ms international federation

Childhood MS

A guide for parents

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We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. The law and government regulations may change. Be sure to seek local advice from the sources listed.

Contributors:
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Childhood MS

A guide for parents

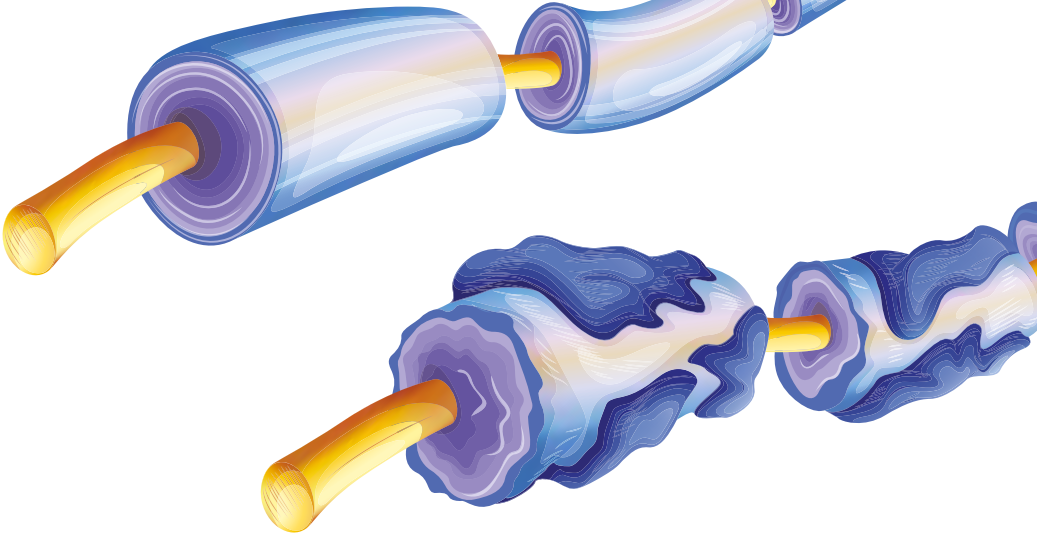
If your child has been diagnosed with multiple sclerosis (MS), or MS has been suggested as a possible cause for your child's symptoms, you may have lots of questions. What caused it? How will it affect my child? Can it be cured? What does the future hold?

This guide is intended to provide answers to some of these questions. It should help you to understand more about the care your child should receive, and the kind of support you are entitled to in order to manage the changes MS can bring.

If you have any more questions about MS, you can find the contact details for useful resources at the end of the guide.

What is MS?

In MS, the immune system attacks the myelin surrounding the nerve fibres. Damage to myelin disrupts messages travelling along nerve fibres.



Up to ten per cent of people with MS experience their first symptoms before the age of 16.

MS is usually thought of as an adult condition, but children and teenagers can also develop it. In fact, children as young as two years old have been diagnosed with MS. There are estimated to be around 2.3 million people with MS in the world. It's not clear how many are under the age of 16, but up to ten per cent of people with MS experience their first symptoms before the age of 16.

To understand what happens in MS, it is helpful to understand what happens in the body's central nervous system (the brain and spinal cord). The brain controls bodily activities, such as movement and thought, by sending messages from the brain. The spinal cord is the main pathway for these messages between the body and the brain.

Surrounding and protecting the nerve fibres of the central nervous system is an insulating substance called myelin, which helps messages travel quickly and smoothly between the brain and the rest of the body.

MS is thought to be an immune-mediated condition. This means that the body's immune system, which normally helps to fight off infections, mistakes the body's own tissue as foreign and attacks it. In MS, the immune system attacks the myelin surrounding the nerve fibres, but since the specific target of the attack within the myelin has not been identified, many scientists argue that we don't yet know for certain whether MS is an autoimmune disease. The immune attack damages the myelin and strips it from the nerve fibres, either partially or completely, leaving scars (also known as lesions, plaques or sclerosis).

This damage to myelin disrupts messages travelling along nerve fibres. The messages can slow down or become distorted. The easiest way to understand what happens in MS is to think of the nervous system as an electrical circuit, with the brain and spinal cord acting as the power source and the rest of the body being the lights, computers, TVs, and so on. Nerves are like electric cables linking the appliances together with myelin being the plastic insulation around these cables. If the insulation gets damaged, the appliances will become faulty or temperamental and there may be a short circuit.

As the central nervous system links all bodily activities, many different symptoms can appear in MS. The specific symptoms that appear depend upon which parts of the central nervous system are affected and the functions of these areas.

What are the possible causes of MS?

Netherlands: Mikki was four years old when she was diagnosed with MS.

MS isn't contagious – people do not 'catch' MS. Neither is it hereditary, so it is not passed directly from parent to child.

MS isn't contagious – people do not 'catch' MS. Neither is it hereditary, so it is not passed directly from parent to child. There appears to be a combination of factors that lead to someone developing MS.

Genes

Although MS is not directly inherited, two types of evidence tell us that genes are important for determining who may get MS. Evidence from population studies shows that people from different ethnic groups have different susceptibility to developing MS. It can occur in any ethnic group, but is more common in people of Northern European ancestry. The evidence from family studies also points to the role of genes. Relatives of people with MS, including children and siblings have a higher chance of developing MS than individuals who have no relative with MS, although the risk remains relatively small. So the chances rise where people have shared genes, but there is no single gene that causes MS. In fact, more than 150 genetic variations have been found to be related to MS.

It appears that a combination of genetic factors and environmental factors make some people more susceptible to developing MS. Studies of identical twins (who are genetically identical) point to a shared role for genetic and environmental factors. If one identical twin has MS, the second twin has about a 30 per cent chance of developing the disease. If genes were solely responsible for MS, we would expect to see a 100 per cent chance of identical twins both developing MS. In other words, genes play a role, but are certainly not the whole story.

