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Diagnosis of paediatric MS can be complex because symptoms can be mild or temporary, or they can be associated with other, more common childhood illnesses.

If your child has been diagnosed with MS, or MS has been indicated as a possible cause of their symptoms, this guide has been created specifically for parents with children under 18 years old. ”

# Paediatric MS

*A guide for parents*

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## Introduction

Multiple sclerosis (MS) is often considered a disease that affects people during adulthood, but it is important to know that it can also affect children and teenagers; it's quite common for adults with MS to trace the origins of their illness back to their childhood or adolescence.

Diagnosis of paediatric MS can be complex because symptoms can be mild or temporary, or they can be associated with other, more common childhood illnesses.

If your child has been diagnosed with MS, or MS has been indicated as a possible cause of their symptoms, this guide has been created specifically for parents with children under 18 years old. It will help you to:

- understand the disease a little better
- deal with any changes that may occur
- provide an answer to the numerous questions and doubts that can arise following a child's MS diagnosis.

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# 1 / What is Multiple Sclerosis?

To understand MS, it can help to understand what goes on in the central nervous system.

- The **brain** sends messages that control our movements and thoughts.
- The **spinal cord** is the main communication pathway sending these messages between the body and the brain.
- The **nerve fibres** in the central nervous system (axons) transmit the information as electrical impulses.
- **Myelin** forms a protective sheath which is wrapped around the nerve fibres and enables rapid transmission of nerve impulses.

With MS, the immune system mistakes myelin for a foreign agent and wrongly attacks it, causing scars called lesions or plaques. This damage slows down or distorts the transmission of nerve impulses. The central nervous system is able to regenerate the damaged myelin, but complete regeneration is not always possible. The intensity of symptoms depends on the extent of myelin loss and the severity of damage to the axon, while the type of symptom depends on where the damage is located within the central nervous system.

This is why each person may experience different symptoms which can vary in time and have different types of impact. People can be affected by MS in different ways and this unpredictability is one of the most difficult aspects to manage and accept: not knowing which symptoms may occur, when, or for how long, creates anxiety both for the person going through the experience and the people close to them.

## Possible causes

MS is not a contagious or hereditary disease; therefore, it is not transmitted directly from parent to child. It's not possible to predict who will develop the disease or when and as of today, nothing can be done to prevent it.

### **Relapsing and remitting MS**

is the most common cause of MS in adults and children. It is characterised by acute episodes or relapses, also defined as flare-ups or exacerbations, which can last for a few hours or days until a phase of stability is reached, usually followed by almost complete recovery. By definition, symptoms must last for at least 24 hours and occur at least 30 days after a previous relapse. The complete course of a relapse can last for a few days, weeks or even months.

### **Secondary progressive MS**

people who initially have relapsing and remitting forms of MS frequently develop secondary progressive MS over the years. Secondary progressive MS is characterised by a gradual accumulation of symptoms which cause increasing disability, and it often becomes difficult to clearly distinguish periods of relapse. It is estimated that the transition to secondary progressive MS can take place after 20-25 years in adults treated with MS medication. Research shows that children tend to develop secondary progressive MS later on compared to adults and the pace at which the disease develops is slower than in people who receive a diagnosis when they are adults.

## **Types of MS**

In children and teenagers, it is possible to identify various forms of progression, although 95% of cases tend to be relapsing-remitting MS.

### **Primary progressive MS**

is quite rare in children (less than 5%). It is characterised by symptoms that start gradually and tend to develop slowly without any relapses.

# 2

## How is MS diagnosed in childhood?

An MS diagnosis can be difficult both in children and adults due to the complexity and variety of symptoms. There is not a single characteristic and specific symptom of the disease nor a unique diagnostic test for MS, so before formulating a definite diagnosis, it is necessary to exclude other pathologies with similar symptoms. There are precise guidelines for the diagnosis of MS in adults, but the process for children has not yet been so well defined.

