



Multiple Sclerosis Society

March 2013

## Factsheet

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# Education for children with MS in Scotland – a factsheet for parents, teachers and local authorities

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**i** Where you see this symbol more information is available from other sources

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## Introduction

Attending school or college can, at times, be difficult for pupils with a long-term condition such as MS. This factsheet is intended as a guide to the services and support that are available to pupils, teachers, parents, schools and colleges.

You might also want to read *Childhood MS - a guide for parents*, for more information about how MS might affect children and teenagers.

## MS and education

MS can affect pupils in different ways, but it might mean patchy school attendance and difficulty completing work because of:

- ▲ Fatigue, pain and sensory symptoms.
- ▲ Cognitive problems, difficulties with attention and memory.
- ▲ Relapses and hospital appointments.

There are a number of ways to manage these issues. Pupils with MS might benefit from:

- ▲ Scribes or extra time to complete exams.
- ▲ A member of staff to coordinate information and support from other practitioners, such as speech and language therapist.
- ▲ An individual health care plan drawn up between school staff, parent(s), pupil and NHS staff.
- ▲ Home tutoring.

Together, pupils, parents and schools can discuss all these different options.

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## How can the local authority help?

The local education authority can help by:

- ▲ Setting a policy, agreed with relevant agencies, for supporting pupils who are unable to go to school because of medical needs.
- ▲ Establishing referral systems for home-based and hospital education, with appropriate referral forms.
- ▲ Making referrals for home-based or hospital education as simple as possible, with appropriate referral forms available and publicised to any professionals who might need to make a referral, whether teachers, health or social care professionals.
- ▲ Making sure that pupils have access to education from the start, if it's clear that they will be away from school for long or recurring periods.
- ▲ Ensuring that pupils receive an education of similar quality to that available in school, with flexible arrangements.
- ▲ Ensuring continuity for pupils, even when education is delivered by specialist services outwith the home authority.

- ▲ Ensuring that appropriate reviews happen for pupils receiving education outwith school.
  - ▲ Setting a policy for schools to provide adequate support for pupils who need additional support within schools in their area.
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## How can schools help?

Schools can support pupils with MS by:


- ▲ Implementing relevant policies and appointing a person responsible for supporting pupils with additional needs because of a medical condition.
  - ▲ Ensuring health and safety procedures are adapted to take account of pupils with additional needs, e.g. including extra time for disabled pupils to evacuate the building during a fire drill or emergency.
  - ▲ Making sure all those who help provide education for the pupil have proper information about their needs and capabilities - and have a programme of work to follow.
  - ▲ Maintaining contact with health professionals involved in meeting the pupil's healthcare needs.
  - ▲ Maintaining contact with the education authority officer responsible for additional support needs.
  - ▲ Providing support to help pupils re-integrate at school after an illness.
  - ▲ Ensuring that pupils are kept informed about school social events and after-school clubs.
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## How can teachers help?

Teachers can help support pupils with MS by:

- ▲ Educating themselves about the issues that a pupil with MS could face in school.
- ▲ Learning about MS through the MS Society booklet, What is MS? or at [www.mssociety.org.uk](http://www.mssociety.org.uk)
- ▲ Making and maintaining contact with the pupil's specialist MS Nurse.

- ▲ Keeping a record of any work that is missed, to help with learning outwith school and when they return

The MS Society and other charities have information to help explain MS to different age groups and in different languages and formats. 

With the permission of the affected pupil, you might want to do something in your class or school to highlight the issues they face, but be sure to talk it over with the pupil and their family first.

## How can parents help?

Parents can help by:

- ▲ Letting the local authority and school know if your child will be (or is likely to be) away from school for more than 15 working days (see page 9).
- ▲ Encouraging your child to stay in contact with their friends - for example, through visits or online chat.

### Free transport

An education authority may decide to provide free transport so that a pupil with a medical condition can still attend school. The authority will usually consult with the health board to make this decision.

Social work services also have the power to pay for transport to and from college. Other potential sources of funding for travel are the college's discretionary support fund or a charitable trust.

Local authorities have a duty to ensure young people with MS are not prevented from attending college because of transport difficulties.

The law allows education authorities to provide free transport even when they don't have a legal duty to do so (called the 'power of discretion'). This means that different education authorities may have different policies about free transport.

