 808 3555**
Open Mon–Fri, 10am–4pm;
Mon, 5.30–7.30pm

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

Contact a Family Head Office:
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Other information available

- Relationships and caring for a disabled child (UK)
- Siblings (UK)
- Grandparents (UK)
- Fathers (UK)
- Disabled children's services (England & Wales/Scotland)
- NHS and caring for a disabled child (England & Wales)
- Holidays, play and leisure (UK)

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