

YOUR MS GUIDE

Be informed.
Be active. Be yourself.

INITIATIVE ME
Be yourself. Even with MS.



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Dear Reader,

After the diagnosis of “multiple sclerosis” (MS), you are probably concerned that many things in your life will now change.

It’s great that you have picked up this **MS guide** and are learning about MS, because this is about you, the health of your body, the protection of your brain, and your well-being.

This knowledge is important. It can help you cope better with your MS and open up new perspectives.

In this guide, we would like to provide you with important information about the “disease with 1000 faces”. It is important for us to clarify possible uncertainties: What is MS? What happens in the body in the case of MS? How is MS treated? And what can you yourself do for your health?

Our ideas and suggestions are intended to help you strengthen your body and your mental fitness.

Keep your strengths in mind, make plans, and look ahead!
In other words: Keep being yourself. Even with MS.

BE INFORMED! MS KNOWLEDGE IS IMPORTANT

What exactly does MS mean?

MS is the abbreviation for **multiple sclerosis**. This is a chronic inflammatory disease of the central nervous system. It is among what are known as autoimmune diseases. In these diseases, the immune system is directed against the body itself – in the case of MS, it is directed against the protective layer of the nerve pathways. As a result, the nerves can be permanently damaged in various areas of the brain and spinal cord. And this can in turn trigger a wide variety of noticeable and unnoticeable symptoms throughout the entire body.

Is MS a common disease?

In Central Europe, MS is the most common inflammatory disease of the central nervous system:

- › Every year, more than 15,000 people are newly diagnosed with MS in this country.
- › In Germany alone, more than 280,000 people live with MS.
- › MS generally first appears at a young age, that is, in persons between the ages of 20 and 40.
- › Women develop MS twice as frequently as men.



Why does MS even develop?

You may be wondering: Why me? So far, nobody knows the exact causes of the development of MS. Doctors and researchers assume a combination of a variety of factors:

- › Impaired immune defence
- › Previous viral infections such as the Epstein-Barr virus
- › Genetic predisposition
- › Various environmental factors (such as a vitamin D deficiency)
- › Personal lifestyle (such as diet, smoking)



Are you interested in scientific theories on the development of multiple sclerosis? Here you will find more information:



What happens in my body in the case of MS?

In MS, the immune system reacts to the body's own nerve cells, more precisely: to the myelin sheaths. Myelin sheaths are a protective layer which surrounds each nerve cell.

It may help you to understand this using a comparison of a nerve and a power cable. This is because the myelin sheath works in principle like the insulating layer of a cable. The electricity is carried only if the insulation material is intact. If it is damaged, the electricity can no longer flow correctly and disruptions result. A similar thing happens in the case of MS with the nerve cells in the brain. If the myelin sheaths are attacked, important signals can get lost en route through the nervous system. This can trigger various symptoms. →

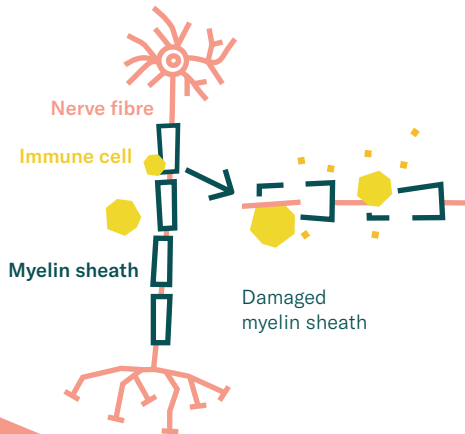
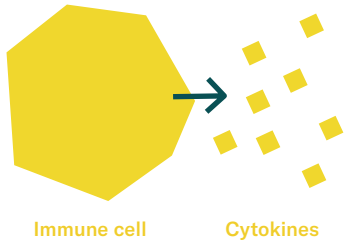
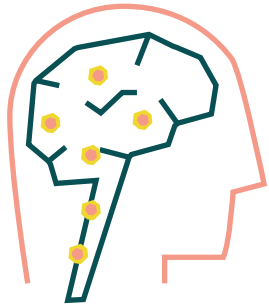
MS simply explained

Immune cells normally protect the body from viruses, bacteria or other intruders.