Environmental factors

MS is less common in areas closer to the equator. This may be because people who live in these areas are exposed to greater amounts of sunlight year-round and tend to have higher levels of naturally-produced vitamin D, which may help protect against immune-mediated diseases like MS.

No single virus has been identified as contributing to MS, but some researchers think that a common childhood virus may act as a trigger by disturbing the immune system or indirectly setting off a process whereby the immune system attacks itself. This theory remains unproven and many people who do not have MS would have also been exposed to these viruses.

Vitamin D

Recent research studies suggest that a lack of vitamin D before birth or in early childhood might increase the risk of developing MS later in life.

We get most of our vitamin D through exposure to the sun. It is made by our bodies in reaction to sunlight on our skin. MS is more common in areas further away from the equator where there is less sunshine, which suggests that there is a relationship between vitamin D and the risk of developing MS. Research is ongoing in this area to learn more about the role of vitamin D.

Smoking

Research in MS has also shown that smoking increases a person's risk of developing MS and of disease progression. One study also found parental smoking to be significantly associated with pediatric MS onset.

These studies offer additional important reasons to encourage children and parents to avoid smoking.

How is childhood MS diagnosed?

Brazil: Beatriz experienced her first symptoms of MS while at school, when she was 13 years old.

To confirm a diagnosis of MS, there needs to be evidence of MS activity in two or more parts of the central nervous system

Diagnosing MS can be difficult, both in children and adults, due to its complexity and variety of symptoms. There is no single diagnostic test for MS and other conditions with similar symptoms need to be ruled out before a final diagnosis can be made. A neurologist – a doctor who specialises in conditions of the central nervous system – is the best person to evaluate your child and determine whether he or she has MS.

Guidelines have been published to help pediatric neurologists diagnose MS in children. However, some pediatric neurologists are unfamiliar with the condition and may need to consult with a neurologist specialising in adult MS about the diagnosis. Sometimes, it can feel as if you and your child will be waiting forever for a diagnosis so that you know what you are dealing with.

To confirm a diagnosis of MS, there needs to be evidence of MS activity in two or more parts of the central nervous system (brain, spinal cord and optic nerves) that occurred at different points in time. If your child has experienced a single episode of symptoms, the diagnosis of MS cannot be confirmed.

You may have been told that your child has 'ADEM' (acute disseminated encephalomyelitis), 'optic neuritis' or has had a 'clinically isolated syndrome'. These can all have the same symptoms as MS, but might happen only once and not return. If further episodes do occur, then MS might be diagnosed.

Neuromyelitis optica (NMO)

Children may also develop NMO. In NMO, immune system cells and antibodies attack and destroy myelin in the optic nerves and the spinal cord, causing optic neuritis (resulting in pain in the eye and vision loss) and transverse myelitis (causing weakness, numbness and sometimes paralysis or the arms and legs, as well as bladder and bowel problems).

The discovery of an antibody (NMO-IgG) in the blood of individuals with NMO now makes it possible to distinguish NMO from MS. NMO attacks are more severe than those seen in MS and in early disease are generally confined to optic nerves and the spinal cord.

Diagnostic tests

The following are the most commonly used tests and procedures. None is conclusive on its own, but each can contribute important information to the diagnostic process. To rule out conditions that mimic MS, other tests may also be done, including blood tests. You will be able to stay with your child throughout most of these procedures.

Neurological examination

The neurologist will ask either you or your child (depending on his or her age) lots of questions about symptoms and problems now and in the past. They will also do a physical examination to check for subtle changes in movement, reflexes or sensation. These tests can pick up even tiny changes which you and your child might not be aware of.

You may want to provide honest information to your child about the diagnosis.

Magnetic resonance imaging (MRI)

An MRI scanner uses a strong magnetic field to create a detailed image of the brain and spinal cord. It shows the exact location and size of any damage or scarring (lesions). To get the image of the brain and spinal cord, your child will lie down and enter a small tunnel in the centre of the MRI scanner. The process can take between 20 and 60 minutes and is painless, but quite noisy. Your child might feel nervous about the procedure – the scanner is a large, noisy machine in a very unfamiliar setting – but you can be in the room to provide reassurance and most MRI facilities offer headphones with your child's choice of music during the scan. See the resources section (page 35) for a link to a downloadable factsheet, video and podcast explaining MRI for children.

Evoked potentials

Evoked potential testing involves measuring the time it takes for the brain to receive messages from the eyes. The neurologist will place small electrodes on your child's head to monitor his or her brain waves as visual stimuli are presented on a screen. These electrodes measure tiny electrical impulses; they are not painful for your child. If MS or a similar condition is active, this test can detect messages to and from the brain travelling more slowly than usual.

Lumbar puncture

During a lumbar puncture (or spinal tap), the neurologist inserts a needle into the space around the spinal cord, under local anaesthetic. Not all children will need this test. A small sample of the fluid that flows around the brain and spinal cord, called 'cerebrospinal fluid', is taken out and tested for abnormalities that occur in MS.

You can usually stay with your child to provide reassurance and comfort. Some children are sedated for the procedure because it is essential to lay very still even though the process can be uncomfortable. Your child will be asked to lie on his or her side, curled up like a ball. The nurse will help your child to stay in the correct position. The doctor or nurse will apply a local anaesthetic to the area before starting the procedure. The doctor will feel your child's lower back and locate the correct space between the vertebrae (the bones of the spine). The doctor will then wash the skin around this area and cover the surrounding parts of the back with a sterile towel before inserting the needle. The fluid will be sent to the laboratories to be examined. In some cases the fluid pressure will also be measured.
People commonly report headaches following a lumbar puncture. This is a recognised side effect and the neurologist can advise on how best to manage this. Bed rest may help with this. See the resources section (page 35) for a factsheet on this procedure.

Telling your child

Should I tell my child about his or her diagnosis? All parents of children with MS will ask themselves this question and will be keen to get it right.

