

# Making the best of an admission to hospital



Staying away from home can be a frightening experience for anyone, especially if we are unwell, around people we don't know and things happen to us without any warning. This is how in-patient treatment might seem to a disabled child, but there is a lot we can do to make it better.

- TIP!** Children have the right to have their parents stay with them in hospital. This is government policy, so check accommodation arrangements for parents beforehand.
- TIP!** You can stay with your child through any alarming procedures if you want to, like being in the anaesthetic room until they go to sleep before surgery or in the recovery room when they come round afterwards.
- TIP!** If your child's condition is likely to be unstable over a long period, try to negotiate an open admissions policy with the hospital, rather than using A&E. It helps to be reassured by familiar faces.
- TIP!** Check whether your child needs to be admitted. Sometimes disabled children are admitted for a common, minor ailment that would usually be treated in the community. Could your GP be supported to feel more confident about managing your child's everyday health needs?
- TIP!** Expect a safe and secure environment. If a situation feels risky, don't be afraid to explain your concerns and negotiate what can be put in place to minimize the potential say, for your child to self injure or wander off. Be prepared – this may mean staying with your child.
- TIP!** Share information. It helps to keep a folder of all relevant reports and make these available to hospital staff. But don't expect information you have given one department to filter through to the next by the time your child gets there. Be prepared to explain again. Stick important messages that you need everyone to know to your child's locker or above their bed.
- TIP!** Talk to everyone whenever you can, so that as many people as possible understand your child's needs, especially ancillary staff. They spend more time on the wards than doctors and are likely to have more time to sit, chat and play, and reassure your child when you cannot be there. Explain to other children in the ward. Get questions out of the way, it lets children get on.
- TIP!** Make sure you ask about the potential risks of different treatments. If you don't, you can't reassure your child or help them make informed decisions. Be sure to tell everyone about any medication your child takes; some lower blood pressure, and new medications may be incompatible.
- TIP!** Try to be honest with your child. Some days are likely to be painful or frustrating. Some treatment will hurt and sometimes they can't choose. **It's important that your child is able to make as many choices as possible**, both about their treatment and about everyday things like who helps them in the bathroom, mealtimes and what to watch on TV.

**TIP!** **How well will your child cope without food or drink** before a general anaesthetic? If they are likely to be distressed and confused, ask that they are first on the list for theatre. You may need to be assertive.

**TIP!** **If your child doesn't use speech to communicate**, you will need to explain how they communicate 'yes' and 'no' and show you what they need or want. You may need to teach staff some signs or how to use your child's communication book and, for some children, the importance of asking closed questions, using simple phrases and 'listening on all channels'.

**TIP!** **Your child may not be able to describe how they are feeling.** So talk to staff about changes in your child's body language, mood or pallor that would alert you that your child is in pain, too hot or too cold.

**TIP!** **Often children find it hard to say what they really think.** It can take a lot of effort and feeling unwell makes it harder to communicate their views. Who will speak up and say if something happens or is about to happen that will upset your child? Is this you? Or does your child need an independent advocate?

**TIP!** **Your child may well miss what's going on at school.** Help your child stay in touch with friends and with school by email. Ask around and see if you can borrow a laptop. Keeping in touch makes returning to school easier.

**TIP!** **Hospitals should be sensitive to any religious or cultural needs** that will make your child's stay in hospital easier to manage, but it may not occur to staff to tell you what is possible and how they can help unless you ask.

**TIP!** **The Children Act 1989** entitles children with ongoing medical or support needs to an assessment of need. Alongside this you should ask for an assessment of your needs as a carer. Discharge planning is about putting together a care package to meet all these needs. Agreeing who is responsible for funding nursing care, training, equipment, aids and adaptations at home can be complex and take time. So it's worth checking that your child's community nursing team are anticipating their needs early on, or your child's stay in hospital may be longer than either of you would wish.

**TIP!** **The government have set** out the standard of care that all children in hospital should receive. You might find it useful to see a copy beforehand. Get a free copy of *What should a really good hospital look like?* from: Department of Health, PO Box 777, London SE1 6HX or from the NHS Response line on: 08701 555 455. **The government also** provide information about access to education for children and young people with medical needs. Check out: [www.dfes.gov.uk/sickchildren/](http://www.dfes.gov.uk/sickchildren/)

**TIP!** **The National Association for the Education of Sick Children (NAESC)** can offer advice and a free directory of education provision for sick children. See [www.sickchildren.org.uk](http://www.sickchildren.org.uk) or call: 01332 63 85 86.



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