

*Finding out about...*

# Learning disability in the family



A guide for parents





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This booklet was developed by the ENABLE Scotland Children's Committee – a group of parents of children with learning disabilities – to let you know that other parents share your experiences and to put you in touch with services and support.

## If you think that something is wrong

Parents discover that their child has a learning disability in many ways. It may be obvious at birth, or very soon afterwards. For other parents there is a long, slow realisation that their child is not developing as quickly as expected. Often parents are worried long before professionals recognise or diagnose a difficulty.

If you are worried that your child is not developing as quickly as you expected:

- talk to your doctor or health visitor
- if your child is already at school, then talk to the head teacher and classroom teacher
- trust your judgement - you probably know best
- don't ever feel that you are over anxious or a nuisance
- be persistent if necessary.

*"I know there's something wrong. I need you to listen."*

Most GPs, health visitors and other professionals will be helpful but if you feel that you are not getting appropriate support or being listened to then contact ENABLE Scotland's Information Service.

You may be referred to a specialist child assessment clinic where your child will see a paediatrician and

*"I just wanted the floor to open up and swallow me when the doctor said my son had cerebral palsy."*

be given a range of tests and be observed. Sometimes it can be a long process to get a diagnosis as health staff try and work out what might be causing your child's difficulties. It can also be frightening for parents. If you want, you can take someone with you to clinic visits for support. This may be especially helpful when you are given a diagnosis. Sometimes getting a diagnosis can be a relief. Sometimes it can be a shock. You may need time to adjust to the news.



If the diagnosis is unclear or you don't agree with the doctor's assessment then you might consider getting a second medical opinion.

If your child has additional support needs you may feel scared and alone. You possibly do not know anyone else with a disability and you will wonder what the future holds for you and your child. You don't need to feel alone. There are lots of people who can give you support when you feel ready to accept it.

*"I felt hysterical for about 2 weeks. Every time I told someone in the family I burst out crying."*

If you are told that your child has additional support needs then some things that may help are:

- talking to your partner or close friends and family
- recognising that you will have strong, and possibly conflicting, emotions
- taking things slowly. It is easy to be rushed into decisions, actions or even feelings because of other people's expectations - or even your own expectations of yourself
- talking to other parents. The ENABLE Scotland Children's Officer or the ENABLE Scotland Information Service can put you in touch with support groups and other parents in similar circumstances
- getting all the information you feel you need - at your own pace.

*"Talking to Sally and the other mums made all the difference."*

When you first hear your child has a disability, you will fear all sorts of things and will worry about all the things that they may not be able to do. This is perfectly normal. In most cases, just like your other children, it's impossible to tell exactly how your disabled child's life will turn out. But it probably won't be anything like you imagine now.

*"I think that it's harder for my husband – at least I can do something practical but he feels so helpless."*



First and foremost your son or daughter is your child and you will love him or her no matter what happens. Look at the child first. All parents want their children to be as independent as possible and not held back. Encourage their development and independence and they will have a good chance of a full and fulfilling life.

*"I had the same fears. I look at my daughter now and can't believe how much she has achieved. She has a part-time job at the local swimming pool. A few years ago she left home and moved into a house with a friend. They get support with managing the house and they're really enjoying their independence. I still worry about her but she's coping really well."*

# Making space for yourself and the rest of the family

Having a child with additional support needs may bring a lot of worry, extra work, and stress. It also brings all the joys of parenthood - and some new insights into yourself and others.

## Think about your own needs

It is very easy for any parent to forget their own needs, and even easier if your child has learning disabilities. You could think about:

- keeping some time for yourself - a regular swim, an adult education class, or pamper yourself with a long soak in the bath, a visit to the hairdresser, a massage or whatever is important to you
- not expecting too much of yourself
- using any supports that help - this might be a formal support group, but may be family, friends or professionals working with your child.
- making sure that your employer understands your situation, and make use of any opportunities for flexible hours, carer's leave etc.

*"I didn't realise that I had to do this until I was in my mid-30s when I started running again. Now I feel robbed if I don't get my daily run."*

*“Getting together with other parents of children with learning disabilities helps some people – but it’s not my cup of tea. I go occasionally because my other friends do not understand some of my frustrations, and I need to be ordinary with my ordinary friends.”*

## **What you can do for the rest of the family**

If you have other family members you could try to:

- include them, as far as is reasonable, in the care of your child
- make specific time for any other children you have
- try to find activities that all the family enjoys
- make space for siblings and others to talk about their feelings and worries
- make time for your partner.

*“I worry that Jamie’s brother and sister are missing out on their childhoods...”*

## **Support for your other children**

Children affected by the disability of another family member are recognised as ‘children in need’ by the Children (Scotland) Act 1995. This means you can ask the council to assess their needs. There are sibling support groups in some areas where your child’s brothers and sisters can share their worries or just have fun.





