

# Choices

## Children with MS



Multiple sclerosis information

# Welcome to this Choices booklet about children with MS...

MS-UK believes in listening 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 booklet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices booklet has been designed with you in mind, and we hope it will answer some of your questions about children and MS. It is important to note that this booklet is targeted at the parents or guardians of children who are affected by MS and should be read in conjunction with our full range of Choices booklets.

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## Introduction

Multiple sclerosis (MS) is a condition that affects the central nervous system (CNS). The CNS consists of your brain and spinal cord, and as the name suggests it plays a central role in the regulation and management of key bodily functions (1).

Nerve cells in the CNS are covered by a protective layer of fatty protein called the myelin sheath, which is a bit like the insulation which surrounds an electrical cable. MS is an autoimmune condition where the immune system gets confused and attacks the nerve cells. Instead of attacking an infection or virus, it damages this protective sheath. This process is called demyelination. The effect of demyelination is to disrupt the messages that are transmitted from and to the brain, causing them to slow down, become distorted or not get through at all.

MS in children, otherwise known as paediatric MS, generally refers to anyone under the age of 16 who has been diagnosed with the condition.

While MS affects around 150,000 adults in the UK it is rarely seen in childhood, and is especially rare in children under the age of 12 (2). It is estimated that globally at least 30,000 children under the age of 18 are living with MS, with the UK figure being around 250 (3).

## Symptoms

The signs and symptoms of MS are dependent upon where demyelination has happened in the brain or central nervous

system. As with adults, there are a wide variety of symptoms that a child with MS could develop. Symptoms may include (2)

- Difficulty with balance and coordination
- Problems with thinking clearly and word recall
- Problems with movement particularly on one side of the body
- Visual symptoms such as blurred or double vision
- Fatigue, extreme tiredness or exhaustion that doesn't seem to relate to physical activity
- Numbness and tingling sensations in the limbs or face

In comparison to adults with MS, children who are affected can experience relapses more frequently, however, they generally recover more completely thereafter (4). Studies have also found that at least one-third of children with paediatric MS experience impaired cognitive functioning, which tends to deteriorate over time (5).

### More information

Our MS Symptoms Choices information booklet offers more information on the common symptoms associated with MS.

[www.ms-uk.org/multiple-sclerosis-symptoms-choices-booklet](http://www.ms-uk.org/multiple-sclerosis-symptoms-choices-booklet)

## Diagnosis

Diagnosis of MS in children can be difficult, as many of the common symptoms of MS such as fatigue, pain, memory problems and lack of concentration, can be attributed to other conditions or associated with the impact of growing up (6).

A child will usually be seen by a paediatric neurologist once MS is suspected. To assess the central nervous system, the neurologist

will conduct a physical examination and take a full medical history. Only a neurologist can give a diagnosis of MS.

More neurological tests will likely be needed to provide an MS diagnosis, and these are summarised below.

## **Blood tests**

These are taken to rule out other conditions or nutrient deficiencies being the root cause of your child's health issues. Some of these may have symptoms that are very similar to MS.

## **Magnetic Resonance Imaging (MRI) scans**

This scan is used to identify any areas of the brain or spinal cord that may have damage indicative of MS. An MRI scanner consists of a large doughnut-shaped magnet with a tunnel in the centre, which along with radio waves is used to take pictures of the brain or spine.

## **Evoked potentials tests**

These are very simple and painless electrical tests which measure the time it takes for the child's nerves to respond to stimulation. Visual evoked potentials (VEP) are most commonly used in the MS diagnostic process. It involves a conducting gel and electrodes being applied to the head and face. Audio and visual stimuli are then used and the outcomes are assessed to identify any areas of concern.

## **Lumbar puncture**

A lumbar puncture is a procedure where a small sample of cerebrospinal fluid (CSF) is taken from the base of the spine. CSF is the fluid that surrounds and protects the brain and spinal cord. This is then analysed for any abnormalities, such as the presence of certain proteins which can indicate inflammatory activities such as myelin damage.