In Italy, various professionals such as paediatricians, childhood neuropsychiatrists and adulthood neurologists, can contribute towards formulating a diagnosis.

The lack of an official and recognised procedure leading to an MS diagnosis and comprehensive disease management, can give families the feeling they are stuck in limbo, waiting for a clear explanation.

### Diagnostic procedure

Reaching an MS diagnosis can take time. There is no individual test that can provide a multiple sclerosis diagnosis: the diagnostic process involves an evaluation of the patient's clinical history, a neurological examination and diagnostic procedures. Further tests, such as blood tests, are fundamental to exclude similar pathologies.

A paediatric diagnosis can be complicated by the presence of other childhood illnesses with similar symptoms. Furthermore, paediatricians may not immediately think of an MS diagnosis, since it is not a common childhood disease.

Confirmation of a diagnosis requires proof of the spread of lesions in various areas of the central nervous system (spatial dissemination) and/or an evolution of the process with time (temporal dissemination).

“ It can be very supportive to talk to your child about the type of test they need to undergo, how the test is carried out and if there is any discomfort involved. Sharing this information can be reassuring and make them feel more prepared to face the test and, therefore, less fearful. During most tests, parents can be at their children’s side. ”

## Clinical history

During the visit to the neurologist, the parents and child or teenager are invited to share current or past symptoms: this information is fundamental to understand the characteristics of the disease. Being able to identify whether symptoms occurred at different moments in time can confirm the diagnosis. Therefore, every piece of information that the family is able to provide is of the utmost importance because the more information provided, the easier for the neurologist to understand the child’s clinical history, formulate a more precise suspected diagnosis and recommend the most appropriate checks to carry out.

## Neurological examination

This examination helps the neurologist to identify even slight variations in movements, reflexes or sensitivities, and detect even minimal neurological changes which may not be immediately obvious. A neurological examination includes an in-depth assessment of key functions such as strength, coordination, balance, sight, sensitivity and reflexes. Fundamental cognitive functions are also checked, such as sense of direction, memory, attentiveness and language.

### What to explain beforehand:

It is important to encourage children and teenagers to describe their symptoms because knowing when the symptoms started, how long they lasted and how intense they were, will greatly help the neurologist to better understand the situation. Reassure your child and point out that working together is fundamental to making sure they can get the best possible help.

### What to explain beforehand:

Before the examination we can reassure children and teenagers that the examination is not invasive and explain that during the visit, the neurologist will carry out a few tests. It is important to underline that there is no right or wrong way to respond during the test, but the aim is to better understand how their body and nervous system are working.



## Magnetic resonance imaging (MRI)

An MRI scan is a non-invasive radiological examination (except for the injection of a contrast medium), which uses strong magnetic fields to create a detailed image of the brain and the spinal cord. It helps to identify the position and size of any lesions. An MRI scan is a fundamental tool both in terms of a diagnosis and to monitor the disease, because it makes it possible to assess the evolution of lesions through time.

### What to explain beforehand:

Prepare children and teenagers for the scan, explaining that it's a non-invasive examination, except for the injection of a special liquid. The machine used to carry out the scan looks like a tunnel you have to lie inside. The scan can last from 20 to 60 minutes and it is painless, but it can be a little noisy.

## Lumbar puncture

A lumbar puncture is necessary to look for antibodies in the cerebrospinal fluid and which indicate an immune reaction is taking place within the central nervous system. To carry out this test, the child or teenager is asked to either sit in a sitting position or lay on one side. It is a disagreeable test which requires keeping still and for this reason a local anaesthetic is administered and younger children may also be given a sedative. Using a very thin needle, a small sample of cerebrospinal fluid is taken from the spaces between the last lumbar vertebrae. There is no risk of damaging the spinal cord because the spinal cord terminates before these vertebrae. A lumbar puncture can sometimes be followed by side effects such as nausea, vomiting or headache.

