



WHEN YOUR CHILD IS IN HOSPITAL – MAKING THINGS MORE MANAGEABLE

Taking your child to hospital can be a worrying time, and it helps to always plan ahead if you can. This factsheet looks at making hospital appointments and admissions better.

FACE-TO-FACE APPOINTMENTS VERSUS VIRTUAL APPOINTMENTS

Many hospitals and clinics are now offering virtual appointments. Virtual appointments can be beneficial if travelling is difficult, expensive, or if your appointment is for something straightforward. But some parents find they prefer to see professionals face-to-face. A face-to-face appointment can be useful particularly for initial diagnosis to make sure you get all the support available. Speak to your child's team about what is being offered.

TELLING SCHOOL

Tell your child's school about your appointment or stay with plenty of notice. This can help school to understand how long your child may be off, what arrangements may need to be in place when they return, and to give them an opportunity to prepare remote school work. Schools must authorise an absence where a child is ill or has a medical appointment. You shouldn't be asked for a doctor's note for every single absence, but it will be helpful to share information with the school about your child's condition and the likely effect on attendance.

Once in hospital your child may find the hospital school a good alternative, and an opportunity for them to have a break from the ward.

SIBLINGS

Try and make childcare arrangements for any brother or sisters if possible, taking them with you can be a challenge. Some siblings will also get anxious about their brother or sister going into hospital, take time to talk this through with them.



WHAT IF MY CHILD DOESN'T WANT TO GO INTO HOSPITAL?

Not wanting to go into hospital for appointments or stays is normal. Your child may associate hospital with negative experiences, like fear or pain. Others may find being separated from family members and friends very hard.

Give your child time to communicate their worries, and try to explain what will happen during their visit as best you can. Some hospitals have Play Therapists and Learning Disabilities Teams who may be able to help, and may have resources you can use to help prepare your child.

What you can do to prepare you child

You might want to prepare your child yourself by using 'social stories' or comic strip conversations to help your child understand what's coming next so they can deal with what's happening. Social stories and comic strips describe a situation and focus on a few key points, such as what will happen and how people might react. They

aim to increase a child's understanding and make them more comfortable in different situations. You could also use "now/next" visual timetables, apps or videos to prepare them. We've listed some resources below.

Resources to help

The National Autistic Society

Information on social stories and comic book conversations autism.org.uk.

The Council for Disabled Children

Information on now/next time tables councilfordisabledchildren.org.uk

My Hospital Journey colouring book

For children to take with them to hospital about what will happen and who will be there, with activities to complete. mefirst.org.uk

Hetty's Hospital

Free interactive app designed to help children reduce their anxiety when visiting hospital mefirst.org.uk

What? Why? Children in hospital

Short videos to help children prepare for many common procedures. They also have a section on anxiety with mindfulness relaxation videos you can play your child. whatwhychildreninhospital.org.uk

BEFORE YOU GO

If your child is to be admitted to hospital, telephone ahead to let them know your child has additional needs.

Ask for a pre-admission meeting with a senior nurse on the ward where your child will stay to discuss your child's additional support needs. If your child has a learning disability, ask if the hospital has a Learning Disability Nurse and try to speak to them as well. They can be very helpful in liaising with hospital staff to make sure the stay is less stressful for your child.

Write down all the things that your child might find particularly stressful and how they are likely to respond. Take this with you. It is also useful to take this with you if your child has to go to hospital in an emergency.

Hospital passports

Some hospitals have their own hospital 'passports', which can include information about your child's needs, what treatments they're receiving and from which different professionals.

The passport is also useful in explaining what might upset your child, how they express themselves, routines they follow and how to tell if they're in pain. You can bring this to GP or hospital appointments.

 Download a [hospital passport template](#) from Mencap.

GETTING THERE

Travelling to medical appointments can be costly. Some hospitals will offer discounted parking fees to parents, or you may be able to claim a refund of reasonable travel costs to attend hospital appointments if you receive a qualifying benefit, or if you meet the NHS low Income Scheme criteria. Some grant-making organisations give grants to help traveling to and from hospital stays and appointments.

WHERE TO STAY

If your child is staying overnight or longer in hospital, you will want to think about accommodation. Generally wards will guarantee that one parent will be able to stay with your child – this may be at their bedside in a chair or fold out bed. The hospital may be able to offer you space in their parent or family accommodation if it is available. Depending on the hospital, there might be charity owned accommodation close by, such as Ronald MacDonald house, or the Sick Children's Trust. Contact your child's ward to ask about these options.

WHAT TO BRING

- *Your child's medicines*
- *Any specialist equipment needed*
- *Your Child Health Record (red book) or Hospital Passport – these can be really useful*
- *Daytime and night time clothes – you may be asked to stay in even if it's a day appointment*
- *Nappies or pads and wipes to last for your whole stay*
- *Toothbrush, toothpaste and other wash things*
- *Any bottles or cups that your child prefers*
- *A favourite toy*
- *Don't forget to pack for yourself as well!*


BENEFITS AND FINANCIAL SUPPORT

Hospital stays can be expensive. After five days or more you may be eligible for certain grants to help with hospital costs, such as from the Family Fund. You can ask the ward staff about these.

You may also be able to claim Disability Living Allowance (DLA). DLA can be claimed from the age of three months or from birth if your child has a terminal illness. If you are already receiving DLA for your child, this should not be affected by a hospital stay so long as they are under 18.

Breastfeeding mums are generally entitled to free meals within the hospital. Meal vouchers for low-income families may be available to parents. Call the hospital ahead of your visit to discuss these.

Some grant-making organisations offer financial help to families with children in hospital.

 Use our grants finder to search for grants and financial support at [contact.org.uk/grants](https://www.contact.org.uk/grants)

TIME OFF IF YOU WORK

Parental leave gives parents the right to take time off work to look after their children. Parental leave is normally unpaid but some employers have more generous provisions. Check your contract of employment.

All parents have the right to request parental leave if they've worked for the same organisation for a year or more. If your child is receiving DLA, you can take leave one day at a time, which you may use for attending hospital appointments. You will need to give at least 21 days' notice. The maximum amount of leave a parent can take for any one child in one year is normally four weeks, but some employers can be more generous

You also have the right to apply to your employer for flexible working arrangements, for example a change to the times or hours you work or the option to work from home.


 Visit [contact.org.uk/flexible-working](https://www.contact.org.uk/flexible-working) for more details about flexible working and time off

WHEN THINGS AREN'T RIGHT


The majority of all hospital admissions and appointments go as planned, but if you feel unhappy with your child's care or support they receive, you may want to get in touch with the Patient Advisory Liaison Service (PALS). PALS can offer confidential advice, support and information on health-related matters. There is usually a PALS office near the hospital entrance.

WHAT IF I DISAGREE WITH A DECISION?

Most decisions about your child's care will be decided together by you and your child's team, but occasionally you may find that you disagree with the decisions made. PALS are a good starting point to resolve this, or you can make a complaint about any NHS service.

 Visit the NHS website to and look for [making a complaint](#)

Sometimes it may be necessary to get a legal opinion or take legal action to put things right. If you would like to look at your legal options, including Clinical Negligence

 Visit [contact.org.uk/clinical-negligence](https://www.contact.org.uk/clinical-negligence) for more details about flexible working and time off

 FREEPHONE HELPLINE
0808 808 3555
helpline@contact.org.uk
www.contact.org.uk

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