1 However in MS, misprogrammed immune cells which are directed against the structures of the myelin sheath reach the brain and spinal cord.

2 There they excrete what are known as cytokines. These are proteins which control the growth and development of cells. These cytokines activate other immune cells and trigger an inflammation.

3 As a result, the insulating layer of the nerve fibres (myelin sheath) is attacked which disrupts the transmission of nerve impulses and can lead to damage of the nerve fibres.



1. Personality and social interaction
2. Hearing, speaking, memory
3. Sensations from the body
4. Vision
5. Fine motor skills
6. Transmission of information between the brain and body

4 Various areas of the brain or spinal cord may be affected by the damage and inflammation. This leads to a wide variety of symptoms throughout the body which manifest in what is known as a relapse. Page 11 explains to you what a relapse is.



This website shows, which regions of the brain are responsible for which body functions.



You can learn more about the connections between MS, the immune system and central nervous system here:



Which symptoms can occur?

Multiple sclerosis can be associated with completely different signs of disease. Some can be seen and felt, while others cannot. MS can be different in each person. This is why it is called the “disease with 1000 faces”.

Mögliche Symptome einer MS sind:

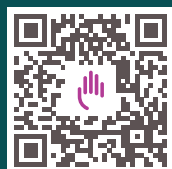
- › Visual disorders and rapid, uncontrollable eye movements (nystagmus)
- › Generalised weakness
- › Rapid fatigue
- › Tingling or numbness of the skin
- › Paralysis symptoms, sometimes also with a feeling of stiffness (spasticity)
- › Coordination and movement difficulties
- › Problems speaking
- › Bladder disorders
- › Pain
- › Dizziness
- › Cognitive disorders: Limitations in attention, retentiveness, and concentration
- › Depressive moods and depression



MS can also be active in your body if you are perhaps not experiencing any symptoms at present and are feeling well. It often causes further inflammation of and damage to your nerves, however only in the background and not noticeably. This is why it is important for you to continuously receive your therapy.



You can find out more about the symptoms of MS here:



What is a so-called relapse?

A relapse is the sudden appearance or worsening of signs of disease which partially or even completely disappear after 24 hours to several weeks. In the pauses between two relapses, you may not notice the MS at all. Sometimes, the disease “sleeps” for months or even years.

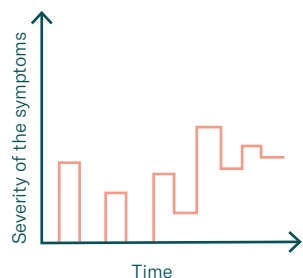
Which forms of MS are there?

The course which MS takes differs significantly between individuals. However, you should be aware that the disease is not severe in every case. It is only rarely associated with severe disabilities. Particularly if treatment is started early, the inflammation of your nerves can decrease, as can the associated disease symptoms, without causing permanent nerve damage. →



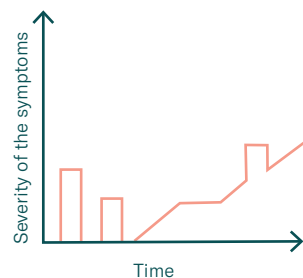
In principle, MS is divided into **three typical forms**:

1| RRMS: Relapsing-remitting MS



85 to 90 percent of newly diagnosed MS patients have this form of MS. It occurs in episodes whose symptoms partially or completely resolve within a few weeks, generally speaking. There may be months or even years between the episodes.

2| SPMS: Secondary progressive MS



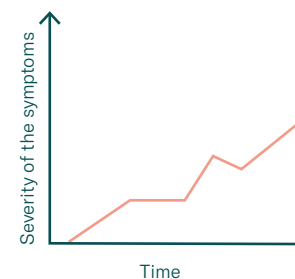
Many patients develop secondary progressive MS over time. This means that, after an initially episodic course, MS changes into a continuously progressive form – independently of relapses which become more and more rare.



