

What is MS?



Multiple sclerosis information

Welcome to this Choices booklet about types of MS

MS-UK believes we must listen to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices leaflet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices leaflets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices leaflet has been designed with you in mind. We hope it will answer some of your questions and also provide some first-hand experience from those who have been in your position - people who can truly understand and empathise with your current thoughts and feelings.

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What is MS?

Multiple sclerosis (MS) is a disease of the central nervous system (your brain and your spinal cord). The central nervous system cells are covered in a protective layer of fatty protein called the myelin sheath (a bit like the insulation on an electrical cable). MS is an auto-immune disease, where the immune system gets confused and instead of attacking an infection or virus, the immune system turns on itself and attacks the nerve cells, damaging this protective sheath. This process is called demyelination. The demyelination disrupts the 'messages' being transmitted from and to the brain, causing them to slow down, become distorted or not get through at all.

The term 'sclerosis' is a Greek word that means scarring. Demyelination causes many scars or lesions in different places within the central nervous system. The symptoms that occur depend on the site and severity of the lesions and this is why people with MS experience different symptoms at different times.

It is estimated that there are more than 130,000 people in the UK diagnosed with MS. MS is commonly diagnosed in people between the ages of 20 and 30 (1). There are roughly three times as many women with MS as men (2).

In the early stages of MS, the central nervous system can sometimes repair the damaged myelin or use different pathways for the signals. This is why episodes of symptoms (relapses) can be followed by periods of time when symptoms improve or disappear altogether (remission).

Common symptoms at diagnosis

- Fatigue
- Optic neuritis (loss of vision in one eye, blurred or double vision)
- Weakness of limbs
- Reduced co-ordination
- Balance problems
- Numbness
- Pins and needles
- Unexplained pain

What causes MS?

Although it is not yet certain why people develop MS, research suggests that combinations of genetic and environmental factors are involved.

Genetic

MS is not directly inherited; however there does appear to be a genetic component, possibly a combination of certain genes which makes people more susceptible. Family members of someone diagnosed with MS have a slightly higher chance of developing MS themselves.

Environmental

Studies have found that the further north from the equator you live, the higher the chance of developing MS. It appears that there is a higher

rate of MS in the UK (MS is more common in Scotland than in the rest of the UK), North America and Scandinavia but a very low chance in countries like Malaysia which are very close to the equator.

Some research suggests that there is a link between MS and vitamin D deficiency. Vitamin D mostly comes from exposure to sunlight so this could be a factor. Research on this matter is on-going.

You can find out more in our Choices booklet, Vitamin D.

How is MS diagnosed?

You will be referred to a neurologist who will look at your medical history and examine you. You are then likely to undergo a number of tests including

Magnetic Resonance Imaging (MRI) scan

This will identify any areas of the brain or spinal cord that may have scarring.

Lumbar puncture

Also known as a spinal tap, is used to take a sample of spinal fluid to test for abnormalities.

Evoked potentials

Simple tests that measure the time it takes for the nerves to respond to electrical stimulation.

A positive diagnosis can take some time and these tests are not always conclusive. You can read more in our Choices booklet - 'Diagnosis'.

Common misconceptions about MS

We asked people affected by MS what were the most common misconceptions they have heard from others about MS.

Below are our findings and explanations.

‘Everyone with MS becomes severely disabled’

For the vast majority of people with MS, this is untrue. Rapid progression is rare and most people with MS do not need to use a wheelchair on a regular basis.

‘I am going to lose my independence’

For most people this is also untrue. Most people with MS continue to enjoy an active life for many years after they are diagnosed.

‘My children will get MS’

MS is not an inherited condition. In children of people with MS, it is thought there is a genetic susceptibility towards developing MS in the future, but it is not directly inherited as many other factors come in to play. The origin of MS is not fully understood. For a child of a person with MS, the chance of that child developing MS in the future is 1 in 48, or less than two per cent over that child’s lifetime (3).

‘MS is a terminal illness and I am going to die early’

Most people with MS live just as long as anyone else. Although MS cannot yet be cured, it is not a life-threatening or terminal illness but what is known as a chronic condition. This means that once you have it, you have it for life; however it will not threaten your life.

‘Everyone ends up in a wheelchair’

This is definitely not true! One of the most common aspects of MS is that everyone’s MS is different. People experience different disease progression at different times and so it is impossible to say that anyone will or will not ever need a wheelchair.

‘You look ok, you must be better!’

