

## Multiple sclerosis: information for families

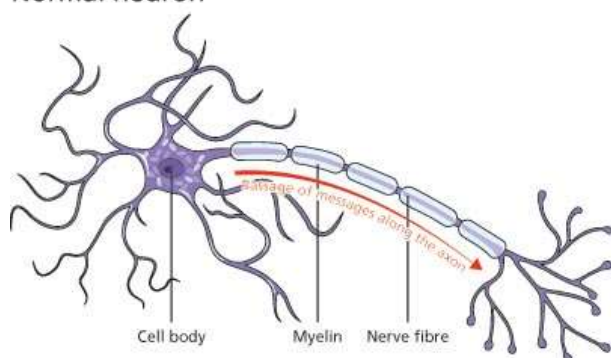
**Multiple sclerosis (MS) is a common neurological condition affecting around 100,000 adults in the UK, but it is rare in childhood – and particularly rare in children under 12. This information sheet from Great Ormond Street Hospital (GOSH) describes the symptoms, causes and treatment of MS.**

Specialist care for children and young people with MS is 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.

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.

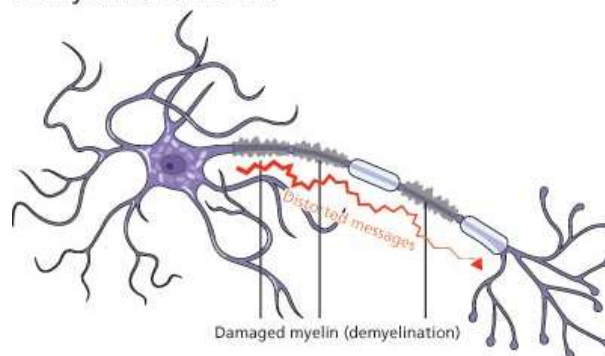
Normal neuron



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 ‘demyelination’.

Demyelination in MS



### What causes multiple sclerosis?

Doctors do not know exactly why this happens, but we know that MS is an autoimmune disease. This means that the cells of the immune system, which normally attack bacteria and viruses to protect the body, start to attack the covering of the nerves of the brain and spinal cord.

Doctors know that genetics is important, in that children with a first-degree relative, such as a parent, who has MS, are more likely to develop it themselves. We know that they have a one in 40 chance compared to a one in 1,000 chance for the general population, but researchers have been unable to identify a direct genetic link.

It is thought that it might also be linked to certain types of viral infection, or even exposure to sunlight as it is less common in countries that are

nearer the equator. Research is currently underway at GOSH to look at the causes of MS in young people.

## What are the symptoms of multiple sclerosis?

There are several different symptoms of multiple sclerosis, depending on which part of the brain or nervous system has been affected. They may include:

- the sudden onset of weakness on one side of the body or face
- sudden onset of problems with coordination and balance
- blurred or double vision
- persistent numbness or a tingling sensation in the limbs or face (over at least a 24 hour period)

## Are there different types of MS?

In children and young people, MS almost always (more than 98 per cent of the time) presents in a relapsing-remitting form. This is when the symptoms appear and then disappear (known as periods of relapse and remission) in an unpredictable cycle.

- Primary progressive MS (when symptoms gradually worsen over time) is extremely rare in children.
- Secondary progressive MS usually comes on after a relatively long period of relapsing remitting MS. Around 65 percent of people with relapsing remitting MS go on over time to have secondary progressive MS.
- Some individuals though seem to have a benign form of MS. This is when the symptoms are less severe and do not appear to worsen over a period of 10 to 15 years. Only around 15 per cent of people with MS have this variation of the condition.

It is very difficult to predict the type of course which someone is likely to have when first diagnosed.

## How is multiple sclerosis diagnosed?

A Paediatric Neurologist will usually see children and young people with suspected MS, take a thorough medical history, and do a physical examination to assess their nervous system.

In addition, your child may need:

- MRI scan: this uses a magnetic field (rather than X-rays) to take pictures of your child's brain and spine. It will enable the doctor to see whether the myelin around the brain and spinal cord has been damaged. Sometimes a dye (contrast) will need to be given intravenously during the scan, to see the areas involved more clearly. As children need to lie still for good quality images, this may need to be done under a general anaesthetic.
- Evoked potential tests: this is a method of measuring electrical activity in the brain and the eye without needing anaesthetic. A few small silver discs (electrodes) will be attached to your child's scalp and face while they carry out a series of audio or visual tests.
- Blood tests to look for common conditions that look like MS
- Spinal tap (lumbar puncture): a doctor may need to take a tiny amount of cerebrospinal fluid (which surrounds the brain and spine) from the base of the spine to check for the presence of particular proteins that might indicate myelin damage. Although a very quick procedure, as children need to lie still for it, this may need to be done under a general anaesthetic.

## How is multiple sclerosis treated?

Unfortunately, there is at present no cure for multiple sclerosis. However, there are treatments available for both the acute relapses, and to prevent relapses. There are also treatments to

manage some of the more upsetting symptoms associated with MS. These treatments can include medications, diet, exercise and lifestyle modifications, and psychotherapy.

### **Corticosteroids**

An acute relapse can be treated by giving corticosteroids. These are normally given intravenously. This will help to speed up the body's own recovery process. However, they will not change the long-term outcome for that attack.

### **Disease Modifying Drugs (DMDs)**

There are also disease modifying drugs which decrease the frequency of the relapses and over time decrease the risk of disability. These drugs would need to be discussed with the child's individual specialist.

### **Dietary changes and vitamin D supplements**

These may be advised – separate information is available about these.

### **Lifestyle modifications and multidisciplinary team management**

Physiotherapy, occupational therapy and psychotherapy are also used to ensure that everyone with MS has the support and help they need as well as to treat specific symptoms such as depression and fatigue.

### **What is the outlook for children and young people with multiple sclerosis?**

Life can be unpredictable for children with MS. Learning how best to manage their condition is key.

## **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. Call their helpline on 0808 800 8000 or visit their website at [www.mssociety.org.uk](http://www.mssociety.org.uk) – they also have a website for young people at [www.youngms.org.uk](http://www.youngms.org.uk)

The MS Trust website is at [www.mstrust.org.uk](http://www.mstrust.org.uk)

The MSdecision website is at [www.MSdecisions.org.uk](http://www.MSdecisions.org.uk)

Shift MS is a social network run by people with MS for people with MS – visit their website at [www.shift.ms](http://www.shift.ms) for more details.