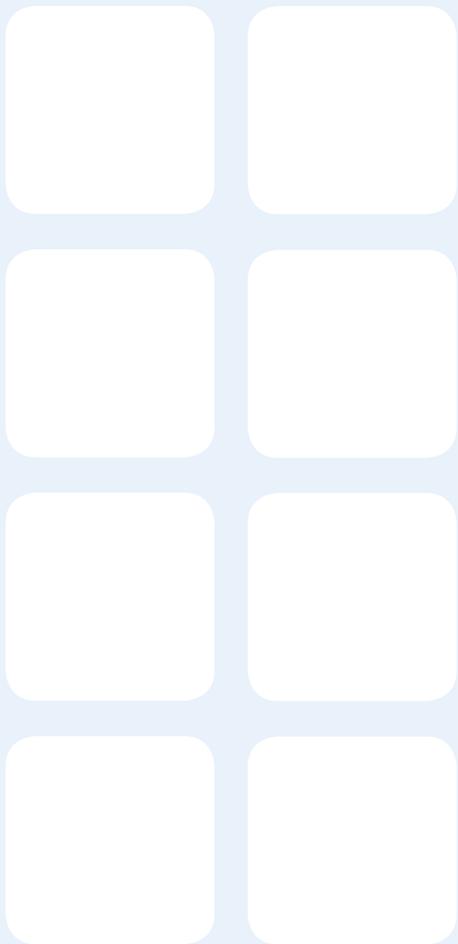


2

Living with MS

*MS and
daily life*

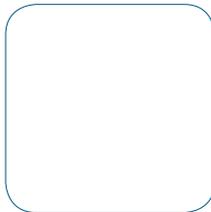
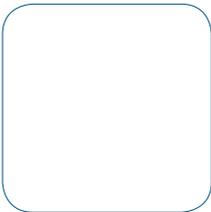
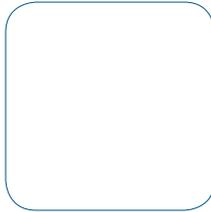
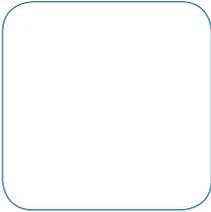




This booklet was created by Biogen. The information has been put together with great care, but it is not a substitute for the opinion, diagnosis or advice of a treating physician.

Table of Contents

1.	Introduction	4
2.	Symptoms and remedies	7
2.1	Fatigue	8
2.2	Sensory changes	11
2.3	Loss of muscle strength	13
2.4	Stiffness, spasticity	15
2.5	Walking, balance and coordination	17
2.6	Pain	19
2.7	Vision problems	25
2.8	Bladder problems	27
2.9	Intestinal problems	29
2.10	Cognitive problems	31
2.11	Mood changes	33
3.	Tips for daily life	35
3.1	Sexuality	35
3.2	Pregnancy	38
3.3	Exercise and physical activity	40
3.4	Vacation	42
3.5	Tips for every day	43
3.6	Tips for the partner	48
4.	Useful addresses	51



1. Introduction

The information series “Living with MS” provides more information about the condition called MS: the various symptoms, the possible treatments, and what you can do to make life with MS as easy as possible. Biogen developed this series of booklets with the help of specialists and experts. The booklets can help you prepare yourself, know what to expect and how to manage your life with MS.

This is booklet 2 in a series of five booklets:

Booklet 1: What is MS?