## Diagnosis considerations

To receive a diagnosis of MS, a child will usually have experienced an acquired demyelinating syndrome (ADS), which is a demyelinating episode and often a precursor to MS. It includes conditions such as optic neuritis, transverse myelitis and clinically isolated syndrome (CIS). They may be affected by multiple symptoms prior to experiencing a second demyelinating event, usually within two years, to meet the criteria required to be diagnosed with MS (7).

While there are additional considerations when diagnosing MS in children in comparison to adults, such as eliminating the possibility of demyelinating syndromes that can appear in childhood, there are also many similarities. For example, when new lesions appear in follow-up MRI scans, there is a strong possibility of an MS diagnosis in children. Evidence of dissemination in time and space is also a key consideration (8). This is when nerve damage has occurred at different points in time and in different areas of the CNS respectively.

Interestingly, a recent study which was undertaken in Germany found that children and teenagers may show a range of early signs and symptoms in the five years prior to MS diagnosis. These early signs can include obesity, sensory changes, and vision problems, which could serve as clues for identifying MS earlier in young people (9).

There appears to be no substantial differences in sex ratio, familial recurrence, relapse rate, ethnicity or clinical symptoms at the time of diagnosis between children and adults with MS. The most common type of MS in children is relapsing remitting MS (RRMS) where symptoms can come and go in a relatively unpredictable way. Progressive forms of MS are seen in children, but instances are very rare (3).

## More information

Our Diagnosis Choices booklet provides more detailed information about how MS is diagnosed.

[www.ms-uk.org/diagnosis-of-multiple-sclerosis-choices-booklet](http://www.ms-uk.org/diagnosis-of-multiple-sclerosis-choices-booklet)

## Treatment

Although there is no cure for MS as yet, research suggests that careful attention to managing the condition, including implementing medication and lifestyle interventions, can result in a child's improved educational performance and overall quality of life (10).

### Care pathway

NHS England has produced a service specification titled 'Multiple Sclerosis Management Service for Children' which covers the provision of services for children with MS or MS-like conditions. This guidance states that once a child is diagnosed with MS, they should have access to a multi-disciplinary team (MDT) who are experienced in the treatment and care of children with MS.

The team will be led by a paediatric neurologist who has expertise in MS. It should also include MS clinical nurse specialists, clinical psychologists, neuropsychologists, occupational therapists and physiotherapists. Once under the care of a specific hospital, a patient should be able to contact their team during normal working hours (11).

In preparation for adulthood, each child and their clinical team will start planning for the transition to adult services from age 12, with the aim of them being transferred just before they reach 18 years of age. Patients will then be seen by their local or most appropriate adult MS service (11).

While this guidance has been developed by NHS England, it provides an example of how public health authorities in other areas of the UK may approach care for paediatric MS patients.

## Medication

There is a range of disease modifying therapies (DMT) that are used to modify the course of MS itself, reduce the number of relapses and delay long-term progression. Some of these are suitable for those under the age of 18. Acute relapses can be treated by a course of steroids which can help those affected to get through the relapse as quickly as possible.

All medications for MS will be prescribed by a neurologist who will talk to children and their families about eligibility, their options and further considerations on an individual basis (2).

## Lifestyle

Lifestyle choices can play a significant role in the management of MS, in both children and adults. These may include exercise, dietary approaches, complementary therapies and psychological support. Your child's clinical MS team can provide guidance on the potential benefits of these approaches, considering their individual circumstances.

## Vitamin D

The link between vitamin D and MS is thought to be both environmental and genetic in nature. It is widely believed that these factors are associated with an elevated risk of developing MS, although more evidence is required for a better understanding.

The team at Great Ormond Street Hospital for Children (GOSH) in London currently advise their paediatric MS patients to take 1,000 international units (IU) of vitamin D per day by way of

supplementation. They also provide regular monitoring of their patient's vitamin D levels to ensure that dosages are kept to an optimum, and safe, level (12).