## **A break for you and your child**

Respite care (short breaks) can provide a break for a child with a disability and also for his or her parent or carer. A good short break service should be:

- based on the needs of your child
- able to give you and your child choices
- of a high standard
- accessible
- affordable – there is often no charge for short breaks services for children.

*“Anne is great with her wee brother, but she needs a break as much as I do.”*

A short breaks service can take many forms. A carer might come into your own home to ‘babysit’ and care for your child while you go out. You might be linked to another family or individual and your child will go and visit their home. Your child might go to a residential unit for a few days or he or she

*"I never wanted respite for my son but it may be a good thing for him. He's always having to compete in the family – both physically and emotionally. I'd like him to access groups where he could meet other disabled children and just have fun."*

might be offered a befriender. After-school care and holiday playschemes can be another form of fun for your child and a break for you.

A short breaks service can offer many positive opportunities to your child. It can help him or her to meet new people, have fun, doing the things he or she likes to do, and achieve some independence.

Using these types of services

does not mean that you are 'failing' to look after your child. In fact, the aim is to help you continue to care by giving you time to catch up with other things. You might simply want to get some sleep or spend time with other family members or friends.

Short breaks services enable you to relax and recharge your batteries knowing that your child is well looked after and doing things he or she enjoys.

You can get more information about respite care and short breaks from some of the organisations in the next section or from your local social work department.

*"We have had to work hard – to keep ourselves going as individuals and as a couple. We accept any opportunity to have a break..."*

## Sources of information and support


Independent and voluntary organisations might be able to advise and provide services such as independent assessments, legal advice or support services for you and your child. Some organisations deal with specific needs such as epilepsy or specific syndromes.



The organisations listed below are all national agencies offering support to children with disabilities and family carers. Some of these organisations will have local services in your area – though the picture will vary across Scotland. Ask them for details of local support groups in your area. The ENABLE Scotland Information Service can also give further information about other groups that might help.

## **ENABLE Scotland Information Service**

6th Floor, 7 Buchanan Street,  
Glasgow G1 3HL

 0141 226 4541

Mon-Fri 1:00pm-4:00pm

**email:** [info@enable.org.uk](mailto:info@enable.org.uk)

**www.enable.org.uk**


*ENABLE Scotland Information Service can give information about rights, services, incapacity issues, specific syndromes and other support groups.*

*ENABLE Scotland can offer networking with other parents through over 60 local branches and local committees of younger parents. It has children's and adult self advocacy groups as well as a wide range of direct care services in many parts of Scotland. The ENABLE Trustee Service can help families to plan ahead through wills and trusts.*

*"I wanted another opinion, just to be sure that we were doing all we could..."*

## **ASCS (Advice Service Capability Scotland)**

11 Ellersly Road,  
Edinburgh EH12 6HY

 0131 313 5510

**Textphone:** 0131 346 2529

**email:** [ascsc@](mailto:ascsc@capability-scotland.org.uk)

[capability-scotland.org.uk](http://capability-scotland.org.uk)

**www.capability-scotland.org.uk**


*A national disability advice and information service. ASCS provides free confidential advice and information on disability issues including advice on living with cerebral palsy.*


## **Contact A Family**

Norton Park,

57 Albion Road,

Edinburgh EH7 5QY

 0131 475 2608

 **Helpline:** 0808 808 3555

Mon-Fri 10:00 am – 4:00 pm

and Mon 5:30 -7:30 pm

**Textphone:** 0808 808 3556

**email:** [scotland.office@](mailto:scotland.office@cafamily.org.uk)

[cafamily.org.uk](http://cafamily.org.uk)

**www.cafamily.org.uk**

*UK charity for families with children with any disability or rare disorder. It enables parents to get in contact with other families and provides a helpline, support groups and information.*

## **Down's Syndrome Scotland**

158-160 Balgreen Road,  
Edinburgh EH11 3AU

☎ 0131 313 4225

**email:** [info@](mailto:info@dsscotland.org.uk)

[dsscotland.org.uk](http://dsscotland.org.uk)

[www.dsscotland.org.uk](http://www.dsscotland.org.uk)

*Down's Syndrome Scotland has a network of branches offering support to people with Down's syndrome, parents, carers and professionals. It provides telephone advice, publications, events and workshops*

## **Enquire**

Children in Scotland,  
5 Shandwick Place,  
Edinburgh EH2 4RG

☎ **Helpline:** 0845 123 2303

Mon-Fri 9:00am-5:00pm, and  
Tue & Thur 7:00-9:00pm

**Textphone:** 0131 222 2439

**email:** [info@enquire.org.uk](mailto:info@enquire.org.uk)

[www.enquire.org.uk](http://www.enquire.org.uk)

*Scottish advice service for additional support for learning (special educational needs). It provides independent advice and information, free publications, outreach for parents and professionals, and services for children and young people.*