You can find more information about the forms of the disease on the website of the DMSG: www.dmsg.de



3| PPMS: Primary progressive MS



In about 10 percent of those affected, MS progresses from the start, often without relapses. This is known by the term “primary progressive”. The signs of disease gradually worsen and generally also no longer resolve.

How does MS affect my life?

You have probably already asked yourself this question. The diagnosis of MS is often associated with many changes, both physical as well as psychological. Of course, it can also have an effect on your lifestyle, relationship, and sexuality. How much your daily routine and life change may depend on the course of your MS. How you yourself deal with your disease is also a crucial factor.

Would you like to learn more about the potential consequences of MS and what other affected individuals have reported about it? Then visit the MS community of the DMSG (Deutsche Multiple Sklerose Gesellschaft, Bundesverband e.V., engl. German Multiple Sclerosis Society) or get to know other people with MS and their relatives.



THINK OF YOURSELF AND YOUR DOCTOR AS A TEAM

How is MS treated?

The choice of a suitable therapy depends on the course of the disease and the severity of the MS. Even if a cure is not yet possible, therapy which is individually tailored to you can have a beneficial effect on the course of the disease and reduce symptoms.

The important thing is: You decide, together with your doctor, what your individual therapy should look like. Also discuss at your medical appointments what you expect from the therapy and what is important to you, for example, in regard to family, hobbies, or your job. These areas of your life should also be taken into account when choosing treatment.

Therapy for MS essentially comprises three key aspects:

1| Acute relapse therapy

- › Short-term treatment
- › Goal: to shorten an acute relapse and relieve symptoms
- › Use of anti-inflammatory medications which help reduce symptoms

2| Disease-modifying therapy

- › Long-term treatment
- › Goal: to reduce the frequency and severity of relapses and prevent progression of the MS
- › Use of medications which act on the immune system

3| Symptomatic therapy

- › Use according to the individual disease picture
- › Goal: to counteract physical, psychological or cognitive symptoms
- › Medical and non-medical therapy, such as physiotherapy, psychological counselling or psychotherapy, cognitive training or speech therapy

In addition: Rehabilitation measures

- › Intensive medical, occupational, and social measures individually tailored to the patient, such as:
 - + Therapeutic exercises
 - + Occupational therapy
 - + Training and exercise therapy
 - + Psychological treatment
 - + Physical therapy
 - + Speech therapy
 - + Neurocognitive therapy



More information about the medical and non-medical treatment methods is available at www.dmsg.de





Important factors in treatment and observation

Promptness

... because the earlier MS is identified and treated, the better the occurrence of damage in the brain and spinal cord can be slowed or even halted.

Consistency

... because the disease process can be positively influenced only by the regular intake of medication. Even if you might be symptom-free right now and feel good: MS is nonetheless still often active and causes inflammation of your nerves. For this reason, it is particularly important to take your medications regularly and exactly as the doctor has prescribed.

Regularity

... because only with continuous medical monitoring can progression of the disease be counteracted and your therapy adjusted as quickly as possible if you have symptoms or changes.



You can learn more about this in the brochure **“Brain health: A guide for people with MS.”** You can download it here: www.msbrainhealth.org



BECOME ACTIVE YOURSELF

In this way, you can strengthen your body and mental fitness.

Along with regularly taking your medications, you can do even more for your health and to protect your brain by adopting a healthy lifestyle. Why is this so important? Today, we know that a healthy and active life have a positive effect on the course of the disease and especially on well-being and thus quality of life increases. It is also about the feeling of having control over your life instead of feeling at the mercy of MS. This can help you cope better with the disease.

The brain, body and psyche are closely linked together. The physical condition can have an effect on the brain and psyche – the psyche in turn has an effect on physical and mental well-being.

