

# Coping when your child is ill: information for families

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We recognise that life can be overwhelming when your child is unwell or in hospital. You may put your own feelings aside to concentrate on looking after your sick child – this is normal. You may have to juggle lots of things. It is important that you take care of yourself as well, so that you feel in a position to tackle the challenges ahead, and be alongside your child or young person as and when they need you.

There may be some small but significant things we can do together to support your wellbeing. We hope this information sheet from Great Ormond Street Hospital (GOSH) gives you a few ideas about some of the things or situations issues you might be facing and suggestions for how you could deal with them.

All the ideas come from our play team, who have spent time supporting and listening to children, young people and families. If you have any ideas of your own or tips or suggestions that have worked for you, please contact us to tell us about them.

## Visiting and staying in hospital

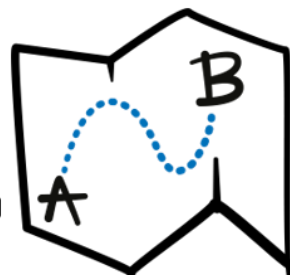
Families have shared with us that sometimes when your child is unwell, or has additional needs, life can seem to be a never-ending cycle of appointments and admissions, both at GOSH and nearer home.

- If there are other adults in your family, can you try to share duties with them to reduce the amount you have to do?
- Perhaps they could help you get to GOSH or keep you supplied with food and drink while you are there.
- Could they collect your other children from school/nursery and provide a snack while you make your way home from hospital.

- When you are staying with your child in hospital, it is easy to forget about your own needs. Things like taking regular breaks – get something to eat and drink, walk around the block, or visit the gardens to get some fresh air or just to have a shower.

Some wards have ‘buddies’ – volunteers who have had training to support you as a parent. They can spend time with your child to give you a break – playing games with them or reading to them.

There may be regular coffee mornings or afternoon teas for parents – this is a good opportunity to meet other parents on the ward and share each other’s experiences – ask your nurse or PALS for details.



## Stay involved

Some parents share with us that they feel 'left out' when their child is in hospital as they are not their child's main carer anymore.

- We recognise you as a valued member of the team caring for your child. We want you to be involved as much as possible in your child's daily care, doing everyday things like washing and feeding your child, changing their nappy or playing games, as much as possible keeping to a routine that is familiar.
- Remember that although the doctors and nurses are experts in caring for children who are ill, you are the expert in your child. You have the best knowledge of how they usually behave, what they like or dislike and how to offer comfort when upset. Please tell the ward team any important information you think they should know about caring for your child.

## Ask questions

Asking questions is always important. You need to know what is happening to your child so that you can carry on caring for them while you are in hospital and once you go home. Your child's nurse is probably the first point of contact for any questions.

If you want to see your child's doctor, please ask the nurse to arrange this. You may want to chat more about the day's decision making. It isn't always possible for the doctor to come immediately, especially if they are in clinic or the operating theatre.

- Writing down questions and thoughts can help you remember things at a time when you may have lots of different things on your mind. Carry a notebook with you or use the 'notes' facility on your phone, so you can write things down as you think of them.
- If you forget something or struggle to understand what we tell you, please ask us to repeat it again. We won't mind, as we want

you to understand what is happening with your child.

## Practical matters

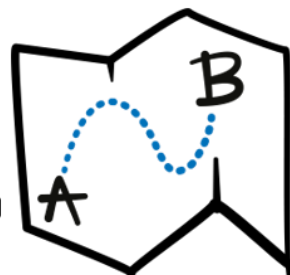
This can be the time to call in favours from family and friends, particularly if there are complicated school runs or activities to organise.

- Even if your children at home have their other parent or another relative they know well to look after them while you are staying in hospital, routines will change and things will be different.
- If they are not sure what needs to happen at what time, filling in a care schedule or a weekly planner can help. There is one in our Family File you can download and complete.
- If at all possible, brothers and sisters should carry on going to school or doing their usual activities – ask for help from other parents if it is difficult to juggle several things at once. Tell the school or activity leader that your child is in hospital – it is helpful for them to know just in case of problems.

## Look after yourself

It is easy to 'forget' to eat and drink when you are concentrating on your child. Although many wards have hot drinks and toast available, you need to have something a bit more substantial to keep your energy levels going.

- Take a break in the Lagoon Restaurant on the ground floor – you can get food and drink to take away as well as eat there. Out of hours, there are vending machines where you can get a snack too.
- In addition, there are lots of supermarkets in the local area – ask at the Pals Office for details.
- If you need some fresh air, visit our Morgan Stanley Garden by Medical Illustration. There's also Queen Square at the end of Great



Ormond Street if you want time out of the hospital.

- Keeping to a daily routine helps you and your child – make sure you both have something for breakfast and schedule breaks for yourself throughout the day.
- Some people turn to alcohol or cigarettes when they are stressed or feeling down. Remember that alcohol and cigarettes (including e-cigarettes) are not allowed anywhere within GOSH.