### What to explain beforehand:

It is important to explain that this test is crucial to understand if their body is fighting against something within the nervous system. It is necessary to keep still and a local anaesthetic (and perhaps also a sedative) will help to eliminate any pain or discomfort. The test can be followed by a brief period of nausea, vomiting or headache: reassure your child or teenager that resting in bed will help to mitigate these side effects.

## Evoked potentials

This test measures how long it takes for the central nervous system to receive and interpret messages sent by our sensory organs (such as our eyes, ears and skin). To measure the electrical impulses, small electrodes are placed on the child or teenager's head to register the brain waves that form in response to stimuli. A slow response time can indicate a lesion to the neural pathway being explored.

### What to explain beforehand:

Before the test, it is important to explain that the test is non-invasive and painless.

During the test, small electrodes will be positioned on the head to understand how the brain responds to sounds, images and touch.



### WHY EXPLAIN BEFOREHAND?

It is important to let children and teenagers know what will happen during the tests they need to undergo, because understanding and transparency help to create trust and reduce anxiety. It is also important to use suitable language for their age and answer their questions honestly and reassuringly, and encourage them to express their feelings. Clarity and empathy encourage open and serene communication, allowing them to face the situation with more awareness and confidence.

The suggestions we have provided are of a general nature. If you have any doubts about what and how you should let your child or teenager know about the tests they will have to undertake, or if you are worried about any difficulties regarding the tests, do not hesitate to ask healthcare professionals for further information and support. They will do their best to help you and your child.

# 3

## How does MS affect people?

### Symptoms

MS can have very varied symptoms, and not everyone will necessarily experience them all. Symptoms can appear together or at different times. It is often difficult to immediately identify symptoms in children and teenagers because they are not always able to precisely communicate the symptoms they are experiencing and they often quickly adapt to any discomfort.

### Here are some of the most common symptoms of MS:

<p><b>Fatigue</b> A lack of physical and mental energy which is different from "normal" tiredness because it is persistent. The feeling of being tired can continue even after the person has rested and can become worse with increases in temperature.</p>	<p><b>Cognitive problems</b> Mainly problems with memory and concentration and it can take longer to process information.</p>	<p><b>Visual problems</b> Mainly blurred or double vision.</p>
<p><b>Sensory problems</b> Numbness, tingling, a decrease in sensitivity to heat, cold or pain and they often affect the hands and/or feet. This may also include feelings of pain.</p>	<p><b>Reduction in muscle strength</b></p>	<p><b>Coordination problems</b> Changes in the fluidity of movement.</p>

“ It is important for parents not to immediately associate every type of discomfort with the disease: just like other children and teenagers, children and teenagers with MS can suffer from typical childhood diseases such as flu or stomach ache, etc. Being properly informed allows parents to distinguish symptoms directly linked to MS more easily. ”

## Invisible symptoms

Some symptoms, such as problems with coordination, can be easier to see while others may not be so obvious: pain or fatigue for example are defined as “invisible” because they are perceived by the person who feels them but they are not externally evident to others. These invisible symptoms can be more difficult to understand especially for people who are not familiar with, or have little experience of MS.

## Fatigue

Fatigue is one of the invisible symptoms of multiple sclerosis: it is experienced by about 90% of people with MS and it can be the cause of misunderstandings. In some situations, it may be easy to think that your child is exaggerating or is being lazy or indolent. MS fatigue is a feeling of profound exhaustion that makes it difficult to carry out normal daily tasks, as well as take part in pleasant and fun activities. It's not easy for children and teenagers to understand how to measure their energy levels so they can end up being overwhelmed by tiredness: the frustration of not being able to do what they want can make managing their energy levels complicated.

### How should this be managed?

It can be difficult to know how to act, whether it's best to encourage them or keep them in check. It can be difficult to understand if they are just tired or if their tiredness is linked to MS: there is a risk of adopting the same attitude regardless of the situation.