### More information

Our Choices range of information booklets covers many areas of MS management including DMTs, diet and supplements, complementary therapies, exercise and more.

**[www.ms-uk.org/multiple-sclerosis-choices-booklets](http://www.ms-uk.org/multiple-sclerosis-choices-booklets)**

## Education

As a parent, you may be concerned about your child needing time away from school or college for hospital appointments. For example, if they are having a relapse or are experiencing issues with MS symptoms. You may also be worried that fatigue or cognitive problems will affect your child's learning. These concerns are completely natural. However, help is at hand.

In the UK every mainstream school must have a Special Educational Needs Coordinator (SENCO). Their main duty is to ensure that any child with specific needs is supported by the school. By speaking to the SENCO at your child's school you can discuss possible solutions which will ensure your child's continued inclusion in learning and other school activities.

You may also wish to talk to the school about whether your child may benefit from the provision of a formal plan, which takes your child's specific and wider needs into account. In England this may be in the form of an Individual Education Plan (IEP) and an Education, Health and Care Plan (EHCP), however there are differences in other areas of the UK. In Scotland your child

may be eligible for a Co-ordinated Support Plan (CSP), in Wales an Individual Development Plan (IDP) and a Statement of Special Educational Needs (SEN) is available for children who reside in Northern Ireland (13).

These plans should reflect your child's goals for the future, as well as their current needs. If your child is attending or planning to attend college or university, it is suggested that you contact the particular educational establishments of interest to talk about the support they can offer, prior to applying for a place.

It is also important to note that your child may be entitled to free school transport. Contact the transport coordinator at your local council to find out more.

Later in this booklet we provide details of organisations that can offer focused support and guidance on special educational matters in your area of the UK.

## Benefits

Supporting a child with a disability can have a financial impact on a family's finances and living circumstances. It may be helpful for you to know that there are some welfare benefits which you or your child may be entitled to claim.

These benefits can include Disability Living Allowance (DLA) in the UK except Scotland or Child Disability Payment (CDP) in Scotland only, which are available to children under the age of 16.

DLA and CDP provide financial support towards the extra costs of bringing up a child with a disability. They can be regarded as gateway benefits given that claimants who are in receipt of them,

their parents or carers, may be eligible for additional financial support. For example, Carers Allowance (CA) for people living in the UK except Scotland and Carer Support Payment (CSP) for residents of Scotland only, are benefits for unpaid carers which you could claim if your child is eligible for DLA or CDP.

Furthermore, if you are claiming benefits such as Universal Credit (UC) you may be eligible for an increase in payments if your child receives DLA or CDP. You will also be exempt from the benefits cap.

If your child receives the higher rate of the DLA or CDP mobility component they will automatically qualify for a Blue Badge. They may also qualify under the assessed route depending on their circumstances (14).

### More information

Our Benefits and MS website resource provides a summary of the benefits mentioned above and more. It also offers links to benefits calculators which will help you to better understand your household's entitlement.

Visit [www.ms-uk.org/benefits-and-ms](http://www.ms-uk.org/benefits-and-ms)

## Further information

More information, resources and support for young people with MS and their families can be found below.

### Multiple Sclerosis International Federation (MSIF)

The MSIF have produced an informative booklet titled 'Childhood MS: A guide for parents'. This booklet covers many topics of concern regarding paediatric MS including how MS can affect

children, cognitive issues, education, getting the best from health and social care services and much more.

[www.msif.org/about-ms/childhood-ms](http://www.msif.org/about-ms/childhood-ms)

### **MS Trust**

The charity MS Trust have launched a YouTube channel called 'MSTV' which is for young people who are affected by MS. Other useful content includes stories from children affected by MS detailing their experiences and links to valuable resources.