These tips are intended to help you do something for yourself:



Keep an eye on your weight

- › MS patients with elevated blood lipid values and overweight often have more centres of inflammation in the central nervous system.
- › You can do something about this with a healthy and balanced diet as well as sports and exercise.

Be physically active



- › An active lifestyle supports the brain.
- › Sports and exercise lead to faster information processing in the brain.
- › There is an opportunity for everyone to be active – depending on the severity of the disease and individual preferences. Talk to your doctor about this as well during your next appointment.
- › Would you like to learn more about “sports during MS”? Here you will find information about the backgrounds and various types of sports: www.dmsg.de → **Multiple Sklerose** → **MS und Sport**



Challenge yourself mentally

- › Those who regularly read and engage in hobbies and creative leisure activities can reduce MS-induced cognitive impairments.
- › This is not just for mental fitness, but also to maintain the “cognitive reserve” – that is, the ability of the brain to compensate for various damages. Mental training and, if necessary, compensation strategies can help here.
- › At www.dmsg.de/ms-kognition/ you can learn more about this and can start various exercises online.

Avoid smoking



- › In the case of MS, smoking can lead to more relapses, increased physical and cognitive impairments, as well as an overall accelerated progression of the disease process.
- › Important! Every person experiences a decrease in brain volume as part of the ageing process. Smoking can accelerate this process. This is particularly pronounced in people with MS.
- › If you find it difficult to stop smoking, talk to your doctor. He or she can help you.

Do not consume too much alcohol



- › In general, rare alcohol consumption is not harmful. But this depends on your individual state of health.
- › Alcohol can, however, worsen MS symptoms such as weakness, fatigue or balance problems. There may also be intolerances with various medications.
- › Your doctor knows more about this.

Seek treatment for any other illnesses you have



- › Diabetes, cardiovascular diseases, high blood pressure or elevated blood lipid values can have an unfavourable effect on the course of MS.
- › Speak to your doctor about this. Have regular check-ups. Do not forget to take your medications as prescribed.

What else you should be aware of



- › Learn how to properly manage your energy reserves.
- › Avoid stress.
- › Ensure you get enough sleep.
- › Seek psychological support and counselling, if needed.
- › Relaxation techniques such as autogenic training, progressive muscle relaxation, qigong or breathing therapy may also help you.
- › Take a look here to see which technique may suit you: www.dmsg.de
→ **Multiple Sklerose** → **MS behandeln** → **Entspannungsverfahren**
- › You might also benefit from music or art therapy. This has already helped many people deal with MS better and work through the disease process.

Be yourself – even with MS!

It is not easy to engage with one's new life situation and cope with all of the changes. It is a learning process which everyone experiences differently. These suggestions are intended to help you in this:

Learn about your disease and treatment. Always contact your doctor if you have questions.

Learn how to handle your energy reserves: Be as active as possible, however do not overexert yourself.

Recognise and accept your performance limitations. It is okay to be sad about lost capabilities. Nonetheless, try to look towards the future with optimism.

Use strategies and aids to compensate for limitations. Have the courage to ask for help.

Focus on your strengths and abilities, not your weaknesses and impairments.

Redefine your self-image. Discover new sides and abilities in yourself. Set new goals for your life.

Have confidence in yourself and take responsibility for your health and well-being.

LEARN ABOUT MS: PRACTICAL TIPS AND LINKS

The more familiar you are with your MS, the more you yourself can do to improve the course of your disease and your well-being.

DMSG – German Multiple Sclerosis Society

www.dmsg.de

- › The DMSG is a nationwide association of people affected by MS, their family members, and medical professionals. They provide support to patients and their family members and also focus on research and treatment of MS.
- › On the website, you will find a complete overview of MS as well as detailed information on the condition, therapy, new findings from research, as well as assistance and tips for dealing with the disease.
- › You can contact your DMSG state association. A list with contacts is available here:

www.dmsg.de/dmsg-bundesverband/landesverbaende

Amsel – The Multiple Sclerosis Portal

www.amsel.de

- › Amsel is the state association of the DMSG in Baden-Württemberg.
- › Here you will find a wide range of information about all of the issues relating to the topic of MS. This also includes numerous informational videos on various topics. The online portal also provides you with the opportunity to contact experts and other persons affected by MS.