**i** If you have questions about:

- ▲ the duties and powers of education authorities
- ▲ the safety of pupils
- ▲ school transport issues

Contact Enquire, the Scottish advice service for additional support for learning for issues about schools (and LEAD Scotland Information Service for college enquiries).

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## What are a pupil's rights in the education system?

Scottish education law and Government initiatives create a framework to make sure children and young people benefit from education and reach their full potential.

### **The Education (Additional Support for Learning) (Scotland) Act 2004, as amended 2009**

In schools and pre-schools: any child who needs more (or different) support to what is normally provided for those of the same age, is said to have 'additional support needs'.

Education authorities must identify any of their pupils who may have additional support needs, make adequate and efficient provision of support as they require and keep this under regular review. This might include, for example, making adjustments to classrooms, alternative approaches to learning and teaching or ensuring extra support in exams.

The legislation is there to make sure children's individual needs are met, regardless of the reasons. This means that a formal diagnosis is not required for support to be put in place.

Education authorities might also be asked to make an assessment of children and young people who are educated at home or in private education. In these cases the authority has a power, rather than a duty to help.

### **Child's plan**

This is a single plan to make sure all agencies involved work together in a coordinated way. It sets out everything that needs to happen to ensure the child's wellbeing.

### **Coordinated support plan (CSP)**

This is more detailed than a 'Child's plan'. It's used for some children and young people who need significant additional support with their education. A CSP, although not always required, is often used if more than one issue affects a child's development.

If you are a parent, you can ask the education authority to find out whether your child needs a CSP (or to review their existing plan).

You can ask the authority directly, or go through the school. If a CSP is needed, the authority will appoint a CSP Coordinator, to make sure people carry out the actions included in the plan.

If a CSP is not required, the education authority must explain the reasons to you in writing. They still have a duty to identify and provide for your child's additional support needs. This might be done through personal learning planning (see below) or with an individualised education programme (see below).

If you disagree with the decision, you have the right to appeal to an Additional Support Needs Tribunal (see below).

### **Personal learning planning (PLP)**

Personal learning planning sets out goals that relate specifically to a child's circumstances. All children should be involved in personal learning planning, and for many this will be sufficient to meet their needs. By monitoring progress in achieving these goals, their progress can be assessed and action taken, if required.

### **Individualised educational programmes (IEP)**

An IEP is a detailed plan for your child's learning. It describes in detail the nature of a child's additional support needs, including short term goals and how they will be helped to reach them. Education authorities should involve health in this process, if appropriate. Schools and local authorities are not legally required to prepare an IEP for your child, and IEPs are not legal documents.

In some authorities these plans will have different names.

## **Additional Support Needs Tribunals for Scotland**

Parents and young people aged 16 and over can make a reference to an Additional Support Needs Tribunal for different reasons, including:

- ▲ a decision to prepare (or not to prepare) a CSP (coordinated support plan)
- ▲ the time taken to prepare a CSP or review an existing plan
- ▲ a decision to discontinue a CSP
- ▲ failure to provide the support in the CSP

The Tribunal has produced a guide for people using or thinking of using the tribunal system. You can get copies from the Additional Support Needs Tribunals for Scotland (details on page 15).

The Scottish Child Law Centre provide a national advocacy service to help young people prepare and present a case at tribunals (details on page 13).

## **Resolving disagreements**

Education authorities must provide arrangements for resolving disputes and publish information on this. They must also provide independent mediation services, free of charge, for parents and young people. Parents and young people are entitled to have a supporter or advocate present at tribunal hearings or mediation sessions.

## **Getting It Right For Every Child**

Getting It Right for Every Child (GIRFEC) is the Scottish Government's national programme to provide a consistent, supportive, coordinated approach for all children and their families.

Information and guidance is available for anyone involved in a child's education, including parents, teachers, schools, nurseries and housing organisations. GIRFEC has a number of useful tools to help parents, teachers and children understand the support they should be getting and how things should work.

GIRFEC resources are available at  
[www.scotland.gov.uk/Topics/People/Young-People/gettingitright](http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright)  
If you don't have access to the internet, call the  
Information Team in Scotland on 0131 335 4050.

**Named person** - As part of GIRFEC, every child and young person will have a 'named person' responsible for making sure that the child has the right help in place to support their development and wellbeing. The support provided must be timely, proportionate and appropriate. The named person might be a health care professional or a teacher, where the child is of school age.