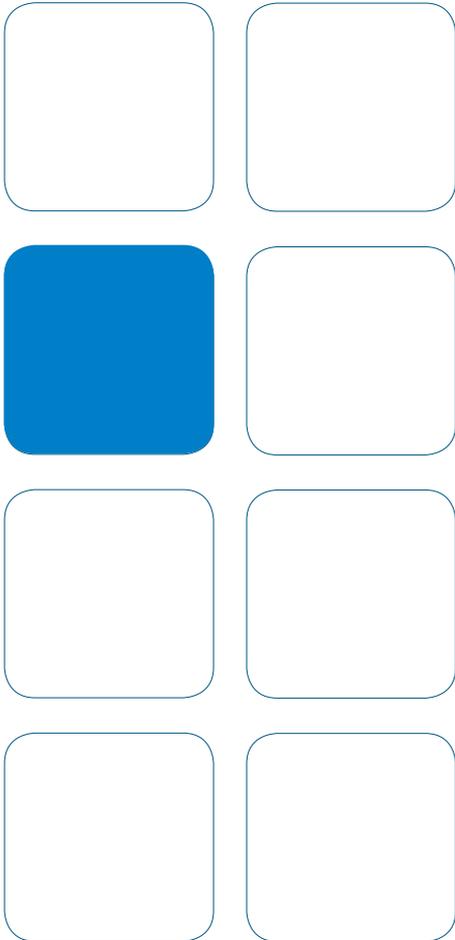
Booklet 2: MS and daily life

Booklet 3: MS and treatment options

Booklet 4: MS, sexuality and parenthood

Booklet 5: MS and cognitive function





Before you start reading:

This booklet addresses all the symptoms someone with MS might experience. MS often remains limited to just a few symptoms. In other words, it is definitely not a foregone conclusion that you will experience all of these symptoms yourself!

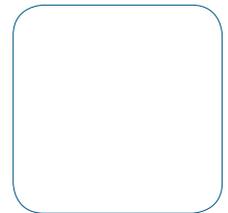
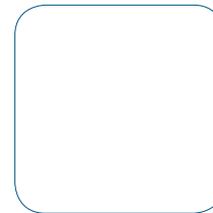
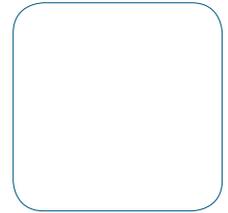
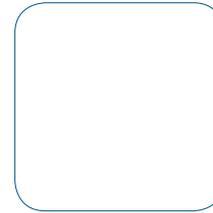
The booklet “MS and daily life”

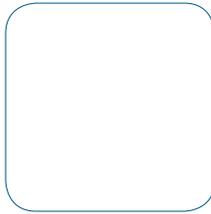
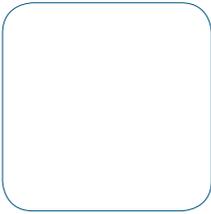
Our entire body is, in fact, controlled by our nerves. This is why a nervous system disorder can cause symptoms anywhere in the body. Different physical functions are localised in different areas of the brain; some areas control more than one function. The type of symptoms that occur depends on the area of the brain where the inflammation occurs (or occurred). This is why the course of MS and the symptoms that occur vary from person to person and are impossible to predict. This booklet describes the most common symptoms and ways to deal with them.

2. Symptoms and remedies

The first booklet in this series, “What is MS”, explains that MS is caused by inflammation in the brain. The exact locations of these inflammations are different for each patient. MS can be accompanied by a wide range of physical and mental symptoms. This booklet lists the most common symptoms, but that certainly does not mean that you will experience all of them; you might just experience a few. Some symptoms are more common than others.

The severity of each symptom may vary as well. One day you can ride your bike or take a walk and everything is fine, and the next day you can't get around without help. One day you can think clearly and have no trouble remembering things, and a few days later you struggle with simple arithmetic.





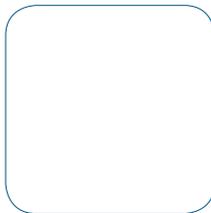
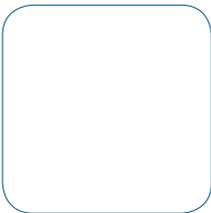
The way in which these symptoms are experienced is different for each individual as well. This has to do with the severity of the symptoms, how much they interfere with daily life, and with the patient's personality.



The following pages provide more information about the most common MS symptoms and ways to deal with them.

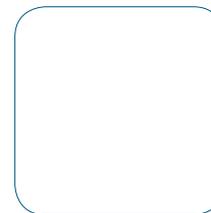
2.1 Fatigue

Almost everyone with MS experiences fatigue, which can increasingly limit your daily functioning. Regular activities take more energy than before, and fatigue can also make you more susceptible to other MS symptoms.