KKNMS – Competence Network Multiple Sclerosis

www.kompetenznetz-multiplesklerose.de

- › The KKNMS is a nationwide German research network which includes experts from a variety of disciplines.
- › The network is a scientific point of contact for researchers and interested parties; it publishes guidelines and patient guides and awards research grants.



GET READY FOR YOUR MEDICAL APPOINTMENTS

After a diagnosis of MS, you no doubt have many questions. It is worth writing them down so that you have them ready for your next medical appointment. It is certainly also a good idea to bring a friend or family member with you to the initial consultations. Four ears simply hear more than two. Here are some important questions for you so that you can get the most for yourself out of the time spent with your doctor.

Questions for the next doctor's visit

Which form of multiple sclerosis do I have?

Which therapies are a possibility for me?

What should I do if I do not tolerate a medication?

What is the best thing for me to do if I have acute symptoms?

Which nonmedical measures are recommended for me to relieve my symptoms?

YOUR QUESTIONNAIRE TO TEAR OUT

NetDoktor

www.netdoktor.de/krankheiten/multiple-sklerose/

- › NetDoktor offers easy-to-understand information on a wide variety of diseases, symptoms, medications and treatment methods.
- › In the section “**Multiple Sklerose**” [multiple sclerosis], you can find up-to-date information on causes, symptoms, and treatment of MS.

Neurologen und Psychiater im Netz

(Neurologists and psychiatrists on the web)

www.neurologen-und-psychiater-im-netz.org

- › The information portal is published by professional associations and societies for psychiatry, paediatric and adolescent psychiatry, psychotherapy, psychosomatics, neuropsychiatry and neurology from Germany and Switzerland.
- › The website provides information on the topics of mental health and neurological diseases. Here you can also see which doctors and therapists are in your area.

Arzt-Auskunft (physician information)

www.arzt-auskunft.de

- › Here you will find all of the doctors, dentists, psychotherapists, hospitals, rehab hospitals, medical care centres (MVZ) and emergency facilities in Germany. You can also find out who is handicapped-accessible.

Rehasport Deutschland e. V.

(Federal Association of Rehabilitation Sports)

www.rehasport-deutschland.de

- › On the website, you will find information about the topic of rehabilitation sports. You can also research rehabilitation sports groups in your area.

Also ask your doctor.

He or she can provide you with more information.

LEGAL NOTICE

Disclaimer

The contents, data and information in this brochure are intended only for uses within the territory of the Federal Republic of Germany. Provided that they contain information on or in connection with states of health, clinical pictures, medical questions or treatment options, they do not replace the recommendations or instructions of a doctor or other healthcare professional. The contents of this brochure are not intended for the diagnosis or treatment of a health or medical problem or a disease. In addition, they do not make any claim as to completeness or correctness. The distribution and/or use of this brochure does not create any contractual relationship, in particular no advice or information contract, between you, the authors of the brochure, and/or Celgene GmbH. In this respect, there are also no contractual or quasi-contractual claims. Our offer contains links to external websites of third parties over whose contents we have no control. We therefore cannot assume any liability for these third-party contents. The respective provider or operator of the pages is always responsible for the contents of the linked pages. The linked pages were checked at the time of linking for possible legal violations. No unlawful contents were able to be identified at the time of linking.

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What should I keep in mind if I still want to have children?

Which occupational limitations should I expect?

What can I myself do for my health and the protection of my brain?

Is there anything I need to be aware of with regard to vaccinations?

Which types of sports would you recommend to me?

How often should I come in for check-ups?

YOUR QUESTIONNAIRE TO TEAR OUT



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www.ms-initiative-ich.de



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