**Lead professional** - Where a child needs help from two or more agencies, a 'lead professional' will be appointed to coordinate planning and make sure all agencies provide the appropriate network of support around the child. For example, if several assessments are needed, the lead professional should ensure that information about the child is not duplicated and that parents and children are not put under stress. The lead professional might be the same person as the named person.

### **Moving on from school**

When a pupil reaches an age when they are no longer obligated to stay in school, the local authority should provide information and advice about their options including:

- ▲ staying on at school
- ▲ entering further or higher education
- ▲ participating in national training programmes
- ▲ taking part in community learning opportunities

The education authority must:

- ▲ Request and take into account information and advice from other agencies that are likely to be involved in support after the pupil leaves school. This must be done at least 12 months before they are expected to leave.



- ▲ Seek and take account of the pupil's views when deciding what information to share with agencies that may be working with them after they leave school.
  - ▲ Pass on relevant information and advice to any agencies that will be supporting the pupil, with their consent. This must be done no later than six months before they leave school.
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## Managing absence from school

### School and education authority responsibilities

Education authorities have a duty to make special arrangements for pupils who can't attend a suitable school because of prolonged ill-health. They must enable the pupil to receive their education elsewhere.

This might mean, for example, arranging access to home teaching, a hospital school, a hospital teaching service, or an integrated hospital and home education service. The education authority should also have a written policy setting out how it will meet its responsibilities.

These special arrangements should come into effect 'without undue delay', according to the Standards in Scotland's Schools etc. Act 2000.

Schools should usually make an automatic referral for education out with school after 15 school days of continuous absence for medical reasons (or 20 school days of intermittent). The referral can happen straight away if the absence is expected to last for at least this length of time.

If a pupil has been taught in hospital, home teaching should automatically take over when they are discharged, if the total period of absence from school is likely to be 15 days or more.

### Parental responsibilities

Parents are responsible for making sure that their child attends school when they are well enough to do so. And parents have a responsibility to tell the school if it becomes clear that their child will be away from school for a substantial amount of time for health reasons. This is especially important if they are likely to be off school for more than three weeks (15 school days). In this case, parents should also notify the education authority.

### **Helping pupils going back to school**

Getting back to school after being away for a long time can be daunting. When coming back to school after an absence pupils might need to choose lessons that they like most to start with, to help them concentrate. Pupils should be encouraged to let their friends know that they're coming back to school and perhaps to meet up away from school ahead of time to catch up and renew friendships if they haven't seen friends for a while.

## **Taking medication at school**

Close cooperation between schools, parents, health professionals and other agencies is crucial in order to help provide a suitably supportive environment for pupils with health care needs to enable them to participate fully in school activities.

### **Parental responsibilities**

Parents or guardians have prime responsibility for their child's health and should provide schools with information about their child's medical condition. If a pupil needs to have access to their medication at school, parents should make an appointment to talk to the 'responsible person' or lead professional about it as soon as possible. This person should be able to explain what support is available.

### **NHS board responsibilities**

NHS boards must ensure that appropriate agreements are in place with education authorities, confirming the respective responsibilities of each in relation to the administration of medicines in schools (local protocols and procedures, including training).

Relevant health staff will help schools draw up individual health care plans for pupils with health care needs, and may be able to supplement information already provided by parents and the child's GP. Other health professionals may also be involved in the care of pupils with health care needs in schools.

Some pupils with MS will receive dedicated support from a specialist nurse. These nurses often work as part of a specialist neurological rehabilitation team and work closely with the primary health care team. They can provide advice on the medical needs of an individual pupil, particularly when newly diagnosed and the pupil is adjusting to new routines.

### **The school's involvement**

NHS boards, usually through the School Health Service, will provide advice and training for school staff in providing for a pupil's needs. The main contact for schools is likely to be the school nurse.

Each educational establishment (e.g. school, pre-school, school hostel) must have a health and safety policy, which includes procedures for supporting pupils with health care needs, including managing medication. Day to day decisions about administering medication will normally fall to the Head teacher. Some staff may have 'meeting the health care needs of pupils' as part of their duties. For the majority, however, there is no legal duty that requires individual staff to administer medication; this may be voluntary. When school staff members volunteer to give pupils help with their health care needs, the head teacher should agree to their doing this, and must ensure that they receive proper support and training where necessary.


