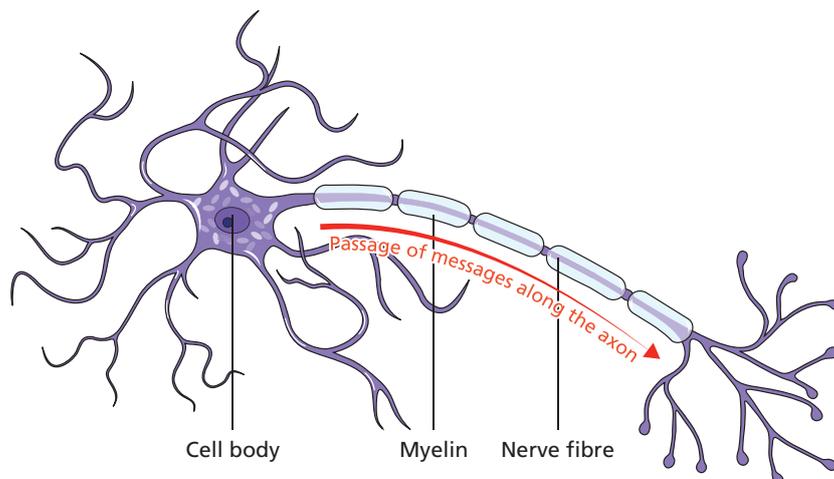




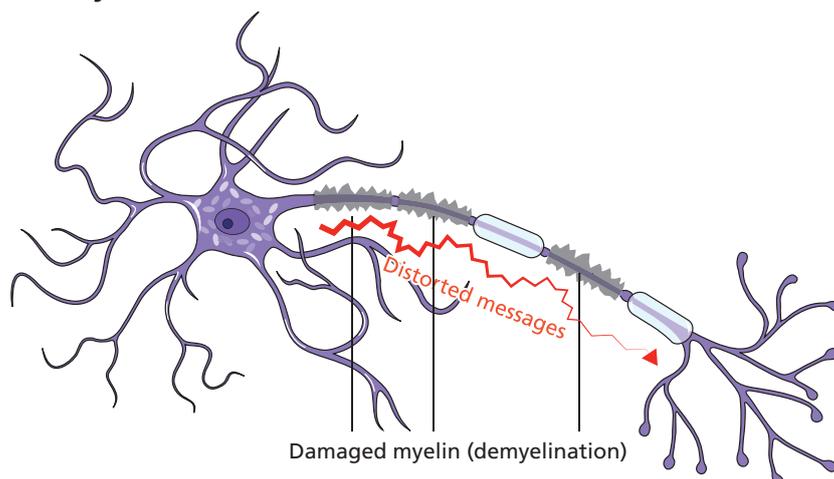
# Multiple sclerosis

Multiple sclerosis (MS) is a common neurological condition affecting around 100,000 adults in the UK, but it is rare in childhood – and particularly rare in children under 12. Specialist care for these children and young people is therefore crucial and Great Ormond Street Hospital (GOSH) has an established Neuroimmunology Centre to manage young people with MS and similar conditions. MS is a lifelong condition, which at present cannot be cured, but for which disease modifying drugs are available which can significantly alter its course and improve its long-term outcome.

## Normal neuron



## Demyelination in MS



## What is multiple sclerosis?

The nerves in the body and central nervous system – that is, the brain and spine – are covered by a fatty protective sheath known as myelin. This myelin allows the electrical impulses to be transmitted quickly and easily from the brain to the muscles. Sometimes, this fatty covering can be damaged – we call this “demyelination”. This then interferes with the normal messages being sent from the brain. Multiple sclerosis is diagnosed when someone has recurrent episodes of what is known as “demyelination”.

## What problems could a child or young person experience at school?

MS varies from person to person and so the symptoms experienced will be different for different young people. The symptoms experienced by one person will also be different at different times. Below are some of the common areas of difficulties you may see in school.

### Attendance

Children and young people diagnosed with MS may miss school for a number of reasons. They may be required to attend a number of hospital appointments. Periods of relapse may lead to further time off, particularly if a hospital admission is required. On-going difficulties such as fatigue may also impact upon attendance.

### **Cognitive difficulties**

As MS affects the brain and eye sight there can be an effect on a person's short-term memory, their ability to work with information quickly or academic work at school.