You may want to provide honest information to your child about the diagnosis. It can be very helpful for children to hear that they do not have cancer, that they are not dying and that the MS is not their fault or due to anything they have done. These are all worries that children with MS tell their neurologists and pediatric teams. There are good reasons for telling your child about the diagnosis, but it is an individual choice and it depends upon your child's maturity and ability to receive the information.

Remember: When you start talking about the diagnosis, you'll be giving your child the opportunity to talk and ask questions and share feelings and concerns.

Your child will be dealing a lot with health care professionals and will need to know why and what to expect. You can help your child by offering information and the vocabulary he or she will need to do so comfortably.

Children will often take their cue from their parents about how they are going to act and react in any situation. If you can discuss your child's concerns and questions calmly and patiently, your child will likely follow your lead.

USA: Heather was diagnosed with MS when she was 14.

How could MS affect my child?

Most people with MS, including almost all children, are first diagnosed with relapsing remitting MS.

Types of MS

MS can affect people very differently and one of the most frustrating aspects of the condition is its unpredictability – not knowing what symptoms may arise, when, or how long they will last.

Relapsing remitting MS

Most people with MS, including almost all children, are first diagnosed with relapsing remitting MS. This means they experience a relapse or flare up of symptoms (also known as an attack or exacerbation) followed by a period of stability between relapses when symptoms settle down or disappear. This period of stability is known as remission. Remissions can last any length of time, even years. No one knows exactly what makes MS go into remission.

A relapse is defined as the appearance of new symptoms, or the return of old symptoms, that last for at least 24 hours, and occur at least 30 days since the start of any previous relapse. If your child has a fever caused by an infection, or becomes overheated from exercise or hot weather, his or her symptoms may worsen temporarily. But this flare-up of symptoms is caused by an elevated body temperature, rather than by new MS activity, and the symptoms will fade as your child's body temperature returns to normal. This is known as a 'pseudo relapse'.

Relapses can take a few days to develop and can last for days, weeks or months. Symptoms can be mild or severe. Most children recover well from relapses. In the early stages of relapsing remitting MS, symptoms can disappear completely during remissions. However, after several relapses there may be some residual damage to the myelin, meaning that some symptoms may remain. These accumulating symptoms may cause your child difficulty, even if only mild.

Secondary progressive MS

Many people who start out with relapsing remitting MS later develop a form that is known as secondary progressive MS. In secondary progressive MS, people experience fewer relapses, or none at all, and the disease slowly progresses over time.

In general, people who develop MS in childhood have a slower rate of progression than people who are diagnosed with MS in adulthood. It is difficult to give exact figures, and even harder to make accurate predictions for individual children. In the largest study to date looking at progression in childhood-onset MS, 50 per cent of people whose MS started before the age of 16 had developed secondary progressive MS after 28 years.

'Benign' MS

People with relapsing remitting MS who only have a small number of relapses, followed by a complete recovery, may be described as having benign MS. It is only possible to make a diagnosis of benign MS once a person has experienced little or no physical or cognitive disability for a period of 20 years.

Argentina: Serena was 13 years old when she was diagnosed with MS.

MS is not a terminal illness. Like diabetes, it's known as a chronic or long-term condition that needs to be managed for life.

However, a diagnosis of benign MS does not mean that a person will be totally free of problems; a relapse may occasionally occur after many years in which the MS has been inactive. Perhaps around 10 percent of people with MS will have a benign form of the condition.

Primary progressive MS

Primary progressive MS is rare in children, with less than five percent of children with MS being diagnosed with this form. It tends to be diagnosed in older people, usually in their forties or later. From the outset, those with primary progressive MS experience steadily worsening symptoms and an increase in disability. Symptoms may level off for a time, or may continue to worsen, often with no relapses. Approximately 10 to 15 percent of adults with MS have the primary progressive form.

Symptoms

There are many possible symptoms of MS, however few people experience them all. Symptoms can come and go unpredictably. Some symptoms, such as problems with walking, balance or tremor may be very apparent to you and others, while other symptoms like pain, fatigue or problems with thinking or memory are less visible and often more confusing. At times there might be several symptoms together, at other times there may be no apparent symptoms. Children can sometimes be remarkably adaptable, not complaining of symptoms because they have found a way to manage despite them, or because they have noticed that some other symptoms clear up on their own.

MS is unpredictable and it varies from person to person. People can have different symptoms at different times. Although some are very common, there is no pattern that applies to everyone.

Some of the common symptoms of MS include:

Fatigue: an overwhelming sense of tiredness making physical or mental activity difficult

Cognitive problems: difficulty with memory and concentration

Mood changes: depression, anxiety, irritability

Balance problems and dizziness: walking difficulties, problems with coordination

Visual problems: blurred or double vision, temporary loss of sight in one eye or both

Numbness or tingling: commonly in the hands or feet

Pain: sometimes mild, sometimes severe

Loss of muscle strength and dexterity

Stiffness and spasms: tightening or rigidity in particular muscle groups

Anxiety, depression or mood swings

Speech problems: slurring, slowing of speech, or changes in pitch or tone

Incontinence: a lack of control over bladder or bowel functions

The less obvious or visible symptoms will be much more difficult for people to understand, especially those who are unfamiliar with MS.

What does the future hold?

As mentioned already, the course of MS is difficult to predict and varies from person to person, so predicting exactly how it will affect each child is not possible. Most children have relapsing remitting MS, with periods of good, if unpredictable, recovery.

Some children can be more severely affected, but rapid progression is rare. MS is not a terminal illness. Like diabetes, it's known as a chronic or long-term condition that needs to be managed for life. Most people with MS live a normal life span, with perhaps a five to 10 year reduction in average life expectancy. Of course averages aren't always helpful and everyone's MS is different. With recent advances in medicine, the gap in life expectancy appears to be getting smaller.

Argentina: Serena with her family.

Treating and managing MS

Netherlands: **Mireille was 12 years old when she was diagnosed with MS.**

When children are included in planning their own treatment, they are more likely to get involved and stick to therapies and medications.