## Make use of technology

In some ways, now it is much easier to keep in touch than it was previously.

- You can use our free Wi-Fi to save data charges on your mobile phone or laptop.
- Video calling can reassure your sick child and family at home – as well as talking to each other, they can keep an eye on their pet if they have one. Talk to ward staff to see when would be a good time to video call when you are unlikely to be interrupted.

Sign up for MyGOSH to help keep yourself organised – this gives you access to certain parts of your child's medical record, such as appointment/admission details and test results. You can access MyGOSH from anywhere on your own device, including when you have gone back home.

Keeping in touch with friends and family is important but it can feel like you are repeating the same information over and over to different people.

- Some families have found nominating a 'buddy' to pass on updates is helpful or you could set up a closed chat group on WhatsApp™ for instance.

## Juggling work and hospital

It can be a struggle keeping up with work when your child is ill. Talk to your employer about your situation to see if they can do anything to help – we can give you a letter to pass on to them.

- You may be able to work remotely while your child is staying with us – ask for details of our free Wi-Fi so you can save data charges on your phone or laptop

## Explaining to other people

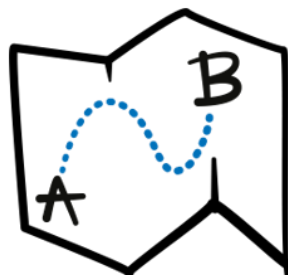
You might be worried about how much information about your child you can share with other people. You know them best so can tailor what you say to what they need to know.

- If you are worried about how they will cope if the information is difficult, give them details of organisations that can help. It is up to them to seek support if they need it – your priority will rightly be your child and family.
- It can be tempting to upload regular updates including photos and video to your contact group. Please remember not to include any members of staff or other families. There are certain areas of GOSH where you cannot take photos or video as well.
- Remember that once something is online, it can easily be shared outside your control. It is likely to be available for ever, so think about how your child will feel when they are older before you share anything.

## Dealing with feelings

Talking about your experiences can be a great release. If you have a partner or family member with you in hospital, make time to have a chat about how the day has gone.

Remember that everyone deals with stress in a different way, so don't be upset if your partner or other family members are not affected by the same things as you.



- If you are struggling, and would like to talk, there are lots of people at GOSH who can help – see the suggestions below. This can be as simple as having a chat with your specialist

nurse or we can arrange more formal support with our psychology team. We want you to ask for help – you are an important part of your child’s team.

## Further information and support

At GOSH, **psychosocial teams** are groups of highly trained professionals, including social workers, family support workers, family therapy and clinical psychologists, with expertise in caring for children, young people and families in hospital. All wards and departments can get in touch with the psychosocial service.

The **Patient Advice and Liaison Service (Pals)** team can give you confidential advice and support about any issues that crop up while you are visiting or staying at GOSH. Drop into the office in main reception, call them on 020 7829 7862 or email [pals@gosh.nhs.uk](mailto:pals@gosh.nhs.uk)

The **Chaplaincy and Spiritual Care** team offer spiritual, religious and pastoral care to staff, families, and children of all faiths or none. They visit the wards regularly and also provide a 24-hour on-call service every day of the year. Visit the Chaplaincy Office by St Christopher’s Chapel, ask a member of the ward team to contact them or email [GOSH.Chaplaincy@gosh.nhs.uk](mailto:GOSH.Chaplaincy@gosh.nhs.uk)

**Support organisations** for specific conditions can be very helpful and the Patient Advice and Liaison Service (Pals) at GOSH can put you in touch with a relevant organisation. The umbrella organisation Contact (previously called Contact a Family) produces helpful information sheets. You can telephone them on 0808 808 3555 or visit their website at [www.contact.org.uk](http://www.contact.org.uk)

**Sibs** is a UK organisation especially for children, young people and adults with a brother or sister who is ill or has additional needs. As well as information, they hold regular family days so your other children can meet others in a similar situation. Visit their website at [www.sibs.org.uk](http://www.sibs.org.uk) for further details.

**Family Lives** (formerly Parentline Plus) is a registered charity that offers support to anyone parenting a child. Call them on 0808 800 2222 or visit their website at [www.familylives.org.uk](http://www.familylives.org.uk)

The **Samaritans** offer emotional support to anyone in distress. Call their helpline on 116 123 (you don’t need a dialling code), email [Jo@samaritans.org](mailto:Jo@samaritans.org) or visit their website at [www.samaritans.org](http://www.samaritans.org)

**Adviceguide** is the online Citizen’s Advice Bureau service that gives you information on a wide range of topics, including benefits and employment, and debt and legal issues. Visit their website at [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

The **Child Death Helpline** is a Freephone service for anyone affected by the death of a child. If you are using a mobile phone call 0808 808 6019. Their website is at [www.childdeathhelpline.org](http://www.childdeathhelpline.org)