### **Motor problems**

Young people with MS may experience walking difficulties, difficulty with balance or co-ordination, or muscle weakness. They may also experience different sensations such as numbness or tingling in the hands or feet. In school, this may lead to difficulty moving around a large site, problems with writing or difficulty accessing the usual programme of physical education.

### **Visual problems**

Problems with vision can include blurred or double vision or temporary loss of sight in one or both eyes. Within the school setting this may lead to difficulty seeing a board at the front of class or reading notes written in small print.

### **Fatigue**

Children and young people with MS often experience significant fatigue. This can have a very substantial impact on day to day life and as a result, on education. It may make continuing a full-time timetable very challenging, impact upon attendance, or affect a young person's ability to concentrate and participate fully.

### **Emotional impact**

The emotional or psychological impact of being diagnosed with and managing a life-long condition is well recognised. Children and young people diagnosed with MS may experience a wide range of emotions in relation to their diagnosis. They may express a wide range of feelings within the school setting, such as anxiety, sadness or anger. At different points in their journey from diagnosis children, young people and families may find additional support in relation to this helpful.

## **How can teachers help?**

Each child or young person diagnosed with MS will have their own individual support needs and these are very likely to change over time. One of the challenges facing those diagnosed with MS is that, for most children and young people, the condition is relapsing-remitting in nature. This means that they will experience episodes of relapse, where symptoms occur or increase and additional treatment may be required. Symptoms will then remit, reducing in severity or going away completely. Teachers have a really important role

in understanding and responding to this, so that support can be offered in a way that meets each child's changing needs.

Below are some suggestions relating to some of the common difficulties we know that children and young people can experience.

### **Attendance**

It may be helpful to plan in advance for how time off school will be managed. It may help for a young person to have a mentor or allocated staff member in school as a main contact point. This can be useful in ensuring someone holds an overview of the amount of work missed and can help the young person to develop a realistic plan for completion.

### **Cognitive difficulties**

All of the children who are seen in the service at GOSH will be offered a detailed neuropsychological assessment, which describe their profile of learning (strengths and weaknesses). In order to support a student who has challenges, some children will require access to a scribe, a reader or extra time during examinations. For each child this will be explained in the assessment report and the psychologist who completes the assessment will be able to review this with a teacher on the telephone.

### **Motor problems**

Children experiencing motor symptoms or difficulties may require adaptations such as extra time to move around school, access to lockers, or text books in each room to prevent the need to carry heavy bags. Some children may also find that their motor symptoms make it difficult to take notes during lessons and at these times may require copies of notes to be provided. Occupational therapists or physiotherapists may be involved in supporting a young person with MS and may make specific suggestions relevant to the school setting.

### **Visual symptoms**

Children experiencing visual symptoms may need to adjust where they sit in the classroom in order to see the board, or require enlarged copies of notes or handouts.

### **Fatigue**

Within the school setting, it may be helpful to plan with a young person how to manage their fatigue and use the energy they have in the most useful way. Helpful strategies can include taking steps to plan activity, prioritising the most important activities and pacing activities in a manageable way with breaks and rest planned in if needed. For some children and young people with MS, it may not be possible to maintain a full timetable. Some may need to reduce the number of subjects studied at GCSE or

A-level through careful discussion with their family and school team. The neuropsychological assessment report can be helpful in highlighting suggestions related to fatigue.

### **Emotional Impact**

In recognition of the psychological aspects of life-long illness, all of the children and young people seen at GOSH have the opportunity to meet with the paediatric psychology service when they attend appointments. Children and families may then be offered further appointments outside of the clinic where helpful. Alternatively, referrals may be made to appropriate local services. It may be helpful to think with a child and their family about what support they are currently getting, what they may find useful within school specifically and to discuss accessing additional services where needed.

## **Further information and support**

The **MS Society** offers plenty of up-to-date, accurate information that you might find helpful and provides support in the form of a helpline and local groups.

Tel: 0808 800 8000

Website: [www.mssociety.org.uk](http://www.mssociety.org.uk)  
and [www.youngms.org.uk](http://www.youngms.org.uk)

**MS Trust** at [www.mstrust.org.uk](http://www.mstrust.org.uk)

**MSdecisions.org.uk**

For young people and children  
[www.youngms.org.uk](http://www.youngms.org.uk)

### **Useful numbers**

- **GOSH switchboard: 020 7405 9200**
- **Pharmacy medicines information: 020 7829 8608 Monday to Friday from 9am to 5pm**