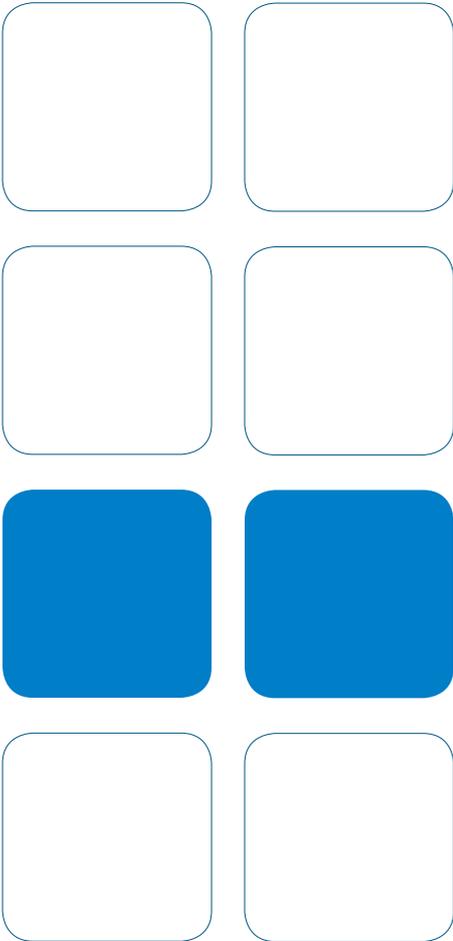
The fatigue is caused by impaired conduction of the signals between the central and peripheral nervous systems (see section 2.2 in booklet 1). The body compensates for this by finding alternative routes, but these require additional energy. This is why fatigue, whether physical or mental, is different for MS patients than for other people.

MS-related fatigue may be totally unrelated to exertion or sleep. It is as if your body's energy level is stuck at a lower setting. The fatigue comes on faster, with more severity, it lasts longer and may be chronic.



General practical tips

- Avoid hot environments like saunas, heated swimming pools, etc.
- Showers with water that gradually becomes more lukewarm (or colder) sometimes works wonders as well.
- Cool yourself down with ice cubes in a towel or with cool packs.



What to do?

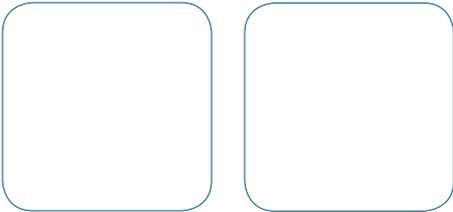
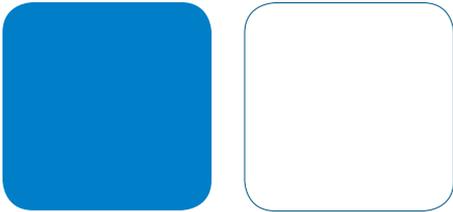
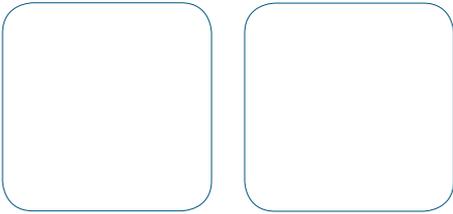
- Because of the unpredictable nature of the symptoms, it is extra important that you adjust your work tempo and lifestyle to the level of your ability.
- The most important precaution is: pay attention to when you start to feel tired and stop to rest at that point. Postponing rest prolongs the recovery time, while the body needs all energy it can get to fight the inflammation.
- Enlist your family, friends and employer to help you find practical solutions. Renegotiate who does what at home and at work. Every day, plan your activities and breaks based on how you feel.
- If the fatigue is severe, consult your treating physician. He or she can assess whether certain medications may help you. Your doctor can also determine whether the fatigue has a different cause, such as anaemia or a dormant infection.

- An occupational therapist can teach you effective ways to manage your energy.
- There are many different types of assistance that are available to you during times when you are not feeling well or are experiencing certain chronic symptoms, from meal services or scooters to home modifications. Some services can be requested via the Social Support Act (Wmo).