There are now drugs that can modify the course of MS for some people. Many of the symptoms can be successfully treated or managed. There is also ongoing research into new treatments and better care.

Some drug treatments commonly used for MS may not be licensed specifically for the condition. Many may be licensed for MS but not be licensed specifically for children. However, this does not mean that they won't be useful or that they can't be used for children, with careful monitoring. As with adult MS, it can be a process of trial and error – the first medication might not be the one that is effective for your child, or the dose may need to be adjusted before the right amount is found. Your child's neurologist, doctor, MS nurse or pediatric nurse will monitor the effects the drugs are having and alter the dosage accordingly.

Drug treatments for particular symptoms are often most effective when combined with other approaches, such as physical therapy or occupational therapy (looking at how everyday activities can be done most effectively).

Children in control

When children are included in planning their own treatment, they are more likely to get involved and stick to therapies and medications. Having a choice and a say in treatments helps anyone to feel more in control. For example, if a child is taking an injectable disease modifying drug, being involved in the preparation of the needle and the injection offers a greater sense of control. Children might want to mark where the injection is given, or prepare the medication or apply pre-medication cream. All this helps a child feel greater 'ownership' of the process.

As children get older they may want to take more control of their care. You might monitor that medication is being taken without actually being involved in the process. Whatever their age, it is vital to be honest, present children with clear information, and involve them in the decision making process. See page 28 for more on teenagers and MS.

Corticosteroid therapy

Corticosteroids (commonly referred to as 'steroids' although they are different from the steroids used by some athletes to build muscle) are commonly used to treat an attack of neurological symptoms – either the first episode, or later relapses. Although they do not alter the course of the condition, steroids can reduce the inflammation in the central nervous system and speed up recovery from the relapse.

A short course of high-dose intravenous steroids is as effective in children as in adults when given during the course of an attack, though the best dose for children will vary. Steroids do not affect the level of recovery from an attack, so if some symptoms remain several months later, steroids will have no impact on them. And although they often speed up recovery, their effectiveness can vary from one person to another and from one relapse to another for a given individual.

To make it easier for children to stick with an exercise program, it is important to find exercise options that suit their needs and that they enjoy.

Neurologists specialising in MS will generally choose intravenous methylprednisolone (IVMP) as the steroid to treat severe MS relapses. Large doses are usually given over 3-5 days via a drip that goes into a vein (intravenous). This method may require admission to hospital, particularly for disabling relapses. Oral methylprednisolone may be prescribed instead of intravenous methylprednisolone.

All medications can have unwanted effects, and steroids are no exception. Steroids are given only for short periods of time and only for relapses that are causing a significant disruption in a person's life. Continuous, long-term use of steroids is known to increase a person's risk of osteoporosis, cataracts and diabetes.

Possible short-term side effects of steroids include:

- a metallic taste in the mouth
- increased heart rate
- hot flushes or a red face
- sleeping problems
- an increased need to urinate, particularly at night
- weight gain

Disease modifying drugs

Disease modifying drugs (DMDs) can affect the course of MS. They are not a cure but they can reduce the number and severity of MS relapses. No controlled clinical trials of the DMDs have been completed in children and as yet, none are specifically approved for use in children under the age of 18. However pediatric clinical trials of several DMDs are currently underway.

There are many different DMDs available for adults with MS. Most of the information and guidance for doctors on DMDs relates to adults, but these drugs can be prescribed to children and adolescents by a physician.

Currently, these are the drugs (with their commonly used trade names) used to modify the disease course in MS. They are grouped according to the route of administration.

Please note that these drugs have different commercial names in different countries.

As more drugs come onto the market, this list may become out of date. Please check the MS International Federation's website for the most up to date information: www.msif.org/living-with-ms/treatments/disease-modifying-treatments/.

France:
An information day for children with MS and their families.

Although MS will sometimes make certain sports or activities more difficult, children with MS should not feel they need to stop being active and rest all the time.

Injectable medications

- beta interferon-1a (Avonex): injected into a muscle once a week
- beta interferon-1a (Rebif): injected under the skin three times a week
- beta interferon-1b (Betaferon): injected under the skin every other day
- beta interferon-1b (Extavia): injected under the skin every other day
- glatiramer acetate (Copaxone): injected under the skin daily
- peginterferon beta 1a (Plegridy): injected under the skin once every 2 weeks.

Oral medications

- dimethyl fumarate (Tecfidera): taken as a capsule, twice daily (also called BG12)
- fingolimod (Gilenya): taken as a capsule, once daily. The first dose is taken under medical supervision to monitor heart rate and blood pressure
- teriflunomide (Aubagio): taken as a tablet, once daily.

Infused medications

- alemtuzumab (Lemtrada): taken as two treatment courses of intravenous infusions. The first course consists of intravenous infusions on five consecutive days. The second course is taken 12 months later and consists of intravenous infusions on three consecutive days
- natalizumab (Tysabri): taken as an intravenous (IV) infusion via a drip once every four weeks. It is generally administered in a hospital infusion clinic by a qualified health professional.

Other drugs have been used to modify the disease course in MS. These include a group of pharmacological treatments called immunosuppressants, which work by inhibiting cell division. They target the immune system so they can be effective for MS but also have a broad range of adverse side effects. They can be useful for some people with MS, for example in rapidly progressing MS or relapsing-remitting MS with a high relapse rate. Neurologists and people with MS need to work together to balance the good effects of the drugs against their potential adverse side effects. These immunosuppressant drugs include:

- azathioprine (Imuran)
- cyclophosphamide (Endoxana)
- intravenous immunoglobulin (IVIg)
- methotrexate (Maxtrex)
- mitoxantrone (Novantrone)

The specific DMDs that might be available to your child will depend upon several factors including where you live, the access to medications that you have, and your child's disease course and symptoms.

If you see a change in your child's mood, appetite, sleep habits, or you notice that your child has lost interest in thing he or she used to enjoy, it is important to report these changes and ask for an assessment.