Even though fatigue is not outwardly visible, it has a profound effect on various physical and psychological aspects. Dealing with this symptom requires a collaborative approach, dialogue, reciprocal understanding, emotional support and finding practical strategies. Involving a network of significant adults such as teachers, educators, sports coaches is very helpful. Together, it's possible to adopt effective measures to manage fatigue and improve the quality of life.

## Cognitive impairment

Cognitive functions include the ability to remember, solve problems, pay attention and process thoughts. These abilities are different for each person.

The lesions caused by MS can stop or slow down the messages transmitted in the form of impulses through the nerve fibres, thus influencing cognitive processes. Even if cognitive impairment is quite common among children and teenagers with MS, not everyone has to deal with this type of issue. Cognitive impairment can make it difficult to quickly recall information from memory, it can be difficult to maintain concentration for long periods of time or deal with disturbing factors (such as doing homework while the television is switched on). Cognitive impairment does not make it difficult to communicate and it does not prevent people from carrying out their normal daily activities.

### How should this be managed?

If you suspect a child or teenager with MS is experiencing cognitive impairment it is important to make sure they undergo a detailed assessment to find the best strategy to help manage and solve the situation.

The neurologist may suggest visiting a specialist, such as a neuropsychologist, to assess the overall cognitive and emotional picture. Thanks to clinical interviews, neuropsychological, psychometric and behavioural tests, the neuropsychologist can identify specific cognitive impairments and create a personalised management and rehabilitation plan. The aim is to support the child and family in identifying the most suitable strategies to compensate for any deficits: any plan aimed at dealing with cognitive impairments must include the whole family and involve the child regardless of their age. Schools and educators must also be involved.

Parents play an important role in supporting children to adopt new compensatory strategies learned and make the strategies part of everyday family life. Helping children to be aware of their strong points and encouraging them to ask for help when faced with difficulties contributes towards reducing anxiety and also mitigates the frustration caused by cognitive impairment.

## **Mood swings, depression and anxiety**

Depression is a common symptom in adults with MS.

Recent studies show that children are also prone to mood swings and anxiety. Just like cognitive impairment, these issues could be linked to the demyelination caused by MS. In adolescence, mood swings are common and are part of everyday family life. This makes it difficult for parents to distinguish “normal” teenage behaviour from a symptom of the disease.

Symptoms pointing towards depression can include loss of appetite, difficulty sleeping, frequent crying, feeling low and a loss of interest in activities the person usually enjoyed doing in the past.

### **How should this be managed?**

If your child is showing signs that they are suffering from this type of problem, talk to the healthcare professionals at the MS Clinical Centre you have been referred to, to identify every aspect that could be affecting their mood and, if necessary, take action. It is important to know that working with a psychologist for a person with multiple sclerosis does not necessarily indicate that they are suffering from serious mental hardship. Deciding the best moment to seek the support of a professional is highly subjective and must directly involve the child or teenager. Psychological support for a child or teenager with MS can be extremely important in helping them to deal with worries linked to the diagnosis, the burden of treatment, emotions such as fear and anger, and all those moments when the suffering feels overwhelming and help is needed to face the situation effectively.

# 4

## Treatment and medication for MS

### Pharmacological treatment

Today there are a number of medications that modify the course of MS and new research is continuously being carried out to find better treatment. Furthermore, many symptoms can be treated and managed by specific medication.

Having a clinical centre with experience in treating paediatric MS as a reference point means guaranteeing the best management of the medication currently available for your child and finding out about new therapies as soon as they become available.

Italy actively takes part in medication development programmes for paediatric MS, thanks to the considerable experience matured in this area.

Before taking the decision to start a pharmacological therapy programme, it is important to have an idea of how the medication can help to manage MS, its progress and symptoms. Neurologists dealing with MS have the important task of helping parents to feel serene about the treatment programme.