[www.mstrust.org.uk/a-z/childhood-ms](http://www.mstrust.org.uk/a-z/childhood-ms)

## **Education and legal advice**

Navigating the education system can be complex and challenging at times. If you need support to know your child's rights in relation to educational issues, there are organisations that can support you.

### **Contact**

The charity Contact offers information, advice and support for families with disabled children around the UK. Their support is wide-ranging and covers issues such as education, finance, work and childcare, health and social care, and has an active online community. Contact has links to many local support groups across the UK and works to improve parent carer participation.

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

### **England only**

#### **Local Offer**

The Local Offer provides information about local services and support available to children and young people in England who have special educational needs and disabilities (SEND). This encompasses education, health, and social care.

Each local authority will have their own statement of the services that they can offer. You can find details of your local authority's Local Offer via their individual websites.

**[www.gov.uk/find-local-council](http://www.gov.uk/find-local-council)**

### **Council for Disabled Children**

There are Information, Advice and Support (IAS) services in every local area in England which provide dedicated and impartial advice to young people, their parents, and carers, particularly in relation to education. The IASS Network (IASSN) is funded by the Department for Education and is based within the Council for Disabled Children in the National Children's Bureau. **[www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)**

### **Independent Parental Special Education Advice (IPSEA)**

This is a charity that offers free and independent information, advice and support in the field of SEND law. Their website hosts a range of resources and guides which are designed to extend awareness. They also provide tribunal support and a helpline.

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

### **Coram Child Law Advice**

This service is operated by Coram Children's Legal Centre. It provides specialist advice and information on child, family and education law to young people in England, their parents and carers. **[www.childlawadvice.org.uk](http://www.childlawadvice.org.uk)**

### **Scotland only**

### **Additional Support for Learning (ASL)**

Under ASL, local authorities in Scotland provide information about local services available to children and young people who

have SEND. This encompasses education, health and social care. Each local authority will have their own statement of the services that they can offer. You can find details of your local authority's ASL support via their individual websites.

**[www.mygov.scot/local-council-website](http://www.mygov.scot/local-council-website)**

## **Enquire**

This organisation is funded by the Scottish Government and managed by the organisation Children in Scotland. Their mission is to share knowledge and expertise to help children, young people, parents, carers and professionals. This includes guidance regarding ASL and where to find local authority ASL contacts. **[www.enquire.org.uk](http://www.enquire.org.uk)**

## **Scottish Child Law Centre (SCLC)**

A specialist hub which provides free legal advice on all aspects of Scottish law relating to children and young people. This includes issues such as education, health and social care.

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

## **Clan Childlaw**

A charity that provides free legal advice and representation for children and young people who live in Scotland.

**[www.clanchildlaw.org](http://www.clanchildlaw.org)**

## **Wales only**

### **Additional Learning Needs (ALN)**

ALN is an umbrella term used for the system of supporting children and young people who have SEND and live in Wales. This encompasses education, health and social care.

You can find details of your local authority's ALN support via their individual websites. **[www.gov.wales/find-your-local-authority](http://www.gov.wales/find-your-local-authority)**

## **SNAP Cymru**

This is a charity whose main aim is to advance the education of people in Wales and support their inclusion. It offers free, independent information, advice and support for children and young people with SEND, their parents, carers and guardians.

**[www.snapcymru.org](http://www.snapcymru.org)**

## **Children's Rights Advice and Assistance Team**

All children in Wales have rights under the United Nations Convention on the Rights of the Child (UNCRC). This includes the right to education, the right to the best possible health care, and the right to be safe. The office of the Children's Commissioner for Wales offers this free and confidential helpline to advise children, young people and those who care for them of their rights, this includes educational entitlement, social services and healthcare access.

**[www.childcomwales.org.uk/about-us/childrens-rights-advice-and-assistance-team](http://www.childcomwales.org.uk/about-us/childrens-rights-advice-and-assistance-team)**

## **Northern Ireland only**

### **Special Educational Needs Advice Centre (SENAC)**

SENAC is a charity that provides confidential and independent guidance on the Northern Ireland special educational needs system.