It will be essential for you to discuss with your child's doctor the options that are available and how they differ, their route of delivery (injectable, oral or infused) and the benefits and risks associated with each of them.

Your MS society may have additional information about DMDs available in your region or country.

Professional rehabilitation and exercise

Although MS affects each child differently, there are exercises that can help children to stay as healthy and fit as possible and to manage their symptoms. Exercising regularly will help keep their growing body working to its full potential. To make it easier for children to stick with an exercise program, it is important to find exercise options that suit their needs and that they enjoy. All kinds of physical movement can be of benefit.

Although MS will sometimes make certain sports or activities more difficult, children with MS should not feel they need to stop being active and rest all the time. Of course, there will be times when they need to take it easy, but children and adults with MS find their own limits and learn to listen to their own bodies.

Your child's pediatrician, neurologist or pediatric or MS nurse can make a referral to a physical therapist who can work with you and your child to find the most appropriate exercises and physical activities. As well as exercise and activities for overall fitness, the physical therapist might also suggest exercises that concentrate on a particular function such as balance, on a particular area of the body that needs strengthening, or on a particular symptom such as stiffness (spasticity).

A physical therapist can also help you and your child find accessible sports facilities and classes for football, yoga, swimming, and a whole range of other activities your child might enjoy.

Complementary therapies

Many people say they also get benefits from therapies which are not prescribed by their doctor – collectively called 'complementary therapies' – which range from herbal medicine to yoga, acupuncture and massage.

The evidence for the safety and effectiveness of complementary therapies varies. Some countries have national regulatory bodies that evaluate these therapies, while others do not. Without this kind of expert evaluation, it can be hard to tell what is a safe, potentially effective therapy and what might cause harm. It would be wise to approach cautiously anything making grand claims for a cure or miraculous recovery. You should always speak to a doctor or other appropriate

If your child feels depressed, health professionals should work with you to identify and change anything that might be making the depression worse.

health care professional before going ahead with any therapy, just as you would with a drug treatment.

Healthy eating

A healthy diet is important for anyone. Although many special diets have been proposed as treatments for MS, none have been proven to prevent MS or affect the way it may develop. Children can usually get the nutrients they need through a well-balanced diet. With careful planning, perhaps with the help of a dietitian, you can make sure you meet their dietary needs – even if those needs change over time. Persuading any child to eat well, of course, may not be a simple task! Whether you have a toddler or a teenager, here are five strategies that might help:

1) *Have regular family meals.*
2) *Serve a variety of healthy foods and snacks.*
3) *Be a role model by eating healthy foods yourself.*
4) *Avoid battles over food.*
5) *Involve children in the process of preparing food.*

Managing mood changes and depression

Everyone with MS will feel down from time to time, but for some people these lows can become more frequent or longer lasting. This is when sadness and feeling low might be classed as 'depression'.

Depression is very common, not just in people with MS, and there are treatments available.

If your child feels depressed, health professionals should work with you to identify and change anything that might be making the depression worse. They should also consider whether there might be other related things affecting their quality of life, such as anxiety about the diagnosis, trouble at school or fears for the future. The school nurse, paediatric nurse or school counsellor may be a good first point of contact. You can ask to be referred to a psychologist or psychiatrist who is used to dealing with children.

If you see a change in your child's mood (including increased irritability, sadness, tearfulness), appetite, sleep habits (including ability to fall asleep or sleep through the night), or you notice that your child has lost interest in things he or she used to enjoy, it is important to report these changes and ask for an assessment. Antidepressant drug treatments and psychological interventions, including talk therapies such as counseling or cognitive behavioural therapy (CBT) for example, may be recommended. If your child is feeling anxious or is worrying to the degree that it's affecting his or her normal day-to-day living, an evaluation by a mental health specialist is very important.

Cognitive issues *memory and thinking*

Germany: Kim was diagnosed with MS when she was 10.

Children who experience cognitive problems might have difficulty keeping up with classroom conversations, learning new material, recalling facts quickly, or shifting their attention from one thing to another.

What is cognition?

Cognition refers to memory and thinking. More accurately, cognition describes the way we:

- process incoming information
  focus, maintain and divide attention
  learn and remember new things
- think, reason and solve problems
- plan, carry out and monitor our own activities
- understand and use language
  recognise objects, assemble things together and judge distances

These skills vary naturally in different people – we all have different strengths and weaknesses. But MS can cause problems with learning, remembering, planning and concentrating – the medical term for this is cognitive losses.

MS causes changes in parts of the brain and these can sometimes affect a person's memory and thinking. Thought processes rely on messages being passed along nerves to different areas of the brain and the lesions (scarring) caused by MS can stop or slow down these impulses. Depression, stress, pain, tiredness and relapses can create temporary cognitive difficulties. Some drugs may have a temporary effect on cognition as an unwanted side effect. There may be alternative drugs if side effects prove too great. Temperature can also affect cognition, particularly overheating which may worsen fatigue and, as a consequence, cognitive function. Children may be especially vulnerable to problems with cognition, but not every child who has MS will experience these problems. If you have any concerns about cognitive changes in your child, talk to the paediatrician, pediatric nurse, MS nurse or neurologist. They can make appropriate referrals and help you or your child to find the best ways to investigate the issue and manage any difficulties.

Children who experience cognitive problems might, for example, have difficulty keeping up with classroom conversations, learning new material, recalling facts quickly, or shifting their attention from one thing to another. There are lots of ways to help compensate for these problems. People with MS rarely have problems with other types of memory and can remember skills (like riding a bike – things that are 'second nature'), general knowledge or things about the past. Most often, people with memory problems due to MS have no major difficulties with communication and are able to carry out everyday activities. If your child does have some cognitive symptoms, it does not mean that he or she will experience all of them. Just like any other symptom of MS, they can affect people quite differently.

