Your guide to

Having a child with a learning disability
About this guide
This guide has been written for parents to give them an introduction to learning disability and receiving a diagnosis. It provides information about supporting other family members and planning for the future, and a guide to some of the professionals you may come into contact with.

This guide also contains lots of information on action you can take. Look for the What next sign for things you can do.
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Having a child with a learning disability

Finding out that your child has a learning disability can be a confusing and emotional time for parents.

While some may receive a specific diagnosis, others may be told their child has global developmental delay, or in some cases may never receive a specific diagnosis at all.

As well as dealing with your own emotions and concerns for the future, you may also need to offer support and advice to other family members such as partners, children and grandparents. You will come into contact with a number of different professionals during this time, and at some stage will want to find out more about your child’s condition and learning disability itself.
What is a learning disability?

For many parents, learning disability can be a difficult subject to understand and explain to others.

While some parents may be told their child has a specific condition, others may only be told their child has a developmental delay, or in some cases they may never receive a diagnosis at all.

There are different types of learning disability, which can be mild, moderate or severe. In all cases a learning disability is lifelong.

Someone with a learning disability may have difficulty in understanding or using written or spoken language, and may need support to do some everyday things. It can be difficult to diagnose a mild learning disability as the individual will often mix well with others and will be able to cope with some of the tasks presented to them. However, they may need support in other areas of their life such as shopping or filling out forms.

“Our son was three months old before I knew he was not as responsive as his two sisters had been. The health visitor assured me not to worry, but by six months I expressed my concerns to my GP. Deep down I knew there was something wrong with my baby.”

For those with a moderate learning disability or profound and multiple learning disabilities (PMLD), more care and support is required to help with areas such as mobility, personal care and communication.
For any parent, the greatest concern will be your child’s wellbeing and their future. As a parent, you can help your child by encouraging their strengths and getting the right support to help them overcome the things they find difficult. Every child is an individual with their own specific needs, but with the right support children with a learning disability can succeed in school and in life.

What next?

- Find out more about learning disability and its causes and conditions at www.mencap.org.uk/learningdisability
- Read the Mencap guide ‘Telling other people about your child’s learning disability’ at www.mencap.org.uk/tellingotherpeople
What causes a learning disability

There are many possible causes of learning disability, which can occur before, during or soon after birth. They include environmental, genetic and chromosomal factors.

Before birth, causes can include:
• if the mother has an accident or illness while pregnant
• any situation that contributes to low birth weight
• when something happens to the central nervous system (the brain and spinal cord)
• how genes develop while the unborn baby grows.

During birth, causes can include:
• trauma to the baby’s head
• other trauma or distress
• if the baby does not receive enough oxygen
• premature birth.

After birth, causes can include:
• physical trauma to the brain as a result of an accident
• childhood illness and infections
• seizures
• cancer, a brain tumour or an infection of the central nervous system.

What next?
• Find out more about learning disability and its causes and conditions at www.mencap.org.uk/learningdisability
Receiving a diagnosis

Parents who have a child with a learning disability may receive a diagnosis at any time.

Some associated conditions may be diagnosed during pregnancy or immediately after birth, but in some cases the learning disability will not present itself for weeks, months or even years.

The early signs of a learning disability can be difficult to spot, but there are some indications to look out for.

• Babies may have trouble nursing, for example sucking and digesting.
• In the early stages children may show delays with sitting or standing.
• Pre-school children may be slow to talk or have difficulty in pronouncing words and short sentences, or learning new words.
• School-aged children may find reading and writing difficult or have problems understanding information and instructions.
• Some children discover they have a learning disability when they become teenagers and their life becomes more complex, with new emotions and responsibilities.

After receiving a diagnosis, some parents find support and information from professionals is essential, and finding out as much as you can about your child’s condition can help you to cope and plan for the future. However, other parents find their emotions are enough to deal with at this time, and prefer to get to know their child as an individual before finding out more about their learning disability.
Reports have indicated that parents sometimes feel isolated after a diagnosis, as professionals can be insensitive or fail to give timely or accurate information about their child’s diagnosis. Professionals can be confused by some characteristics of learning disability, and experts themselves can struggle to make an accurate diagnosis.

