

Children with MS



Welcome to this Choices booklet about children with MS

At MS-UK we believe 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 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.

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Introduction

Multiple sclerosis (MS) in children, otherwise known as Paediatric MS, generally refers to anyone under the age of 16 who has been diagnosed with the condition. 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). It is believed that MS is a condition where 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. It is not known what causes the onset of MS, although there are researchers around the world continually looking at potential triggers and treatment options.

While MS affects around 107,000 adults in the UK, it is rarely seen in childhood. Although it is a rare condition, and particularly rare in children under 12 (1) at least five per cent of people with MS will have paediatric-onset MS (POMS) and will experience a diagnosis before the age of 18 (2).

Symptoms

Depending on where demyelination has happened in the brain or central nervous system, this will affect the signs and symptoms of MS. As with adults with MS, there are a wide variety of symptoms that a child could develop. Symptoms may include (1)

- 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 (that last for more than 24 hours)

Though in the majority of instances children with MS do not have significant physical disability at the time of diagnosis or the onset of symptoms, at least a third of children with MS have cognitive issues (3).

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 growing up (3). 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. It is likely that more tests will be needed to give a diagnosis and these are listed below.

Blood tests

These are taken to rule out other conditions that may have symptoms that are very similar to MS.

Magnetic Resonance Imaging (MRI)

This scan is used to identify any areas of the brain or spinal cord that may have damage. 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. This allows clinicians to see clearly if damage has occurred. Sometimes a contrast dye is used intravenously during the scan; this allows clinicians to see clearly if damage has occurred. As the scan needs a child to lie very still to get a clear image, it can be conducted under a general anaesthetic. If this causes any anxiety or distress you may wish to speak to your clinicians and ask to be able to see the scanner and have the procedure explained in full beforehand.

Evoked potentials tests

This is a very simple electrical test that measure the time it takes for the child's nerves to respond to stimulation. A conducting gel and electrodes (small discs) are applied to the head and face. Audio and visual stimuli are then used and the outcomes recorded. The test is absolutely painless.

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 (presence of certain proteins) that can indicate myelin damage.

To receive a diagnosis of MS, the child will need to have experienced onset acquired demyelinating syndromes (ADSs), which is a demyelinating episode and often a precursor to MS. This may include the child being initially diagnosed with either acute disseminated encephalomyelitis (ADEM), optic neuritis, transverse

myelitis, or another clinically isolated syndrome (CIS). This would also involve either single or several symptoms prior to experiencing a second incidence (usually within two years) to then meet the criteria to be diagnosed with MS (5).

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 with MS and adults with MS. The most common type of MS in children is relapsing remitting MS, where symptoms can come and go in a relatively unpredictable way. Progressive forms of MS are seen in children, but are very rare (2).

Treatment

Although there is no cure for MS as yet, research suggests that careful attention to the management of relapses and symptoms, including lifestyle changes and medication therapies, results in improved educational performance and overall quality of life (6). There are medications and interventions available to treat symptoms, help with relapses and to help modify the course of the disease.

Symptomatic therapies may include exercises and psychological support. Acute relapses will usually be treated with steroids, these can help get through the relapse as quickly as possible, however, it will not change the outcome of the relapse. There are also a range of disease modifying therapies that are used to reduce the number of relapses a child will experience and reduce the risk of disability. All of these medications will be prescribed by the neurologist and they will talk to children and families about eligibility and options on an individual basis (1).

NHS England have 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. The service specification says that once a child is diagnosed with MS they should have access to a multi-disciplinary team (MDT) experienced in the treatment and care of children with MS. The team will be led by a paediatric neurologist with an expertise in MS and will likely include MS clinical nurse specialists, clinical psychologists, neuropsychologists, occupational therapists and physiotherapists. Once under the care of a specific hospital there should be the availability of the MS clinical team during normal working hours (6).

In preparation for adulthood each child and their clinical team will start planning for the transition to adult services from age 12. In most cases children will then be seen by the local or most appropriate adult MS service (6).

Vitamin D

Vitamin D is needed to absorb different nutrients to help keep bones, muscles and teeth healthy. For the majority of the population enough vitamin D will be gained through exposure to sunlight. Vitamin D can also be found in some foods, such as eggs, oily fish, milk and margarine. There are also some foods such as cereals which are fortified with vitamin D. It is felt that vitamin D plays a role in people with MS, although exactly what that role is and how vitamin D can help with MS is still being looked into by researchers and clinicians. MS-UK has a Choices leaflet on 'Vitamin D and MS' and this may well be worth reading as it has information on research and the possible links with MS.

When it comes to taking supplements to ensure that your child has enough vitamin D, vitamin D3 is generally recommended over vitamin D2 as it produces higher blood levels of Vitamin D. The team at the Great Ormond Street Hospital (GOSH) in London currently advise all of the children with MS they treat to take 1000IU (international units) supplementation a day. Although this may seem like a large dose, side effects at this level are thought to be very low (7).

Education

As a parent, you may be concerned about your child needing time off from school or college for hospital appointments, if they have a relapse or are having issues with symptoms. You may be worried that fatigue or cognitive problems will affect your child's learning. You can talk to the Special Educational Needs Coordinator (SENCO) at your child's school to ensure your concerns are discussed and adjustments made to ensure your child's participation and inclusion in learning and school activities.

You may also wish to talk to the school about whether your child may benefit from the provision of an Education, Health and Care (EHC) Plan (in England, Wales and Northern Ireland) (8) or a Coordinated Support Plan (in Scotland) (9). These plans should reflect the child or young person's goals for the future, as well as their current needs and should stay with them until they are aged 25 if needed. If your child is attending or planning to attend college or university, it is suggested that you contact the educational establishment to discuss your child's needs.