Managing cognitive issues

It is important that a thorough assessment of cognitive problems is carried out. A doctor, neurologist, MS nurse or pediatric nurse can make a referral to a psychologist. Cognitive change can get mixed up with changes in mood – which may or may not be directly linked to MS, so a psychologist will look at both these areas to help make sure the best solutions are being found.

Work with your child to establish person and household routines so that he or she will have less to remember.

Any plans to manage cognitive issues should include the whole family and involve the child in decision making, whatever his or her age. The school and special needs coordinators should be involved, as well as educational or pediatric clinical psychologists. Your MS or pediatric nurse will be able to assist with specific strategies to help your child.

There are many things you can do to help your child minimise the effects of cognitive changes such as:

- Help your child to relax and try to have a sense of humour about the situation.
- Encourage your child to tell people about the difficulties. This can help reduce the number of misunderstandings. It may also prevent people from interpreting the behaviour as boredom or lack of interest.
- Encourage your child to be aware of his or her strengths and weaknesses, so that goals can be set appropriately and unnecessary failure can be avoided.
- Different activities can help children to practise cognitive skills and use different resources. There are many books and puzzles to practise with, as well as online resources. Kids' crosswords, word and number games are also excellent ways to practise.
- Encourage your child to recognise his or her limits and not be afraid to ask for help with difficult tasks.
- Help your child to learn to recognise fatigue and try to arrange appropriate rest breaks.
- It is important for your child to concentrate on one thing at a time, for example not having the TV on when doing homework.

Memory tips
If your child has difficulty remembering things, 'memory aids' can be simple but effective:

- A mobile phone or a computer can be useful to organise and store information. Your child can download memory aid apps – such as reminders or to do lists – to a smart phone or tablet.
- Encourage your child to keep a notebook close at hand for jotting things down.
- Get a family planner so you are modelling the use of planning as a good strategy.
- Many schools give children daily planners to write down tasks that need to be done. This kind of planner can also be used to track things like

Most often, people with memory problems due to MS have no major difficulties with communication and are able to carry out everyday activities.

addresses, phone numbers or the school timetable. If your child's school doesn't have this, encourage your child to design and use his or her own unique planner.

- Get into a regular routine of checking your child's planner and the family planner, for example at meal times.
- Encourage your child to use post-it notes in obvious places – perhaps the refrigerator door or the back of the front door – with lists or reminders.
- Your child can set alarms on a watch or mobile to signal appointments or things that need to be done.
- You can help your child make up mnemonics (pronounced ne-mon-iks) as memory aids. Mnemonics are rhymes, rules or phrases.
- You child can use visual imagery as a memory aid. This involves making up pictures to tell a story or visualizing the information he or she wishes to recall. For example, instead of just trying to memorize the directions to the library, it may be helpful to picture the route.
- Encourage your child to be more organized. Having set places for things such as keys, which are easily misplaced, can be extremely helpful.

At home

It can sometimes be difficult to know what is a cognitive symptom and what is a normal part of growing up. Children with MS may not remember that you have told them to do something or to go somewhere. They may not take in all that is said to them first time, or they may understand but then forget. Make sure that you have explained things clearly and check that your child has understood. You might need to explain the same thing a number of times. This may sound a little too simple, but sometimes these simple adjustments can be enough to help.

In school

Schools should make allowances for any symptoms, including cognitive changes, if they happen. Many countries have specific laws related to a student's rights. At school, children are asked to pay attention and study in a fairly fast-paced environment that can have a lot of distractions. Difficulty with memory, in processing information quickly or in focusing on a subject might be misunderstood as being lazy, inattentive or sleepy. Keeping the school informed can help to minimize this problem. The cognitive issues in MS can be more difficult to deal with when they happen in a youngsters who are still in the learning environment of a school, where they are constantly being compared and comparing themselves with others.

With friends

Keeping your child's friends and their parents informed might be helpful. If they are aware of the basic facts then they will feel more able to cope with the situation and make simple adjustments such as those mentioned above. Of course it should be up to your child how much information he or she wants to share with friends. Your child might not want to say anything at all.

MS and the family

USA: Claire was seven years old when she was diagnosed with MS.

A lack of understanding about MS and how it affects your child can add to any other stress your family may be going through.

MS is a condition that affects the whole family. It can affect communication, relationships, mood and daily interactions. Symptoms such as extreme fatigue, weakness, bladder problems and cognitive changes may alter the child's ability to participate in normal childhood activities. Children may also exhibit a range of emotions and behaviours such as aggression, depression and anxiety as a reaction to the diagnosis. Learning how to live with an unpredictable and changing condition can be hard on anyone. MS will inevitably bring about changes – and everyone in the family will be aware that things are different.

Open discussion of the family's concerns is critical. A lack of understanding about MS and how it affects your child can add to any other stress your family may be going through. Additionally, MS relapses, fatigue and hospital appointments can result in missed schooling. Other siblings may feel resentful or jealous of the attention that the child with MS receives and this can lead to bad behaviour from them as they try to redress the balance. As parents, you might not always get the understanding from friends that you need – however well-meaning their intentions. Equally, you may come across healthcare professionals who are not aware of MS as a childhood condition. You're not alone if you feel you are spending a lot of time explaining the basics.

There are no firm and fast rules for the best way to deal with MS as a family, but parents in similar situations have found the following tips helpful to remember:

- Try to keep the lines of communication open - between everyone in the family, and with friends and healthcare professionals.
- Remember that not every change in the family and every issue to be tackled will be MS related. For example, moody teenagers are still moody teenagers, whether or not they, or their brother or sister, have MS.
- Use support groups for families. Talking to other parents and families going through a similar situation may be helpful.
- It is important that you get to have time out for yourself as a parent. Respite care is sometimes available to give parents and the person with MS a break.
- Healthcare professionals can help you care for your child with MS, and also with maintaining the health and wellbeing of the family.