In many cases, there are no obvious physical signs that someone has a learning disability, which can also make it harder to diagnose. It is often parents or teachers who first become aware that a child is having difficulties in certain areas of their life, long before any assessments are carried out.

If your child has not received a diagnosis but you have concerns about their development, you should contact your GP who should be able to offer advice and refer you to a specialist if necessary.

“I knew straight away my daughter had Down’s syndrome, having had three daughters before. I just wanted to go straight home where I could feel secure.”
Getting the right support after a diagnosis

Being told that your child has a learning disability can be a distressing experience for parents.

Your emotions may vary wildly, and parents have told Mencap that they were quite frightened by the feelings they had at this time. However, it is important to remember that this is perfectly normal, and you are not alone.

Such news can bring forth feelings of disbelief, disappointment, self-pity, shock, anger, numbness, guilt, and denial. For some parents it feels like a period of mourning, while others feel like it is like a bad dream, or that they are living in a bubble outside of reality. Parents may try to blame themselves, or even one another, but it’s important to remember no one is to blame, and there may be no answers for many parents.

One of the biggest challenges is coming to terms with the fact your child’s future will be different to the way you imagined it. Getting in touch with national and local organisations, support groups and other families can help you to deal with a diagnosis, and can be a valuable source of support and advice. It is also important to remember that, with time, your emotions will become easier to manage – many parents have told Mencap that after a diagnosis they discovered qualities of strength, determination and positivity that they didn’t even know they had.
How will I cope with a child with a learning disability?

Every parent wants to give their child the best they can.

However, this can be harder for parents who have a child with a learning disability. For some parents the mixed emotions that follow a diagnosis can take a long time to come to terms with, so finding ways of coping are very important.

1) Some parents have told Mencap that finding out about their child’s condition allowed them to help themselves and their child. Making contact with organisations that support people with your child’s specific condition can be especially helpful.

2) Find out where to get information, support and advice, and look out for social opportunities in your local area. This can help you to feel more in control, and can provide opportunities for other family members to get involved.

What next?

- Listen to a mother talk about how she felt when she received her daughter’s diagnosis at www.mencap.org.uk/hearingthenews
- Read more about pregnancy and diagnosis, and where to find support, in ‘ages and stages’ at www.mencap.org.uk/agesandstages
- Search our database of national organisations at www.mencap.org.uk/resources
- Find a local Mencap group at www.mencap.org.uk/localgroups
3) Contact other families in a similar situation through local groups. Sharing your experiences with others can be valuable and very rewarding, and can help to remind you that you are not alone.

4) Most importantly, don’t forget yourself. Having family and friends to talk to at difficult times can help to relieve emotional stress. If you need a break from your caring responsibilities you should contact your social worker or health visitor who will be able to offer advice and support.

What next?

• Find a local group in your area at www.mencap.org.uk/localgroups

• Join the Mencap families forums at www.mencap.org.uk/forums or get in touch with other parents through Contact a Family at www.makingcontact.org

• Search our list of national organisations for information at www.mencap.org.uk/resources
Thinking about the future

Parents have told Mencap that one of their biggest concerns is thinking about the future for their child.

Planning ahead, and making sure you have the right support, can help to make the future feel less daunting.

What next?
• Find out what to expect at each stage of your child’s life in ‘ages and stages’ at www.mencap.org.uk/agesandstages

Take one day at a time
Although it is important to plan ahead, you may also need to face new challenges as they arise, and deal with each new day as it comes.

Talk to your child about their learning disability
As your child gets older, you will want to explain their condition to them. Remind them of their strengths and build their self-esteem, and let them know that they are just as good as anyone else – they just have a different way of learning.

Share your experiences with other parents
Contact local support groups to share your experiences with other parents, and to keep up to date with what’s happening locally.

