



**Supporting children  
with a learning  
disability in hospital-  
a resource for parents of  
children aged 0-5**



**As the parent of a child with a learning disability, you'll know how important it is that they get the best quality of healthcare possible – just the same as anyone else. That is why Mencap is campaigning to transform how the NHS treats people with a learning disability in hospital.**

We have partnered with Bradford People First and Bradford Talking Media to produce this resource for families supporting children with a learning disability in hospital.

Medical staff play a vital role in making sure that, right from the very start, your child has the most positive hospital experience they can. These first interactions can help to pave the way for more equal healthcare throughout your child's life. Good, positive treatment, communication and support can make a big difference.

## Life with a learning disability

Having a learning disability is just a small part of who your child is - the disability does not define them. Every child with a learning disability is a unique individual, with their own needs. With the right support, children with a learning disability can grow up leading fulfilling, happy lives in the way they choose.

The life chances of people with a learning disability is significantly influenced by their ability to receive the right care and support in their early years. Hospitals are uniquely placed to have these early interactions and therefore to act to ensure support is in place in a timely way.

## Diagnosis

Understanding a person's needs is often the first step in helping to make sure they get the support they might need to live a healthy, fulfilling life.

Professionals may refer to this process as diagnosis, but what it really means is knowing what areas of someone's life they might need more help in.

A diagnosis can be seen as a positive step - it can help you to understand what your child is experiencing. It can also give you access to resources that will help you and your child, including support around education, health and social care.

As a parent of a child with a learning disability, one of the biggest challenges could be coming to terms with the fact that your child's future may be different from the way you imagined it.

This may be a challenging time for you.

Support is also available for you as a parent. Looking after yourself is an essential part of caring for someone with a learning disability. Support groups, helplines and information and advice are available if you need them. Your local authority's online Local Offer will set out what is available to you locally.

For more information about diagnosis and the support that's available read our resource for parents – [Supporting families through a learning disability diagnosis](#).



## Getting the right healthcare is the law

Did you know that all disabled people have the right to reasonable adjustments when using public services such as healthcare?

This is the law under the Equality Act 2010, which exists to protect people from discrimination.

**72% of families are not aware of what reasonable adjustments are in relation to the hospital care of their child (Mencap early years survey, 2020)**

Reasonable adjustments are simple changes that could help your child get better healthcare. Any member of staff you encounter in hospital is required to help with a reasonable adjustment, whether they are a porter, receptionist, nurse or doctor.

Reasonable adjustments can be anything, including appointments at a time that works best for your family, providing a quiet space to wait, communicating in a way that your child understands, for example by using Makaton, and providing easy read information.

**33% of families feel unconfident about asking for reasonable adjustments for their child when attending hospital (Mencap early years survey, 2020)**

There are lots of reasonable adjustments that can be made and it is important that you ask for anything that would meet your child's needs. It is your right to ask.

**You can find a list of our Top 10 Reasonable Adjustments on Mencap's website: -**

[https://www.mencap.org.uk/sites/default/files/2020-03/2019.070%20Treat%20me%20well%20childrens%20campaign\\_Make%20your%20childs%20voice%20heard%20V1.pdf](https://www.mencap.org.uk/sites/default/files/2020-03/2019.070%20Treat%20me%20well%20childrens%20campaign_Make%20your%20childs%20voice%20heard%20V1.pdf)



## Supporting your child in hospital

It is important that you know your rights when supporting your child in hospital. Knowing what you are entitled to will help make sure they get the right treatment and care.

Remember that you know your child better than anyone and can act as a voice for them. You can ask for things that can help them, such as reasonable adjustments, and you can influence the care they get in hospital.



## Speak to hospital staff about your child

Good communication can make a big difference to the support that you and your child receive.

By talking to healthcare professionals, you can explain what is best for your child. Remember, you are the expert on your child and professionals will benefit from what you tell them.

It is important that healthcare professionals listen to what you say about, for example, how your child expresses pain or how they show that they are happy.

Also, encourage healthcare professionals to speak and listen to your child, not just speak directly to you. This will help build rapport and empathy.

**It is important that all hospital staff that you come into contact with understand that your child has a learning disability.**

If you feel that a member of staff does not understand or does not make the reasonable adjustments you ask for - for example, if a hospital receptionist does not allow you a quiet space to wait - you can ask to speak to the learning disability team on site.

**The hospital's staff should work with you to make sure that appointments are as positive as they can be.**

Healthcare professionals often use complicated terms or medical jargon, but it's important that you understand what is going on.

**Speak out if you don't understand what they're saying and ask them to use clear, simple language. And as your child grows up, encourage them to do the same - this will empower them in the future.**

Make the hospital staff aware if you have additional caring responsibilities, and ask them to be flexible and make appointments that fit around your family's needs.



## Use the hospital passport

The hospital passport is a document that explains important medical and personal information about your child.

### It's your child's right to have a hospital passport.

It includes information about their health, ability and needs. For example, what their interests are or how they must have their food prepared.

It can even include information like your child's favourite football team or their favourite cartoon.

This information can help healthcare professionals relate to your child on a personal level, which can help reduce their anxiety.

The passport allows the person reading it to have a better understanding of your child so that they can treat them more equally.

Check that the staff have read your child's passport so they know how to support their needs.

The passport can be updated regularly as your child grows and their needs change.

There are lots of different versions of the hospital passport, but your hospital learning disability team will be able to point you toward the version that they use, and can support you with filling it in.



You can also download a hospital passport template from the Mencap website - <https://www.mencap.org.uk/advice-and-support/health/health-guides>.

## During COVID-19

Some hospitals may have special measures in place because of COVID-19, and this may affect what reasonable adjustments they can make during the pandemic.

However, hospitals should still try to be flexible and accommodate your child's needs wherever possible.

Mencap ran a survey with 116 parents or carers of a child with a learning disability aged between 0-5 years responding. We asked families in Northern Ireland, England and Wales about hospital care for their young children. The survey ran from 28/09/2020 to 21/10/2020