Under 'Health and Safety at Work' legislation, the education authority is responsible for both staff and others who may be affected. This should include procedures for supporting pupils with health care needs, including managing medication.

The Scottish Executive produced guidance on 'The administration of medicines in schools 2001'.

 [www.edlaw.org.uk/guidance/admin.pdf](http://www.edlaw.org.uk/guidance/admin.pdf)

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## **Equality legislation**

Schools and education authorities have had a duty to provide reasonable adjustments for disabled pupils since 2002 (originally under the Disability Discrimination Act 1995 (DDA) and, from October 2010 under the Equality Act 2010). You can learn more about the Equality Act 2010 on the Equality and Human Rights Commission website [www.equalityhumanrights.com](http://www.equalityhumanrights.com) 

The duty is 'to take such steps as it is reasonable to have to take to avoid the substantial disadvantage' to a disabled person caused by a provision, criterion or practice applied by or on behalf of a school or by the absence of an auxiliary aid or service.

The new element of the duty for schools is the provision of auxiliary aids and services for disabled pupils effective since 1 September 2012. Technical guidance is available online for both schools and higher education providers at [www.equalityhumanrights.com/legal-and-policy/equality-act/equality-act-codes-of-practice](http://www.equalityhumanrights.com/legal-and-policy/equality-act/equality-act-codes-of-practice). This may be helpful for school and education authority staff to understand and comply with the duty, including the new auxiliary aids and services provision.

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## Useful organisations

### **Enquire**

The Scottish advice service for additional support for learning provides information to help families find their way through the education and additional support needs system. They also provide advice to practitioners working with families, and to children and young people themselves.

Helpline: 0845 123 2303  
[info@enquire.org.uk](mailto:info@enquire.org.uk)  
[www.enquire.org.uk](http://www.enquire.org.uk)

Enquire's website for children and young people  
[www.enquire.org.uk/yp](http://www.enquire.org.uk/yp)

### **Education Law Unit - Govan Law Centre**

Scotland's expert legal resource in the field of school education, the unit provides legal representation in appropriate education law cases to parents or pupils. Their solicitors provide representation in cases heard by the Additional Support Needs Tribunals, Sheriff Courts, and the Court of Session.

Education Law Helpline: 0141 445 1955  
[advice@edlaw.org.uk](mailto:advice@edlaw.org.uk)  
[www.edlaw.org.uk](http://www.edlaw.org.uk)

### **Lead Scotland Information Service**

Information and advice for disabled learners over 16 and carers thinking of taking up learning.

Helpline: 0800 999 2568

[info@lead.org.uk](mailto:info@lead.org.uk)

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

### **Equality Advisory and Support Service (EASS)**

This service replaced the Equality and Human Rights Commission Helpline in December 2012. It is aimed at individuals who need more expert advice and support on discrimination than advice agencies and other local organisations can provide. Email enquiries can be sent via the website below.

Telephone: 0808 800 0082

Textphone: 0808 800 0084

[www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)

### **CHIP+ (Children in the Highlands Information Point)**

CHIP+ offers information, support and advice to the families and carers of children and young people with additional support needs in Highland, and to professionals who work with them.

Telephone: 01463 711189

[info@chipplus.org.uk](mailto:info@chipplus.org.uk)

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

### **Kindred**

A voluntary organisation based at the Royal Hospital for Sick Children in Edinburgh. Kindred provides information, advocacy and emotional support to parents of children and young people with additional support needs and their carers.

Helpline: 0131 536 0583

[kindred.enquiries@gmail.com](mailto:kindred.enquiries@gmail.com)

[www.kindred-scotland.org](http://www.kindred-scotland.org)

### **The Scottish Child Law Centre**

The National Advocacy Service for the additional support needs tribunal for Scotland is available to children, young people, their families and carers who believe that they need to make a reference to the Additional Support Needs Tribunal.

Telephone: 0131 667 6333 (or free for under 18's 0800 328 8970)

[enquiries@sclc.org.uk](mailto:enquiries@sclc.org.uk)

### **The Law Society of Scotland**

Find a solicitor or legal firm in your area of Scotland.

Telephone: 0131 226 7411

Textphone: 0131 476 8359

Fax: 0131 225 2934

lawscot@lawscot.org.uk

www.lawscot.org.uk

### **Association of Lawyers for Children**

The Association of Lawyers for Children is a membership organisation, including lawyers involved in work relating to children, psychiatrists, psychologists, social workers, paediatricians and guardians, and organisations seeking to promote the interests of children and young people within the legal system.