MS treatments can be divided into four categories:

- Treatment for relapses
- Medication that modifies the progress of the disease
- Symptomatic medication
- Rehabilitation

## **Treatment for relapses**

### **Medication targeted to reduce acute episodes of the disease**

Treatment with steroids is commonly used to treat neurological symptoms during relapses, both during the first episode as well as during any subsequent relapses. Cortisone helps to reduce inflammation and recover from symptoms but it does not change the course of the disease: in general, a short regimen of high doses of intravenous corticosteroids is effective in children and adults. Subsequently a decreasing dose of cortisone administered by mouth may be prescribed.

There are some possible side effects, such as a strange taste in the mouth, increased heartbeat, hot flushes, problems sleeping and other side effects. Your doctor will be careful not to prescribe this medication for long periods of time as it can cause problems such as diabetes or osteoporosis.

***“ It is important to involve children and teenagers in the administration of the medication, explaining that doctors are doing their best to help them feel better faster by providing extra help for a little while. ”***



## **Medication that modifies the progress of the disease**

**This type of medication aims to slow down the progress of MS over time and reduce the number of relapses**

Similarly to adults with MS, the aim of this medication in paediatric MS is to restrict the activity of the disease, intervening on the mechanisms that lie at the basis of the development of the disease itself, preventing or slowing down the development of new lesions in the central nervous system.

Paediatric MS has a bigger “inflammatory” component compared to adult MS, so medication commonly used for adults (which acts on the mechanisms that cause the development of inflammation hotbeds) is also effective for children.

The medication currently used for children and teenagers is the same medication used for adults: this medication has not been tested on children with the same rigorous methods used for adults. In spite of this, there have been numerous research projects carried out by the scientific community that confirm the safety and efficacy of this medication: even if the use prescribed does not comply with the indications in the information leaflet, the use of this medication in paediatrics is supported by international guidelines.

## **Symptomatic treatment**

**Medication that relieves symptoms, improves quality of life and deals with specific issues linked to the disease**

Symptomatic treatment relieves some of the troublesome symptoms related to the disease that can condition everyday life. Symptomatic treatment does not have any effect on the mechanisms causing MS and which damage the central nervous system. Therefore, they do not modify the evolution of the disease, but they can improve a person's quality of life.

*“ An open dialogue with doctors can be fundamental to guarantee your child or teenager's well-being, as well as effective management of the medical situation. Encourage your child to disclose any annoying symptoms: this will allow the neurologist to accurately assess the available therapeutic options and adopt a targeted treatment programme. ”*

## Rehabilitation

Rehabilitation from MS requires an interdisciplinary approach that involves various professional figures, for example, physiatrists, physiotherapists, occupational therapists, neuropsychologists, rehabilitation nurses and others. Rehabilitation always aims to promote autonomy, starting with a personalised programme that encourages full participation in family, school and social life.

- **Physiotherapy** can play a very comprehensive role in rehabilitation.
- **Cognitive rehabilitation** supported by a neuropsychologist can be particularly important to help children and teenagers adapt to difficulties with school work.
- Support from an **occupational therapist** can also be part of the rehabilitation process. An occupational therapist can, for example, teach techniques to manage fatigue and save energy, and to better deal with daily commitments.

*“ The reference neurologist at the MS clinical centre will assess when appropriate to involve the rehabilitation team in the child or teenager’s rehabilitation based on the clinical picture and their symptoms. ”*

## Food

At the moment, there is no diet or eating regime proven to prevent multiple sclerosis (MS) or influence its progress.

- However, it is essential that children and teenagers maintain **a suitable body weight** to ease the management of any symptoms such as fatigue. Recent research has highlighted that obesity could indirectly facilitate the disease, underlining the importance of taking care of weight and diet.
- It is also important **to eat foods that provide energy**. Carbohydrates provide energy keeping the organism active without affecting sugar and fat reserves: if they are missing from the diet, the body tends to use proteins, compromising muscle mass. This is one of the reasons why a diet poor in pasta, legumes, cereals and sugars can worsen fatigue and not be recommended for a person with MS.
- A balanced diet provides all the nutritional substances most people need, therefore **there is no need to take dietary supplements**.

