

Supporting you when your child is ill or has additional needs: how GOSH can help

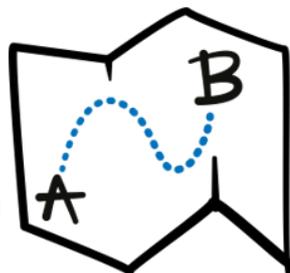
We recognise that life can feel overwhelming when your child is unwell or has additional needs. You may put your own feelings aside to concentrate on looking after your child – this is normal. You may have to juggle lots of things – everyday life, work and family – with little time to look after your own health and wellbeing. 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 issues or situations you might be facing and suggestions for how you could deal with them. Remember, we want you to be as well and happy as you can be so you can work with us to help your child reach their full potential.

Many of these ideas are based on suggestions from the Patient Experience team, but we have also spoken to families of children who are unwell or have additional needs to find out what works for them. If you have any helpful tips and tricks that you would like to pass on to other families, please get in touch with the Pals team in the first instance.

Living day to day

It can be hard to juggle looking after your child when they are ill or have additional needs – we know this from talking to many families over the years.

- Try to get a routine – this helps to know what needs doing, what time it needs doing, where you need to be and when. This can be hard enough with one child but if you have other children too, it will take some organisation! Some families have a calendar on the fridge, colour coded to show which family member needs to be doing what and when. Others find an app on their phone helps. You know your family best, so try lots of different things until you can find something that suits.
- If each day seems to be an unending cycle of feeds, dressings, exercises and so on, let alone other daily tasks like getting washed and dressed, talk to your clinical team. They may be able to advise on whether there is any flexibility around when you do things or make suggestions as to alternative approaches.
- Share information about your child – families have told us that making sure everyone has the same level of understanding about what your child needs can be hard. Why not keep a hospital passport (or equivalent) so all the information is in one place – what support your child needs with everyday tasks such as washing, dressing and eating, as well as care needs, such as medication. You can also include your child's likes and dislikes in the



passport too, so that someone looking after your child knows what to do, what is important to them and what to avoid.

Managing healthcare appointments

Families have shared with us that sometimes when your child is unwell or has additional needs, you can have so many appointments and admissions that it is difficult to fit in anything else.

- 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 the appointment 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.

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 away, 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.
- 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.

Look after yourself

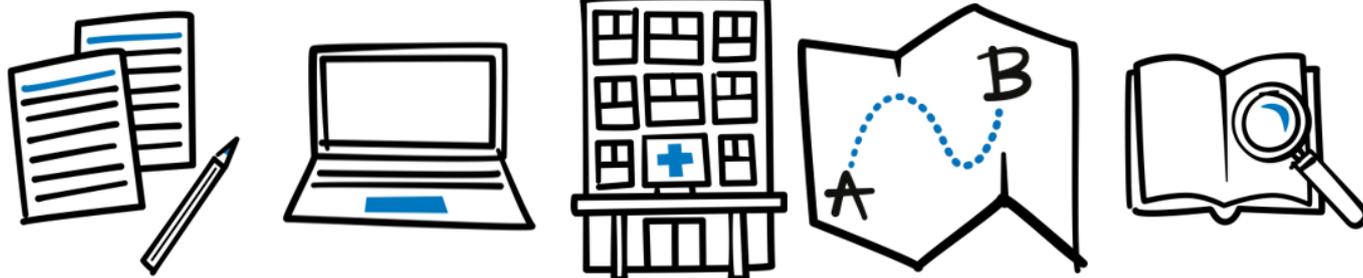
It is easy to 'forget' yourself when you are concentrating on your child. We know that when a parent is struggling, their child may pick up on this too.

- If you're finding things difficult, tell someone. This can be anyone – family, friends, your family doctor (GP), faith leader or anyone who can listen to what you're saying. There are also people you can call or text – see suggestions at the end of this information sheet.
- Find out if you're entitled to any further support – many families of children who are unwell or have additional needs are entitled to benefits. Check with your local Citizens Advice or visit their online directory at www.adviceguide.org.uk.
- Think about how you can have some 'me' time. There may be some time during the day when you could have some time to yourself – perhaps when your child is having a nap, at school or nursery, in respite care or with their other parent. Tempting though it might be to use this time to catch up with household tasks or even having a sleep, try to find a way to unwind.

How we can help

At GOSH, our commitment is to always put the child and young person first and to work in partnership with you, their family, to make sure they reach their full potential. As much as we care for children and young people, we can't do it without you, so if we can help at all, we will. If you need help and support, please contact a member of your child's clinical team. Where possible, we will work with your local services to make sure you have what you need. We will always ask your permission before we involve other organisations, unless we are concerned about the safety of your child or someone else.

If you don't receive a call, you can always contact our Patient Advice and Liaison Service (Pals) who can find the right person to help. Call them on 020 7829 7862 or email them at pals@gosh.nhs.uk.



Further information and support

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

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

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

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 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

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 or visit their website at www.samaritans.org

Adviceguide is the online Citizens Advice 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

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