## **Epilepsy Scotland**

48 Govan Road,  
Glasgow G51 1JL

☎ 0141 427 4911

☎ **Helpline:** 0808 800 2200

Mon-Fri 10:00am – 4:00pm

and until 6pm Thurs

**email:** [enquiries@](mailto:enquiries@epilepsyscotland.org.uk)

[epilepsyscotland.org.uk](http://epilepsyscotland.org.uk)

[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)

*Help and advice on epilepsy including a confidential helpline, community support services and training.*

## **National Autistic Society**

Central Chambers,  
1st Floor, 109 Hope  
Street, Glasgow G2 6LL

☎ 0141 221 8090

☎ **Autism Helpline:**

0845 070 4004

☎ **Parent to Parent**

**Line (24 hours):**

0800 9 520 520

☎ **Advocacy for  
Education Service:**

0845 070 4002

**email:** [scotland@nas.org.uk](mailto:scotland@nas.org.uk)

[www.autism.org.uk](http://www.autism.org.uk)

*Impartial, confidential advice and information to people with autism or Asperger syndrome and their families.*

[www.info.autism.org.uk](http://www.info.autism.org.uk) - directory of autism services in the UK.

*"They already knew more about autism than a lot of the professionals we deal with..."*

## **PAMIS**

Springfield House,  
15/16 Springfield,  
University of Dundee,  
Dundee DD1 4JE  
☎ 01382 385154  
**email:** [pamis@dundee.ac.uk](mailto:pamis@dundee.ac.uk)  
[www.dundee.ac.uk/pamis](http://www.dundee.ac.uk/pamis)

*Support for families of children and adults with profound and multiple learning disabilities through practical help and advice, contact with other families, training and assistance in accessing community resources. It has local offices in Glasgow, Fife, Tayside, Grampian and South Lanarkshire.*

## **The Scottish Society for Autism**

Hilton House, Alloa Business Centre, The Whins,  
Alloa FK10 3SA  
☎ 01259 720044  
☎ **Education & support services:** 01259 222001  
**email:** [info@autism-in-scotland.org.uk](mailto:info@autism-in-scotland.org.uk)  
[www.autism-in-scotland.org.uk](http://www.autism-in-scotland.org.uk)

*Services for people with autism and their families including care, education, and advice.*

## **Sense Scotland**

43 Middlesex Street,  
Kinning Park,  
Glasgow G41 1EE  
☎ 0141 429 0294  
☎ **Textphone:**  
0141 418 7170  
**email:** [info@  
sensescotland.org.uk](mailto:info@sensescotland.org.uk)  
[www.sensescotland.org.uk](http://www.sensescotland.org.uk)

*Services for adults or children with communication support needs because of deafblindness, sensory impairment, learning or physical disabilities.*

*"It was great not to have to explain about Peter's condition."*

## **Shared Care Scotland**

Unit 7, Dunfermline Business Centre, Izatt Avenue,  
Dunfermline, KY11 3BZ  
☎ 01383 622462  
**email:** [office@  
sharedcarescotland.com](mailto:office@sharedcarescotland.com)  
[www.sharedcarescotland.org.uk](http://www.sharedcarescotland.org.uk)

*Promotes the development of appropriate, flexible, affordable and good quality short breaks (respite care) services and has a database of information on different services.*

## Where to find books and resources


When you are ready, you may want to read about the experiences of other parents or find out more about different conditions, practical ideas, relevant laws or policies. ENABLE Scotland has an extensive library containing books, videos, DVDs and information packs - most of which you can borrow if you live anywhere in Scotland. You can visit the library in person or telephone us if you are looking for information on a topic. We can post books or other resources out to you. You just have to send them back at the end of the loan period.

ENABLE Scotland is a library partner of the Scottish Consortium for Learning Disability. There are other libraries based at Capability Scotland, Down's Syndrome Scotland and PAMIS. You can find out what resources are held in all the libraries through the SCLD website [www.sclد.org.uk](http://www.sclد.org.uk).


Please contact any of the partner libraries. All are happy to lend books to parents.

*Contact the SCLD library partners:*


### **ENABLE Scotland**

 0141 226 4541  
library@enable.org.uk


### **Capability Scotland**

 0131 313 5510  
ascس@capability-scotland.org.uk

### **Down's Syndrome Scotland**

 0131 313 4225  
info@dsscotland.org.uk

### **PAMIS**

 01382 385154  
pamis@dundee.ac.uk

ENABLE Scotland is the country's leading organisation for children and adults with learning disabilities, their families and carers.

**ENABLE Scotland**

**6th Floor**

**7 Buchanan Street**

**Glasgow G1 3HL**

**☎ 0141 226 4541**

**email: [enable@enable.org.uk](mailto:enable@enable.org.uk)**

**🌐 [www.enable.org.uk](http://www.enable.org.uk)**

Information Service open

Monday – Friday, 1pm – 4pm

**☎ 0141 226 4541** or

**email: [info@enable.org.uk](mailto:info@enable.org.uk)**

This is part of a series of information booklets for parents and carers. All of the booklets are available on the ENABLE Scotland website or from the Information Service.



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