*“ If you have any doubts, even if you think they may be trivial, do not hesitate to ask the centre specialised in paediatric MS looking after your child: they will be able to give you the best and most specific advice for looking after your child. ”*

# 5

## How to talk about MS Talking to your child about MS

Should I Let my Child Know  
About the Diagnosis?

When is the Best Time to talk about it?

All parents ask themselves these questions in an attempt to do what is best. There is no standard answer, but we do know that sincerity is fundamental to having a healthy parent-child relationship. Even very young children can have great awareness: they perceive that something is wrong and pick up on their parents' anxiety. They compare themselves with children their own age who don't usually undergo tests such as MRI scans or lumbar punctures. Often in the attempt to protect and safeguard their child, parents prefer not to talk openly about MS, but **if there is a lack of clear communication, the child or adolescent will tend to imagine even worse scenarios, thus increasing their anxiety.**

The decision **not to tell your child about their diagnosis can also undermine feelings of trust in your relationship.** It is difficult to hide every single aspect of the disease, especially when there is frequent contact with hospitals or medication needs to be taken. Children, and especially teenagers, often discover for themselves that they have a chronic disease, often by looking up information on-line. Discovering that their parents already knew about it but didn't say anything, can create misunderstandings and undermine trust.

### Can I choose to hide MS from my child?

Letting your child know about their diagnosis is your personal decision.

However, there are some aspects of the disease that need to be considered openly.

MS is complex with various more or less obvious **symptoms** that often influence a person's quality of life, and it causes unpredictable relapses: ignoring the cause can create doubts, questions and many anxieties for the child or adolescent.

Every aspect regarding **taking medication** can be managed better if your child is aware of what is happening. Sometimes the ways medications are administered are invasive, they can provoke side effects and require long-term effort. If your child doesn't understand the reason they have to take the medication, they could struggle to accept it and even refuse to take it, therefore hindering the efficacy of the treatment.

### How much does open communication about MS influence the well-being of my child?

It is normal to feel frightened about the impact that news of an MS diagnosis may have on your child, but it is equally important to consider how destabilising it may be for them to hide it in the long-term. It is fundamental to provide honest information about the diagnosis, because not being able to name or provide a reason for what is happening can cause confusion, dismay, a sense of inadequacy, anxiety. Furthermore, this allows the child or teenager to actively take part in the management of their health, in proportion with their age.

## Can open communication have an impact on my child's future?

Talking openly about MS allows the child to grow up with skills and information about their disease. This approach facilitates management of the disease in adult life. For this reason, it's important to stop MS from becoming a taboo, something to hide or to be so afraid of that you never openly discuss it. The possibility of having an open and honest dialogue between parents and child about MS can also have a broader positive effect on various aspects of family life beyond the disease.



## HOW TO TALK ABOUT MS

### How to talk to children?

- **choose simple but correct terminology:** use simple and precise medical language
- **use clear comparisons:** explain complex concepts using comparisons or similarities suitable for their age. For example, the central nervous system can be compared to electrical wires that illuminate a light bulb, and if the wires are damaged, the light bulb will switch off. If you need any suggestions, you can ask healthcare professionals for advice.
- **support trust in the medical team:** to show you have trust in the medical team looking after your child, talk positively about the doctors, nurses and the healthcare professionals with whom they have to interact on a regular basis.
- **encourage questions:** encourage children to ask questions to help understand doubts and fears. If you don't know how to answer a question, be honest and reassure them with an "I

don't know, but we can ask so and so" or "I don't know but we will try to find out".

- **share emotions:** talk openly about emotions and feelings linked to the disease. Children often use us as a reference point for knowing how to behave in some situations. If we are able to talk to them about the things they are worried about and any questions they may have, they will be able to manage the situation with more tranquillity.
- **choose the most suitable moment:** tackle the topic when your child is not tired or distracted and be prepared to grasp unexpected opportunities when they occur.