Get involved with your child’s education
Contact your local education authority (LEA) to ask about part-time pre-school placements for children aged 3–5 years.

It is also a good idea to keep good communication links with your child’s school. By taking an active interest you can support your child with what they have been learning in class, and you can help to monitor their progress.
Find out what support you are entitled to

As a parent, it is a good idea to find out exactly which benefits and assessments you are entitled to. On average it costs more to bring up a child with a disability, due to additional costs of things such as clothing, heating and equipment. As a result, other family members can end up missing out. Single parent families and black and minority ethnic families are more likely to be subject to poverty, often because they lack information and support when claiming benefits and tax credits.

Under the Employment Act 2003 the parents of young and disabled children have the right to apply for flexible working, and since April 2007 this right has been extended to the carers of adults. Flexibility in the workplace can mean part-time, flexi-time, job-sharing, staggered hours or term-time working, to name but a few. However, you must make sure that you have a contract of employment flexibility that can cover hours, times and places of work.

What next?

- Read the Mencap guide ‘Understanding community care assessments’ at www.mencap.org.uk/communitycareguide
- Read the Mencap guide ‘Understanding carer’s assessments’ at www.mencap.org.uk/careraudits
- Read ‘The right to apply for flexible working; A short guide for employers, working parents and carers’ on the Acas website at http://tinyurl.com/476th6

Be prepared for transition

Transition into adult life can be a difficult process for both parents and children. Parents have told Mencap that services are no longer so readily available for adults, and at this stage it can feel like your choices have become much more limited.

Make sure you are prepared for transition by keeping a close eye on your child’s transition plan, which should be drawn up when they are 14 years-old. At the same time a person-centred plan (PCP) should also be put in place, and your child should work with everyone who supports them to create their plan for the future.
Think about employment

There are now many more opportunities for people with a learning disability to find work. Supported employment offers employment and training, while Jobcentre Plus has a co-ordinated disability employment advisor to provide support.

What next?

• Find out more about transition in ‘ages and stages’ at www.mencap.org.uk/agesandstages

Think about employment

What next?

• Visit the JobcentrePlus website at www.jobcentreplus.gov.uk
• Find out about Mencap’s jobs and training opportunities at http://www.mencap.org.uk/jobsandtraining
Will my other children have a learning disability?

Some genetic conditions are passed on in families – Down’s syndrome is one example of a condition associated with learning disability that could be passed on to more than one of your children.

However, other genetic conditions occur occasionally, so other children may not be affected.

If you are thinking of having a child but have concerns about learning disability, you can contact a genetic counsellor through one of the various regional genetic centres across the UK. A genetic counsellor can offer advice and support to families who already have a child with a learning disability and who wish to have another child, or to couples who want to start a family but have concerns about existing genetic problems.

Some women may also be offered extra tests during their pregnancy if there are concerns about their baby’s development. All tests carried out during pregnancy carry risks, and not all women will decide to go through with them. It is important to consult carefully with your doctor when making this decision.

“During my second pregnancy I was offered a lot of support and advice, and my GPs explained the tests and risks very carefully. I received genetic counselling and was offered an amniocentesis.”
Some families also turn to the internet for genetic information. This can be reliable, providing it is an authorised site and you are aware that general information might not be accurate for each individual family. You should always check any information you receive on the internet with your GP.

If you think you need genetic counselling, you should speak to your GP or ask your obstetrician, gynaecologist or paediatrician about a referral to a genetic centre.

**What next?**

- Find out more about tests during pregnancy in our ages and stages section at www.mencap.org.uk/agesandstages
- Visit the Genetic Interest Group website at www.gig.org.uk or call them on 020 7704 3141.
Support for brothers and sisters

Siblings growing up with a disabled brother or sister often develop a very special relationship, and demonstrate affection, understanding and sensitivity towards them.

However, brothers and sisters can also feel under a great deal of pressure. At times they may feel jealous, show signs of anger or make hurtful remarks to their brother or sister with a learning disability because of the extra attention they need. Younger siblings may sometimes show bad behaviour because they are frightened that the disability could happen to them.