Telephone: 020 8224 7071

admin@alc.org.uk

www.alc.org.uk

### **Disability Rights UK**

Disability Rights UK is a national charity working to improve the living standards of disabled people.

www.disabilityrightsuk.org

Disabled Students Helpline: 0800 328 5050

Advice on post-16 education, training and employment issues for disabled people in England and general information for students in Scotland and Wales on the Equality Act, welfare benefits and access to Higher Education.

Tuesday 11.30am-1.30pm

Thursday 1.30pm-3.30pm

### **The Family Fund**

Helps families of disabled or seriously ill children under 16. They give grants and information related to the care of the child, including holidays, leisure, laundry equipment, driving lessons and lots more.

4 Alpha Court

Monks Cross Drive

York YO32 9WN

Telephone: 08449 744 099

Textphone: 01904 658085

info@familyfund.org.uk

www.familyfund.org.uk

## **Education Scotland**

HM Inspectorate for Education (HMIE) and Learning and Teaching Scotland (LTS) were combined in 2011 into a new national body to support quality and improvement in Scottish education. You can find more information on their website: [www.hmie.gov.uk/Default.aspx](http://www.hmie.gov.uk/Default.aspx)

## **Additional Support Needs Tribunals for Scotland**

ASNTS considers appeals (references) made by parents and young people against decisions of Education Authorities on certain matters relating to the provision of additional support. If you need general advice on how to make a 'reference' to the Additional Support Needs Tribunals for Scotland you can contact:

Helpline: 0845 120 2906

Fax: 0141 242 0141

[ASNTSinquries@scotland.gsi.gov.uk](mailto:ASNTSinquries@scotland.gsi.gov.uk)

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## **Useful resources**

### **Available from the MS Society:**

*Childhood MS - a guide for parents*

*What is MS?*

*Annie and Dan talk about MS - A DVD with puppets explaining MS for ages 0-5 years.*

*Living with the effects of MS*

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

A website dedicated to children and teenagers who either have MS or who are affected by MS.

### **Other resources:**

***Keep S'myelin***

A colourful, engaging, informative and reassuring newsletter for parents and children from the MS Society in the USA. Available online at [www.nationalmssociety.org](http://www.nationalmssociety.org)

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## Other useful publications for parents

***The parents' guide to additional support for learning***  
If you're new to additional support for learning it explains - in simple language - your and your child's rights, the roles and responsibilities of staff involved with your child, what to expect at meetings and much more.

Available from Enquire  
Telephone: 0131 222 2425  
info@enquire.org.uk

***Additional Support for Learning booklet***  
For parents of children educated in the Highland Council area, available from CHIP+

Telephone: 01463 711189  
info@chipplus.org.uk  
[www.chipplus.org.uk/documents/education/asl-booklet-final.pdf](http://www.chipplus.org.uk/documents/education/asl-booklet-final.pdf)

***The Administration of medicines in schools***  
Guidance document produced by Scottish Executive 2001  
[www.scotland.gov.uk/Publications/2001/09/10006/File-1](http://www.scotland.gov.uk/Publications/2001/09/10006/File-1)

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## More from the MS Society

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is touched by MS. We provide a freephone MS Helpline; grants for home adaptations, respite care and mobility aids, education and training, support for specialist MS nurses; and a wide range of information.

For more details, visit our website or contact the Information Team in Scotland on 0131 335 4050 (weekdays 10am-4pm) or email [msscotland@mssociety.org.uk](mailto:msscotland@mssociety.org.uk).

### **MS Helpline**

The MS Helpline offers confidential emotional support and information to anyone affected by MS, including family, friends, carers, newly diagnosed or those who have lived with the condition for many years. Calls can be made in over 150 different languages, via an interpreter.

Call freephone 0808 800 8000 (weekdays 9am-9pm, except bank holidays) or email [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)

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## Authors and contributors

**Disclaimer:** We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. The law and government regulations may change. Be sure to seek local advice from the sources listed.

Suggestions for improvement in future editions are welcomed. Please send them to [msscotland@mssociety.org.uk](mailto:msscotland@mssociety.org.uk) for the attention of the Scotland Information Team.

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