

# News breaking and survival strategies



**Finding out that your child has special needs is likely to be very painful. For many parents this isn't the child that you expected or hoped for. You probably feel unprepared and fearful of what might happen in the future. If this is how life is for you right now, it may be worth thinking about what you can do to make better sense of what you are finding out and make life more manageable. Remember: You have the right to be given information in a respectful and sensitive way, delivered by specially trained staff.**

- TIP!** **If you are expecting news, take someone with you for support.** Distressing news is hard to hear and it's just not possible to take in all you are told, ask questions and keep an eye on your child at the same time.
- TIP!** **If English is not your first language, ask for an interpreter.** A good interpreter will help everyone understand each other's concerns more easily. Ask that letters, reports and assessments are translated into your language.
- TIP!** **Don't worry unnecessarily,** make a list of questions you want to ask and take this with you. Ask about the things you are most afraid of. Sometimes a consultant can give accurate information or advice that may reassure you.
- TIP!** **Ask if you don't understand** what has been said. If you are still confused, ask again until whatever is unclear has been explained so it makes sense.
- TIP!** **Ask what will happen next.** What is the plan? Who can you speak to regularly for advice? Where can you get written information about your child's condition, about services, benefits and practical help? Can services name someone who will co-ordinate information for you? (Some places call this person a 'keyworker' or 'care co-ordinator')
- TIP!** **Don't be rushed, take time to think.** If you have to make a difficult decision, say about treatment or surgery, and you don't feel confident that you have explored every avenue on your child's behalf, ask for another opinion.
- TIP!** **Professionals can't always tell you how things will turn out.** Accept that they try to respond to your worries as honestly as they can, even when they can't make a firm diagnosis, or predict how things might turn out for your child in the future; sometimes they just don't know.
- TIP!** **Professionals should do their best to share news sensitively** and use an approach and language that is respectful to you and values your child. If you are unhappy about the way you are treated, write and complain. If you just sit with your hurt or anger and say nothing, their practice won't change.
- TIP!** **Sharing news with other significant people** in your child's life, like siblings, grand parents and friends can be really tough, so ask for help. Your health visitor may also be a valuable source of help and support.

- TIP!** **In the early days or during a crisis**, appoint someone outside your immediate family, like mum, or best friend to be the contact person to field calls; let someone else pass on messages.
- TIP!** **Don't be afraid to say if you are struggling.** Unless you look like you are falling apart most people will imagine you are coping well. Gather people around you who listen and really try to understand.
- TIP!** **Try to keep a balance in your life.** Put yourself first sometimes – if you go under everyone will suffer. Not every minute of your child's life needs to be crammed with therapies and useful stuff. Everyone needs to relax and enjoy fun times as well, so make time to do things as a family.
- TIP!** **Talk about how you are feeling** with the rest of the family but avoid blaming each other. Families who talk, support each other better.
- TIP!** **Practice asking for help.** When you know what you need it makes it easier to accept the right offers of help, making your life easier.
- TIP!** **Be prepared to deal with well meaning but insensitive comments** sometimes, even from family and close friends. In time you'll find that you get better at hearing what people mean to say.
- TIP!** **Joining a parent support group can be a life-saver.** Meeting parents of older children with the same condition who have survived can help you feel that you will be able to manage. Other parents can be a great source of support and information. But make sure any groups that you join are supportive – if you come home feeling worse then it's not worth it.
- TIP!** **Specialist health visitors** are good at signposting to local sources of support.
- TIP!** **Contact a Family (CaF)** can help with general information about the diagnosis and the help that is available. They can put you in touch with a parent support group for your child's condition or disorder, even if it is a rare condition, or try to link you directly with another family if there's no suitable group. They have a free helpline: 0808 808 3555 (Monday to Friday, 10am to 4pm). [www.cafamily.org.uk](http://www.cafamily.org.uk)
- TIP!** **SCOPE's free CP Helpline** can put you in touch with a parent support group near you. Tel: 0808 800 3333 or access the Face to Face website at [www.face2facenetwork.org.uk](http://www.face2facenetwork.org.uk)



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