As a parent, it can be difficult to make sure the needs of all your children are equally balanced, and it is important to let your other children know that they are valuable members of the family, even if you are not able to spend as much time with them. Some parents have told Mencap that they were worried about explaining learning disability to their other children, in case it upsets them even more. However, in many cases being open and honest allows siblings to gain a better understanding of their brother or sister and the reasons for their behaviour.

“Our older son loves his brother but he will ask: ‘why did he have to have autism’, ‘why won’t he play football with me’ and ‘why does he do the things he does?”

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\[\text{Having a child with a learning disability}\]
As siblings get older, they may feel embarrassed when talking about their brother or sister or when introducing them to friends. Some siblings may also be bullied because of their brother or sister's disability. If your child asks you for help, you may want to explain more to them about learning disability, or suggest they invite their friends round to meet their brother or sister. Some siblings may also want some space to spend time with their friends on their own.

If you think one of your children is being bullied because of their brother or sister’s disability but they do not want to talk to you, you could suggest they speak to another adult they trust, such as a relative, teacher or family friend. The organisation Sibs also offers support for brothers and sisters of disabled children and adults.

What next?

- Visit the Sibs website at www.sibs.org.uk
- Call Childline on 0800 1111 or visit the Childline website at www.childline.org.uk
Many fathers play an important role in caring for their child with a learning disability, combining household tasks with the pressures of work and supporting other family members.

However, their needs and feelings are often overlooked.

In some cases, fathers may react differently to their partners when they find out their child has a learning disability. Some men may find it hard to deal with their emotions, and may struggle to support other family members while coming to terms with how they are feeling.

Traditionally fathers have been seen as the main breadwinners, and they may feel under extra pressure to provide for their family, especially if they are facing extra costs as the result of a diagnosis. Some fathers may also have to reduce their hours at work or even give up their job to support their partner in the caring role, which can have a considerable impact on the family income.

If they do work, fathers are less likely to attend meetings involving their child, which can make them feel excluded from decisions being made and can alienate them from the professionals working with their family. Getting in touch with other fathers in a similar situation, or finding contact details for a fathers’ group, can be valuable sources of support.

What next?

- Read the Contact a Family factsheet for fathers and get in touch with other families on the Contact a Family website at www.cafamily.org.uk
- Find out about ‘Recognising Fathers’, a project by The Foundation for People with Learning Disabilities which hopes to change policies and increase awareness of the needs of fathers at www.learningdisabilities.org.uk/our-work/family-support/recognising-fathers
Support for grandparents

For grandparents, hearing that their grandchild has a learning disability can also be a difficult experience.

They may feel mixed emotions of confusion, disbelief and sadness, and even a sense of responsibility that the condition may be hereditary.

It is worth remembering that many grandparents also lived through an age when disability was understood very differently to today, and they may still have misconceptions about the subject.

In many cases grandparents can benefit from finding out more about learning disability themselves. You can either speak to them about your child’s diagnosis, or direct them to local and national organisations, libraries and GP surgeries for information and advice. Friends can also be a good source of support, although finding grandparents in a similar situation may be difficult as there are very few groups specifically for grandparents.

For some families, encouraging grandparents to get involved in their grandchild’s life can also help them to come to terms with a diagnosis. You may want to invite them to a parents’ support group with you, or suggest they meet your child’s teacher at an open day at their school.

Giving them time to get to know your child as an individual is also very important, and with time, grandparents can offer vital support to families of a child with a learning disability.

What next?

• Read the Contact a Family factsheet for grandparents at www.cafamily.org.uk/grandparents.html
• Pass on the Learning Disability Helpline number to grandparents – 0808 808 1111.
Telling friends and relations

Telling friends and family members about your child’s diagnosis can be daunting, but for many parents it is a relief to let others know about the situation.