There are Information, Advice and Support (IAS) services in every local area in England who provide dedicated and impartial advice

to young people and parent carers particularly in relation to education. The IASS Network is funded by the Department for Education and is based within the Council for Disabled Children in the National Children's Bureau (10).

Your child may also be entitled to free school transport. Contact the transport coordinator at your local council to make an enquiry.

Research

Paediatric UK Demyelinating Disease Longitudinal Study (PUDDLs) is an ongoing piece of research that hopes to see patterns and trends yet to be seen in adults with MS. The study looks at the relatively short time period from when symptoms appear (and are presented to specialist doctors) and exposure to environmental factors which may influence the onset of MS. The study believes this offers a unique research opportunity as observing a paediatric population from very early in the disease course will allow the study to investigate more about the course of MS, and may offer further valuable insights into the genetic and environmental factors involved (3).

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 there are some welfare benefits you or your child may be entitled to claim. These benefits can include Disability Living Allowance (DLA) and Carer's Allowance (CA). DLA provides help towards the extra costs of bringing up a child

with a disability. CA is a benefit for family or unpaid carers, which can possibly be claimed if your child is eligible for DLA. DLA is sometimes called a gateway benefit, as claimants who are in receipt of DLA may be able to access other help such as a Blue Badge, higher payments of benefits you already get and you may not have to pay vehicle tax. DLA is not a means tested benefit and it can be paid in addition to other welfare benefits. DLA comes in two parts; a mobility component and a care component. A claimant may be entitled to either component or both.

DLA is normally only available for children under the age of 16. A person who is over 16 can claim Personal Independence Payment (PIP), which is a very similar benefit for adults.

If your child has mobility problems, you may be able to apply for a Blue Badge from your local council, even if they are not in receipt of DLA. (11)

For more information on benefits or the Blue Badge scheme, call MS-UK on freephone 0800 783 0518.

Further information

Multiple sclerosis

The Multiple Sclerosis International Federation (MSIF) has a booklet to download via their webpage on 'MS in children'. This booklet is titled 'Childhood MS A guide for parents'. The booklet covers; what is MS, how could MS affect my child, cognitive issues, education, getting the best from health and social care service and much more.

www.msif.org/about-ms/childhood-ms

The MS Trust has been doing a lot of work with children and young people with MS in recent years. They have launched a YouTube channel called 'MSTV', which is for young people aged 11 to 17 who are affected by MS. The MS Trust also has a collection of childhood MS stories that shares valuable insights and experiences from younger people about their lives with MS.

www.mstrust.org.uk/a-z/childhood-ms

Support for families with a disabled child

The charity 'Contact-a-Family' has recently rebranded as 'Contact – for families of disabled children'. It gives advice and support relating to education, finances, work and childcare, health and social care services and have an active online community. Contact has links to many local support groups across the UK England, Scotland, Wales and Northern Ireland and works to improve parent carer participation. It also operates a free national helpline which can be reached by calling 0800 803 3555.

www.contact.org.uk

Benefits

Turn2us is a national charity that helps people with a financial

need gain access to welfare benefits, charitable grants and support services. The Turn2us website has detailed information on benefits and grants. It also has a useful benefits calculator, grant search tool and a helpline. The Turn2us helpline is a free, confidential and independent service for people who do not have internet access, need help to use it or have additional support needs.

Call 0808 802 2000 (9am-8pm Mondays-Fridays)

www.turn2us.org.uk

Citizens Advice has many local centres where you can gain hands on help along with quality web based information on all benefits available. There is also information about payment of benefits and problems with benefits. Citizens Advice has a good introduction to welfare benefits, an A-Z of benefits and much more.

www.citizensadvice.org.uk/benefits

Law Centres provide free legal advice and representation to disadvantaged people. There are a network of approximately 50 independent Law Centres across England and Northern Ireland. Unfortunately, not all areas of the country have access to a Law Centre. To find out if there is a Law Centre local to you; their website has an interactive Google map along with a list of all the Law Centres.

To find a Law Centre in England, Wales or Northern Ireland, visit

www.lawcentres.org.uk

<https://childrenslegalcentre.wales>

To find a Law Centre in Scotland, visit:

www.scottishlaw.org.uk/lawfirms/lawcentres.html

Education and legal advice

You can find contact details for your local Information, Advice and

Support services by looking on the Council for disabled Children's website. They have an interactive map, which will help find your nearest service.

www.councilfordisabledchildren.org.uk/information-advice-and-support-services-network

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 and your child.

England

The charity Independent Parental Special Education Advice (known as IPSEA) offers free and independent legally based information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities (SEND).

www.ipsea.org.uk

Child Law Advice is operated by Coram Children's Legal Centre. It provides specialist advice and information on child, family and education law to parents, carers and young people in England.

www.childlawadvice.org.uk

Scotland

The charity Scottish Child Law Centre provides services to the whole of Scotland. It provides a free legal advice service, by telephone, email and text message, on all aspects of Scots law relating to children and young people, including education, health, and social care.

www.sclc.org.uk

Wales

SNAP Cymru is a charity whose main aim is to advance the education of people in Wales and support their inclusion. SNAP Cymru offers free and independent information, advice and support to help get the right education for children and young people with all kinds of special educational needs (SEN) and disabilities.

www.snapcymru.org

Northern Ireland

The Children's Law Centre works to protect the rights of all children living in Northern Ireland. In particular, it focusses on those who are the most disadvantaged, especially children who are living with disabilities and have special educational needs.

www.childrenslawcentre.org.uk

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.

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