Explaining things to siblings

Family members may have as many questions as your child with MS, and some of the same concerns as you have: What will happen? Why us? Will I get it? Will things ever get back to normal? Is it my fault? They can also feel fear, resentment and guilt. All of these are perfectly normal reactions, which might be more or less obvious and might surface in different ways. To encourage your other children to ask the questions they have, it's a good idea to have some knowledge of the basic facts of MS. A pediatric nurse, a MS nurse or a social worker may be able to help explain the condition to your other children.

Begin by reassuring your children that MS is not contagious and they cannot 'catch' it. Many young children and teenagers need to have those fears addressed at the very start. You can also assure them that their brother or sister with MS can be expected to live a long life, and that their own risk of developing MS is very low.

After a diagnosis of MS, teenagers can withdraw from parents and not talk much about what's going on. They may even go into denial and just pretend that nothing is wrong. Although it's difficult to separate typical adolescent turmoil from a reaction to having MS, it is possible.

Some practical suggestions for explaining MS to other children:

- Choose a time of day when children are not tired or distracted.
- Make sure you can look them in the eye and gauge their reactions.
- Give them a conversational warning. Try, "We have something important to talk about."
- Don't feel you have to share all the details at once: state the basics, then answer questions.
- It's OK to say "I don't know, but I'll try to find out" to any question.
- Use basic medical terms, and explain them. Express confidence in the doctors.
- Explain what the illness may mean to the siblings' routine: will someone else be caring for them while you're taking care of doctor visits?
- Check in from time to time to make sure that children understand and feel supported.
- Inform important people in your children's world – teachers and babysitters, for example – so they can watch out for signs of stress.
- Allow siblings individual time with you so they don't feel left out or ignored. Your local MS society may have information written specifically to explain MS to children and young people.
- Siblings can sometimes benefit from support groups and 'young carer' organisations, even though they probably think of themselves first and foremost as brother or sister, rather than 'carer'. There are details of such organisations at the end of this booklet.

Teenagers and MS

Children grow up, and as a parent you may not even be aware of this because you're living with them every day. When they become young adults they may need more information, and in greater detail than they had before. Knowledge is power, and it's very important for them to feel that they have some control over their illness.

After a diagnosis of MS, teenagers can withdraw from parents and not talk much about what's going on. They may even go into denial and just pretend that nothing is wrong. Although it's difficult to separate typical adolescent turmoil from a reaction to having MS, it is possible. Listen carefully to what your teenager says and be alert for signs of depression or cognitive problems (memory, or attention span issues). Help your teenager talk about whatever it is that might be causing worry or concern. Often these conversations happen in the car or while running errands, when teenagers might be more likely to open up. A favourite teacher, or someone your child trusts and respects, can also be people for your child to turn to.

It is important to try not to control what your teenager should or shouldn't be feeling or how he or she should react. Everyone is different. Your child may want to cry or may have nothing to say on the subject.

It's not unusual for teenagers to feel guilty or wonder what they've done to deserve MS. Or they may feel relief if they've had unexplained symptoms for a while – now they have an answer. They may take some time to settle down and accept things. They may be in denial, especially if they are in remission, but sad, angry or scared feelings may return if they get new symptoms or the MS gets worse.

Adapting to life with MS can take time, and in some ways is an ongoing, life-long process, but a positive attitude from you can help both you and your child to manage the condition well.

When a child is diagnosed with MS, parents often report feeling 'lost'. As they disclose the diagnosis to others they often hear statements such as, "MS does not happen in children".

Driving

As parents, we are all somewhat anxious when our children start learning to drive. Given some of the symptoms that can occur in youngsters with MS – including fatigue, sensory symptoms in the feet and hand, vision problems, problems with attention and concentration, you might be especially worried about your child's ability to drive safely. However, learning to drive also can be a lifeline, not only in helping young people get around more easily but as a boost to their independence. You can speak with your child's doctor or other healthcare providers about your child's particular symptoms and whether there are safety issues to be considered.

Once your child's doctor has cleared her/him medically to drive, you would be wise to contact a local driver rehabilitation specialist for a driving evaluation including any equipment recommendations or vehicle modifications your child may need.

Alcohol and drugs

Some medications for MS symptoms can interact with alcohol, causing unwanted and potentially dangerous side effects. If your son or daughter is – or may be – drinking, it's important that he or she knows about the risks of mixing alcohol and medication. Your physician or pharmacist can give you information about any possible interactions.

Some people with MS say that using cannabis can help them to feel better, or alleviate some of their symptoms, although there is no research evidence to support this. Furthermore, cannabis is potentially harmful and is illegal in many parts of the world. If you suspect your son or daughter is smoking cannabis, or taking any other drug(s), it's important that you have a conversation about it.

An oral spray containing cannabis extract, called Sativex, is now licensed in a few countries as a treatment for spasticity in adults with MS. It has not been approved for use in children or young people, nor is there any evidence to show whether it is safe or effective in this age group.

Relationships and sex

Being diagnosed with MS may affect the way children see themselves which, in turn, may affect their relationships, both forming them and in keeping them going. MS may also affect a person's sex drive and sexual function. Some medicines can have side effects that alter sexual function or make the contraceptive pill less effective. It can feel embarrassing to talk about these things, but anyone who is worried can talk in confidence to a doctor or MS nurse with whom they feel comfortable.

Taking care of yourselves as parents

When a child is diagnosed with MS, parents often report feeling 'lost'. As they disclose the diagnosis to others they often hear statements such as, "MS does not happen in children". There may be few opportunities to meet and network with others in the same situation, yet establishing a relationship with other parents is helpful in coping with the diagnosis and growing as a family in the process. Telephone conference calls and internet chat rooms can be useful to make links with support groups for parents of children with long-term conditions and others living with MS.

Parents of children with chronic illnesses like MS often mourn for the loss of the healthy child and the loss of the dreams they had for their child's future. As a parent you will inevitably find yourself in the position of providing comfort rather than receiving it. However it is important as a parent to come to terms with the complex feelings surrounding a diagnosis of MS for your child, so take time to acknowledge how you are feeling, to yourself and those around you. Take care of yourself as well as your family and get the comfort that you need from a partner, friends or family. Details of organisations that can also offer help for parents and carers are at the back of this booklet.