Friends and relatives will have different levels of understanding of learning disability, and some may be unsure how to react. Providing them with simple information and contact details for support organisations can help them to come to terms with the diagnosis, without putting too much pressure on parents to offer explanations.

What next

• Read the Mencap guide ‘Telling other people about your child’s learning disability’ at www.mencap.org.uk/tellingotherpeople
Parents and relationships

Having a child with a learning disability brings many families closer together, and brings with it many rewards.

However, for some parents it can put a strain on their relationship, as they have little time to spend together and find their conversations focus on their child.

In some cases, one parent may be unable to attend meetings or meet professionals, for example due to work commitments, and may feel excluded from their child’s life. In this case, it is a good idea discuss your feelings together, or with a relative or close friend.

If possible, it is also important to try and continue to do the things you used to do together, such as joint hobbies, going out for meals or going to the cinema. Finding out about short breaks and childcare facilities in your area can give you back some time to spend as a couple. You can also look for support from other families in a similar situation.

If your relationship is under pressure and you need extra support, you can speak to a relationship counsellor or contact an organisation such as Relate.

What next?

- Find out more about childcare and short breaks in ‘ages and stages’ at www.mencap.org.uk/agesandstages
- Get in touch with other families. Join the Mencap families forum at www.mencap.org.uk/forums or visit the Contact a Family website at www.makingcontact.org
- Get advice and information on relationships from the Relate website at www.relate.org.uk or the One Plus One website at www.oneplusone.org.uk
Which professionals will I come into contact with?

If your child has been diagnosed with a learning disability, you may come into contact with:

- **benefits agency**: provides information on benefits for people with a learning disability and family carers
- **child psychiatrist**: works with children and young people with mental health problems
- **clinical psychologist**: supports children in learning new skills
- **community team for learning disabilities**: is made up of professionals and therapists, and provides information and assistance
- **GP**: your GP will often be your first point of contact, and will be able to refer your child to other specialists if required
- **health visitor**: your health visitor will check on your child’s health and development through visits to the family home
• **learning disability associations and support groups:** provide information and advice, and can put parents and family carers in touch with others in a similar situation

• **paediatrician:** specialises in children’s health and development

• **social worker:** can offer help and advice in getting you and your child the support you need

• **special educational needs co-ordinator (SENCO):** creates a supportive learning environment for special needs pupils at school

• **specialist health visitor:** specialist health visitors have knowledge of special needs and can provide help and advice

• **therapists:** these might include:
  - **speech and language therapist:** helps with communication problems
  - **occupational therapist:** helps with everyday tasks
  - **physiotherapist:** helps with movement
  - **voluntary organisations:** provide information, support and advice.
Further information and resources

Contact a Family
Website: www.cafamily.org.uk

Afasic - unlocking speech and language
Website: www.afasic.org.uk

BILD - British Institute of Learning Disabilities
Website: www.bild.org.uk

Carers UK
Website: www.carersuk.org.uk

Shared Care Network
Website: www.sharedcarenetwork.org.uk

Down’s Syndrome Association
Website: www.downs-syndrome.org.uk

NAS
Website: www.autism.org.uk
Contacts

England
If you live in England and would like more information on learning disability, you can contact:

The Learning Disability Helpline
Telephone: 0808 800 1111
Typetalk: 18001 0808 808 1111
Email: help@mencap.org.uk

If English is not your first language and you would like access to a translation service, please contact the Mencap Learning Disability Helpline and ask for Language Line.

Northern Ireland
If you live in Northern Ireland and would like more information on learning disability, please contact:

Mencap’s Information Service
Telephone: 0808 800 1111
Email: mencapni@mencap.org.uk

Wales
If you live in Wales and would like more information on learning disability, please contact:

Wales Learning Disability Helpline
Telephone: 0808 800 1111
Email: information.wales@mencap.org.uk

Scotland
If you live in Scotland, and would like more information on learning disability, please contact:

ENABLE Scotland
Telephone: 0141 226 4541
Email: info@enable.org.uk
Website: www.enable.org.uk