### How to talk to teenagers?

- **acknowledge the complexity of teenagers:** adolescence is a complex time full of changes, a search for identity full of conflicts that influence the parent-child relationship. It is often defined as the most difficult age, and an MS diagnosis can be a further hurdle to overcome. It is important to recognise that misunderstandings and teenage mood swings are a normal part of growing up and are not necessarily linked to MS.
- **allow each person to take their time:** teenagers can become distant from parents and not talk about what is happening, withdraw into themselves or try to deal with everything on their own. They can be in denial about the situation or pretend that everything is OK. With patience and trust, allow them to take their own time: in the face of a stressful event, it is normal to need time to assimilate and understand what is going on.
- **be open to dialogue:** always be ready for dialogue and embrace unplanned opportunities to talk. More spontaneous conversations, even about serious topics, can happen at the most unexpected and unplanned moments.
- **try not to be overprotective:** try to avoid overprotective behaviour that can cause insecurities or the sensation that MS is an insurmountable obstacle.



## How to talk about MS in the family

### Outbreak of symptoms and diagnosis

The outbreak of symptoms and the start of the diagnostic procedure are certainly the most difficult moments: everything is still very confused, there is a lot of uncertainty, fear and anguish. It is normal for parents to feel that they are constantly hounded by an unknown threat, but it is important to underline that it is possible to deal with and manage these emotions.

*“ Openly sharing feelings and emotions in this complex context can help to prepare the family to knowingly face what is yet to come.*

*With time, there will be various moments when it will be appropriate to reopen the dialogue, to deal with new aspects depending on the different moments of life, in the face of any changes during the disease or in case of choices that must be made.* ”

### Management of daily life

MS is not easy to forget during daily life: even when the child or teenager is well and is not suffering from symptoms, it is difficult to pretend nothing is happening. Trying to maintain a serene and normal attitude can help overcome fear, worry and anxiety about what you are going through.

*“ It is vital not to allow the disease to condition every aspect of your child and your family’s life, or link everything to the context of the disease.* ”

## How to talk to siblings

If there are any siblings, their daily lives can also undergo changes and everything that happens can have an effect on their emotional state.

Seeing a sibling not feeling well, going to hospital or taking medication can be concerning for them, and without suitable information they can imagine scenarios which are much worse than MS.

It is normal for siblings to feel afraid, angry or worried, and it is easy for them to ask themselves questions such as "What is happening?"; "Is it contagious?"; "Can it happen to me?" They can feel bitter or jealous of the attention their sibling with MS is receiving; this can provoke feelings of guilt and/or dysfunctional behaviours in the attempt to re-establish the lost equilibrium.

*“ If your child has siblings, it is essential to talk to them about MS using transparent, simple and clear language, answer their questions, encourage them to ask questions and express their emotions. Open communication leads to better understanding of the situation, helps to dissipate doubts and fears, better manage daily challenges and creates an atmosphere of trust within the family for members of every age. ”*

## Emotional and psychological support for parents

Having a child with a diagnosis of a chronic disease is a great source of anxiety for any parent. The reality of MS can destabilise the couple's relationship. To be able to deal with the disease and their child, parents need to process the diagnosis, each at their own pace.

The main hurdle is when parents are unable to get over the emotions caused by the diagnosis, thus slowing down their child's pathway to pharmacological and psychological treatment.

“ Parents dealing with the challenge of MS in the family need to take care of themselves if they want to be able to provide the best support possible to their child with MS, as well as other family members. Therefore, it is fundamental for parents to be able to count on moments when they can take care of themselves, use support networks, receive adequate psychological support, if and when necessary.

