

# Supporting and advocating for your child with additional needs: information for families

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When your child has additional needs their voice may not always be heard and you might find yourself speaking up for them. This is called ‘advocacy’ and is something that a lot of parents do naturally for their child. Being an advocate is more than complaining when something isn’t right – there’s a lot you can do to effectively advocate for your child, working with professionals to reach the right solution. This information sheet from Great Ormond Street Hospital (GOSH) explains how you can gain the skills you need to be an advocate for your child.

Advocacy means supporting someone to make their views heard, be as involved in decision making about them as they want and ensuring that they have all the support they need. Lots of people could benefit from having an advocate – especially children and young people with additional needs – to ‘fight their corner’.

Remember, you know your child best so you will already have a good idea about what they need. Try some of these suggestions to make your advocacy more effective.

## Know what’s going on

It helps to know the full situation first – if changes are proposed at your child’s school, see what the head teacher says rather than what you hear at the school gates or on social media.

For instance, it might be helpful to find out how many people the proposal might affect. Will it affect some, such as those who are on family credit, more than others?

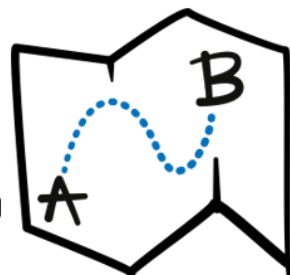
An awful lot of problems are due to poor communication – get the facts before you start making up your own mind.

## Think about how this could impact your child

It’s natural to fear change but rather than fight change, it’s sometimes worth looking at the situation dispassionately to see if and how it could affect your child – either positively or negatively. You could think about:

- Whether this would stop your child taking part or make it more difficult?
- Would this free up some time for your child to do something else they enjoy?
- Could this make things easier for your child and ‘level the playing field’ a bit?

Don’t be afraid to think ‘what if’ to find solutions – they won’t all cost money so might be possible. Talk over your plans with your child and the rest of the family. Perhaps talk to a support organisation



or other families in a similar situation to see if they have any ideas.

## Prepare your solution

If you're upset about something, it's easy to go in 'all guns blazing' and argue passionately for or against it. However, it can be more effective to keep calm and present your solution in an organised way, showing you have thought through the idea logically.

Don't be afraid to make a bullet point list of your key points so you can work through them in order. This can be useful if you are speaking face to face to someone as well as a reminder if you are writing to them.

Try to find out who will be involved in making the decision. Check their website or talk to someone in children's services. Are the proposals due to be discussed and are they taking 'evidence' from families affected?

Identify people or organisations who can support you. This could be support organisations for your child's condition or more general ones around disability or schooling. You could contact your Member of Parliament – you can find their details on the [www.gov.uk](http://www.gov.uk) website – or someone of standing in your community. If you know of similar proposals elsewhere, get in touch with people involved to learn valuable lessons from them.

## Check that you understand the response you get

It can be helpful to repeat back what you have heard to make sure you've got the message right. You could say something like:

*"Can I just check I've got this – you're proposing to ..."* or *"So this would mean ..."*

Remember, if you don't understand what they are saying, ask them to explain in a different way.

## Understand your child's rights

It can be useful to have a working knowledge of the law and how it applies to your child. For instance, the Equality Act 2010 protects the rights of people with a disability or from a specific background. Contact the Children's Law Centre at [info@childrenslawcentre.org](mailto:info@childrenslawcentre.org) for help. Your local Citizens Advice Bureau could help too.

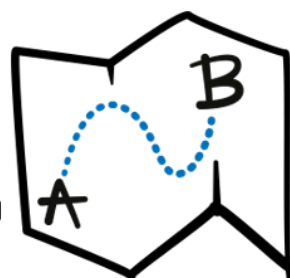
## Help your child to advocate for themselves

As with everything, your child will learn how to do something by copying what you do – if they see you approach change in a calm way, they are likely to do the same.

You can help your child to become more independent in lots of ways – perhaps you could read stories or watch programmes that feature children and young people standing up for themselves and speaking out when something isn't right. You could help them develop a 'script' of things to say if something questions their additional needs or the support they need.

## Ask for help

Remember, you are not alone – there are lots of people at GOSH and in your local community who can help you be an advocate for your child. They don't have to be a professional advocate – just someone who can listen to you and help you to speak up for yourself and your child.



## For example

*You may have heard at the school gates that the local authority is looking to cut costs and limit transport to your child's school. Taking your child yourself isn't possible because of your work but you can't afford to pay more.*

*The first thing is to find out the facts – what is the local authority proposing? How would their proposal work in practice?*

*Work out how this could impact your child – are the local authority limiting the distance travelled to school and how far away do you live? Is there anyone else in the area going to the same school and could share transport?*

*Think about possible solutions – if your child didn't go to school, how would you manage with home-schooling or childcare, how would this affect the rest of the family, could you carry on working or would this be more difficult? Is there another way of getting your child to school – if the minibus is only half-full, would using a local cab firm for fewer children be more reasonable?*

## People who can help

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)

**Mencap** – call their helpline on 0808 808 1111 from Monday to Friday from 8am to 6pm or visit their website at [www.mencap.org.uk](http://www.mencap.org.uk)

The **National Autistic Society** – call their helpline on 0808 800 4104 from Monday to Friday from 10am to 3pm or visit their website at [www.autism.org.uk](http://www.autism.org.uk)

**Scope** – call their helpline on 0808 800 3333 or visit their website at [www.scope.org.uk](http://www.scope.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)