Of course we all know that a diagnosis of MS is not going to go away, so unfortunately ‘getting better’ is not an option, but there will be good days as well as bad and others will notice this.

People who care about you may well wish that you did not have this condition, so it may be a concern for you that prompts that kind of response, in the hope that it has all just gone away!

‘Fatigue is cured by a night’s sleep’

Fatigue is not a symptom that can be cured by just having a good night’s sleep. Fatigue has been described in many different ways such as ‘bone weariness’, ‘feeling lead-like’ etc. Fatigue is a symptom that has to be managed carefully so that people can still feel that something is achievable each day.

‘MS is the same as ME’

The symptoms of ME (or CFS – Chronic Fatigue Syndrome) sound a lot like the symptoms that people with MS describe. Such as - severe and debilitating fatigue, painful muscles and joints, disordered sleep, gastric disturbances, poor memory and concentration. However,

unlike MS, ME is not an auto-immune condition, it is more likely to be linked to a variety of contributing factors (including infectious, traumatic, environmental, etc.)

Although there is currently no cure for MS there are ways to manage the disease, including drug therapies, complementary therapies and various aids to give you relief from your symptoms. We have a range of Choices booklets which go into each of these in more detail.

MS does not need to be as devastating a diagnosis as it may first seem. If you have access to good information, the right treatments and support from both your family and healthcare professionals, you can still live a happy and fulfilling life.

Further information

MS-UK Choices booklets

Is it MS? Types of MS, MS symptoms

www.ms-uk.org

About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis; whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people's rights to make informed decisions for themselves.

The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.



New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

Available in print, audio version, large print and digitally.

MS-UK Counselling

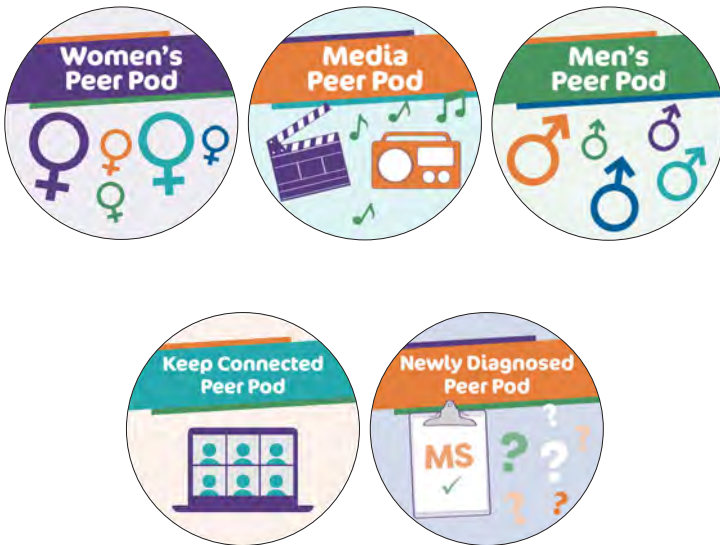
MS-UK Counselling is open to anyone living with MS and is the only service of its kind available in the UK. Whether you want support coming to terms with a diagnosis or to improve your mental wellbeing, our counselling service is focused on helping you.

All of our MS-UK counsellors are BACP registered or accredited with an in depth knowledge of MS.

About MS-UK

Peer Support Service

Our Peer Support Service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more www.ms-uk.org/peer-support-service or email peersupport@ms-uk.org.





MS-UK Online

MS-UK Online offers a range of activities for people living with multiple sclerosis (MS). Our aim is to help people manage their wellbeing independently through exercise, information and connecting with others.

The activities offered online have been chosen by the MS community and future activities are guided by the feedback we receive.

Our current online activities include exercise classes, chair yoga, information sessions, interactive workshops and courses such as mindfulness and poetry.

To get involved, please visit the website www.ms-uk.org/ms-uk-online-exercise or email register@ms-uk.org.

Sources

- (1) NICE Multiple sclerosis Quality standard 108. 14 January 2016. Accessed 26 October 2016. nice.org.uk/guidance/qs108 and www.nice.org.uk/guidance/qs108/resources/multiplesclerosis-75545244362437
- (2) Jeri Burtchell, Healthline. Study Explains Why MS Is More Common in Women than in Men. 14 May 2014. Accessed 26 October 2016. www.healthline.com/health-news/why-do-morewomen-than-men-get-ms-051414
- (3) Risk of developing MS. MS Trust. Last updated 24 August 2016. www.mstrust.org.uk/a-z/risk-developing-ms

All links accessed 26 October 2016

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