School, college and university

If your child is being bullied, explore whether there are organisations that you or your child can contact for further support and advice.

What issues might my child face in school?

Having MS can disrupt schooling. However, there is support available to help your child to continue to study. If your child is affected by fatigue, early mornings or late afternoon might be challenging times for concentrating or doing active things at school. Your child may not have to stay at school all day –this is the kind of adjustment that a school might make. Help your son or daughter to choose the most comfortable and productive time of day, as well as the classes or courses that would be most enjoyable and engaging.

Checking where the classes will be held is important. They may be up long flights of stairs or at the end of long corridors. Changing some classrooms could be another reasonable adjustment. Similar adjustments can be made for other symptoms which might affect the school day. Your MS healthcare professionals will be able to assist your child with fatigue management.

Bullying

If your child is missing a lot of school, or is perceived as different, then he or she may be subject to bullying. Children with MS are no different from other children in this regard. They may be badly behaved themselves as they 'act out' their feelings of fear and being out of control, which could lead to them bullying others.

Netherlands: **Pieter was diagnosed with MS when he was 13.**

Who is involved in your child's care

Who is involved in your child's care?

There are many ways that health and social care services can help you and your family, but knowing who to contact and how-to access them is not always easy. You will, no doubt, want to be a strong self-advocate for your child and family but this may require time and support. Many MS societies have resources available to help you in this very complex area. Local sources of information, such as your nearest MS Society office, or other volunteer organisation, can offer further pointers about what's available and how to get hold of it.

There may be many different people involved from the outset, and these may change over the years. There may be a combination of pediatric and adult services involved. This may seem confusing but different specialists can bring different expertise.

Local sources of information, such as your nearest MS Society office, or other volunteer organisation, can offer further pointers about what's available and how to get hold of it.

Your child
He or she will know the most about their own symptoms and their impact. They will understand when regular therapies and treatments are needed and if they are working.

You
You will know more about your child than anyone else, and know how symptoms affect them mentally and physically.

Your family doctor or pediatrician
This is your first point of contact; they can supply repeat prescriptions, help deal with some symptoms and refer to more specialist help when it is needed. They can also liaise with an MS nurse or neurologist. They will hold all your child's medical records.

MS nurses
Where available, they are often brought in to work with children with MS – they can be a vital point of contact as they work closely with neurologists and have an in-depth knowledge of the condition.

Pediatric nurses
Where available, they specialise in children's illnesses and often work in partnership with MS nurses.

Paediatric neurologists
Key in diagnosing, treating and prescribing appropriate treatments for children.

Adult neurologists
Key in diagnosing, treating and prescribing appropriate treatment for adults.

Pediatricians
Doctors who specialise in children's illnesses can often help deal with some symptoms. They can also refer on to therapists or psychologists.

Child psychologists
They specialise in working with children with cognitive and behavioural problems. They will have experience of dealing with children going through difficult situations.

Child psychiatrists
They specialise in working with children with behavioural and mental health problems, for example depression. They will be able to prescribe medication and psychological 'talking therapies'.

Occupational therapists
They can provide practical help for problems that affect daily life at home, for example dealing with fatigue.

Physical therapists
Can give advice and offer treatment regarding mobility issues and other physical problems.

Educational psychologists
Where available, they tackle the problems encountered by young people in education, which may involve learning difficulties and social or emotional problems.

They regularly liaise with other professionals from the departments of education, health and social services.

Social workers
Can give advice about relevant programs or organisations and which benefits your family and child may be entitled to.

A short break gives a valuable opportunity for you and your child to rest and recharge your batteries, get out and meet people, spend quality time with family and friends, or pursue a hobby. It could even be as simple as getting a change of scenery. Check to see if there are programs available in your area for short breaks.

Useful Resources

Beat Bullying
Through anti-bullying programmes in schools and their website, Beat Bullying works with children and young people to stop bullying.
www.beatbullying.org

Child Demyelination UK
Useful resource for families and health professionals, including an update of UK research in childhood demyelination from the UK & Ireland Childhood CNS Inflammatory Demyelination Working Group.
www.childdemyelination.org.uk

Great Ormond Street Hospital
www.gosh.nhs.uk
Search **'multiple sclerosis'**

Guthy Jackson
American website providing information about neuromyelitis optica (NMO).
www.guthyjacksonfoundation.org

Kids Health
American website with ideas for healthy eating for children, and lots more.
www.kidshealth.org

Lumbar puncture
The Great Ormond Street Hospital has detailed information at
www.gosh.nhs.uk/medical-information/procedures-and-treatments/lumbar-puncture

Magnetic Resource Imaging (MRI)
The Great Ormond Street Hospital has detailed information at
www.gosh.nhs.uk/medical-information-0/procedures-and-treatments/mri-scans

Mind
Information, advice and support on mental health issues, including specific information for children and young people.
www.mind.org.uk

MS Society of Canada
Useful resources in English and French for teenagers and for parents of a child with MS, including a microsite specifically for young people.
www.mssociety.ca
www.someonelikeme.ca

MS Society (UK)
Information about coping with school, and the effect MS can have on the family.
www.mssociety.org.uk/what-is-ms/types-of-ms/ms-in-children

National Multiple Sclerosis Society USA
Runs a network for families with a child or teenager who has MS. Resources include Keep S'myelin, an online magazine aboutMS for younger readers, and online message boards.
www.nationalmssociety.org/What-is-MS/Who-Gets-MS/Pediatric-MS

Talk to Frank
Friendly, confidential drugs advice.
www.talktofrank.com

Transition Information Network
Information for parents about the transition from children's to adult services.
www.transitioninfonetwork.org.uk

Young Minds
Charity committed to improving the emotional wellbeing and mental health of children and young people.
www.youngminds.org.uk

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