**[www.senac.co.uk](http://www.senac.co.uk)**

### **Children's Law Centre**

This organisation works to protect the rights of all children living in Northern Ireland. In particular it focuses on those who are the most disadvantaged, especially children who are living with disabilities and have special educational needs. Their services extend to providing free legal representation at special educational needs and disability tribunals (SENDIST). **[www.childrenslawcentre.org.uk](http://www.childrenslawcentre.org.uk)**

# Give a gift that lasts all year

Make a regular donation to MS-UK  
and get your **free MS-UK pin badge**.

[www.ms-uk.org/regular-donations](http://www.ms-uk.org/regular-donations)



# About MS-UK

MS-UK is a national charity 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.

## 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

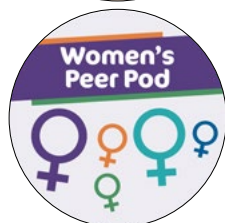
Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

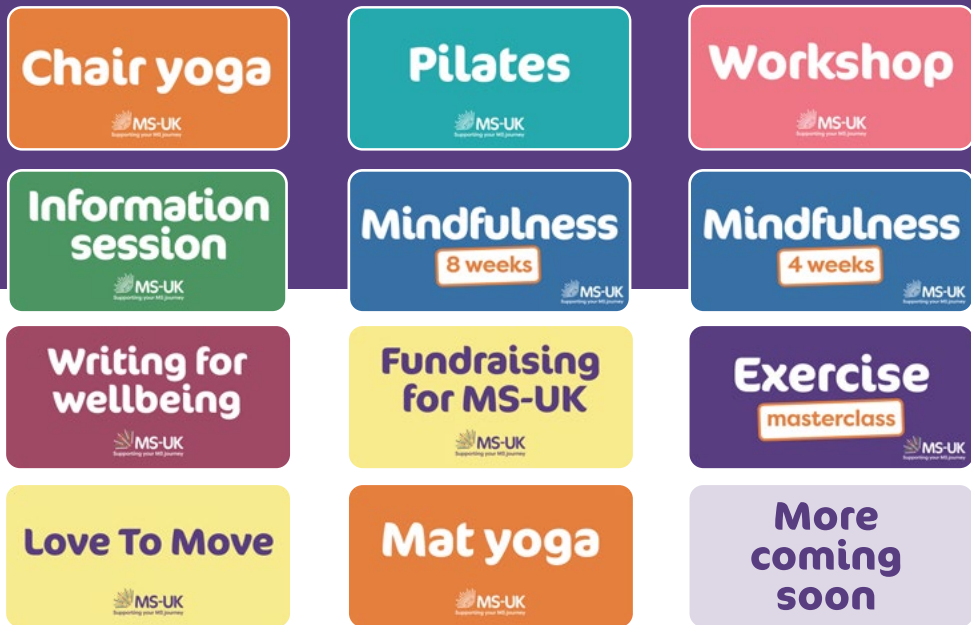
Available in print, audio version, large print and digitally.

# 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 [ms-uk.org/peer-support-service](https://www.ms-uk.org/peer-support-service) or email [peersupport@ms-uk.org](mailto:peersupport@ms-uk.org).





## MS-UK's online activities

MS-UK offers a variety of online activities for those affected by MS to stay active, connected with others and to manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. To get involved, please go to [www.ms-uk.org](http://www.ms-uk.org) or email [register@ms-uk.org](mailto:register@ms-uk.org).

## MS-UK E-learning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created an accredited eLearning course that can help you do this. Visit [www.ms-uk.org/ms-awareness-e-learning](http://www.ms-uk.org/ms-awareness-e-learning) to find out more.

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**Reviewed January 2025**







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**Registered Company Name**

Multiple Sclerosis-UK Limited, trading as MS-UK

**Company Number** 2842023

**Registered Charity Number** 1033731

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