Psychological support can provide a safe space where it is possible to explore and deal with the complex emotions linked to MS. The help of mental health professionals not only contributes to individual well-being, but also has a positive impact on every family relationship. ”

## Letting the school know about MS

### The impact of ms on the school environment

School is where children and teenagers should spend most of their day, where they create social relationships and make friends. At school, children learn how to pay attention and study in an environment where the pace can be very fast and full of distractions. For children with MS, school can be a place of stress and anxiety if they feel alone in dealing with their disease, without being understood and accepted.

“ Some features of the disease are difficult to hide, making it important to let the school know about the child or teenager’s situation. This transparency means the school can be provided with the necessary information to guarantee an environment suitable for a child or teenager with MS, and it creates a common ground for effective collaboration. ”

## Absenteeism linked to MS

The relapsing and remitting nature of MS can be the cause of frequent absenteeism from school, not only due to relapses, but also due to medical visits or the side effects of some drugs.

“ *A collaborative approach and regular communication means working together to minimise the impact of absences and maintain continuous learning, for example by scheduling planned absences, organising and coordinating activities during unexpected absences.*

*Furthermore, it's important to allow children and teenagers to take part in educational outings and other activities. These can be important opportunities that should not be missed. If there is reciprocal dialogue and collaboration, these opportunities should be evaluated from time to time so that teachers feel secure and capable, and parents feel confident and serene.* ”

## Necessary adaptations at school

The difficulties caused by some symptoms, for example problems with memory, attention and fatigue, can be interpreted as negligence, laziness or sleepiness, and have a negative impact on how the child or teenager is perceived. It may be necessary to make a few adjustments to ease the child or teenager's daily life at school, such as for example, extra time to sit tests or exams or the possibility of being able to sit exams in a quiet environment.

“*Teachers and educators should be adequately informed about MS and which symptoms have the greatest impact on school learning (and participation in school in general), so they can understand the effective use of making some adjustments and being flexible.*”

*To guarantee this type of support, it can be a good idea to schedule some meetings with teachers and the school head to explain the impact of MS and the main symptoms.*”

**Involving  
professionals  
and support  
from AISM**

It's not always easy to explain the complexities of MS, its unpredictable nature and the invisibility of some symptoms.

“*Choosing to rely on the support of professionals who deal with MS can help you feel more confident about how to explain the symptoms and their impact on your child or teenager's performance at school.*”

*Furthermore, you can seek support from AISM, who can provide informative material about MS to share with teachers and educators. This can contribute towards guaranteeing accurate and comprehensive communication.*”

## MS and sport and out of school activities

### The Benefits of physical and other activities with ms

There are no absolute contraindications for physical activity in children and teenagers with MS; on the contrary, playing a sport at one's own pace can be extremely positive from various points of view.

Even though MS makes it a bit more difficult to practice some sports and activities, children with MS should not give up their activities in favour of complete rest. Naturally, there will be times when it is necessary to slow down or situations where it can be more tiring (for example when the weather is hot).

“ *It is important for children and teenagers to gradually learn their limits and listen to what their body is telling them.* ”

### The Choice of sports and/or out of school activities

MS affects people in different ways. Furthermore, each individual can have specific preferences regarding the type of out of school activity they want to practise.

“ *Parents must avoid trying to condition their children's choices as well as out of school sports and activities. Parents play a fundamental role in encouraging their children to try out different activities and sports, especially if their child wants, and feels, ready to try them.* ”

*Guaranteeing an environment where children feel supported and trusted is fundamental to allow them to explore their inclinations and develop a variety of interests.* ”

**Communication  
with significant  
adults**

Sports and school activities are important for developing relations with peers and significant adults. Just like in school, close collaboration between parents, children, sports coaches and educators is fundamental to guarantee participation in these occasions.

“ Remember that most people know nothing about MS and its characteristics: sharing information about the nature of MS and its most significant symptoms can help to create awareness and understanding.

Open communication facilitates information about unexpected events, it helps to find common strategies to guarantee participation and to plan activities when everything is going well, it allows children to explore their interests in a positive and supportive context. ”

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