2.2 Sensory changes

MS is often accompanied by sensory changes, meaning changes in sensation and touch. This can manifest in many different ways. Examples are: tingling, pins-and-needles sensation, numbness of the skin, cold feet and/or lower legs.





The sensory function of your skin plays an important part in walking, grabbing and anything you do with your hands.

These symptoms can make it more difficult to do certain things, like writing, tying shoelaces or buttoning clothes. It also makes it more difficult to feel whether something is too hot to hold, so be careful when you are cooking, washing dishes or ironing clothes.

Another common experience is: an electric shock down the back, arms and sometimes legs when bending the head (also called Lhermitte's sign).

These symptoms come and go. Periods with symptoms may last longer as the disease progresses.

What to do?

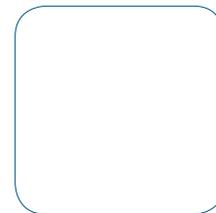
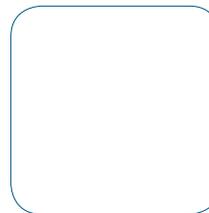
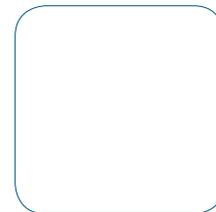
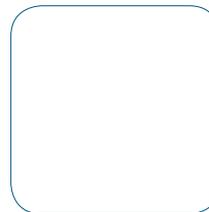
- You can avoid bending of the head (and therefore Lhermitte's sign) by wearing a soft neck collar.
- The occupational therapist can give you tips for retaining your independence as long as possible with regard to daily activities like getting dressed. The occupational therapist also gives

advice about the use of assistive devices (like button hooks or zipper pulls for getting dressed). Assistive devices can be ordered from home care organisations.

- The physiotherapist can teach you the best way to walk. He can also help you set up an exercise schedule.
- Hypersensitivity can be tempered with medications if necessary. Talk to your treating physician.

2.3 Loss of muscle strength

In MS, signals from the central nervous system are not always able to reach the muscles. You experience this as loss of strength. This means you start using your muscles less, and they become weaker over time. You may lose muscle strength anywhere in the body. It often starts in the arms and especially the legs: standing and walking become more difficult (“heavy legs”).



Movement is good, but it should be done in consultation with a good physiotherapist to prevent overload.



An example of other muscles that may become weaker are the muscles around the mouth and throat. This can make talking, eating and drinking more difficult. The coordination of small, precise movements may become more difficult as well. Writing, pouring a cup of tea, blinking or even talking (since vocal cords are muscles as well) starts to take more effort than it used to.

Sometimes you suddenly feel better for a while. In other cases the muscle strength continues to decrease and never comes back. Some muscles may eventually become paralysed.

What to do?

- When certain muscles can no longer do their job, other muscles have to take over. This can lead to overload. The physiotherapist can give you exercises to prevent this.

- If your mobility decreases at some point, an occupational therapist can help you. Home care can be provided as well if necessary.
- The speech therapist can help you with speech problems.
- If you have difficulty swallowing, you can (have someone) cut the food into smaller pieces or puree it. That way you still get the nutrients you need.

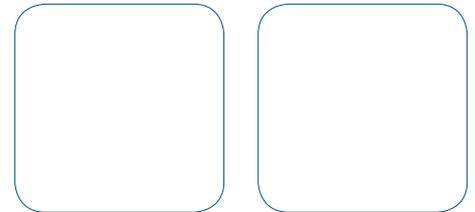
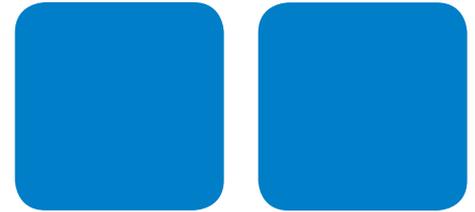
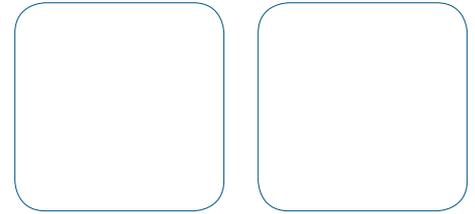
2.4 Stiffness and spasticity

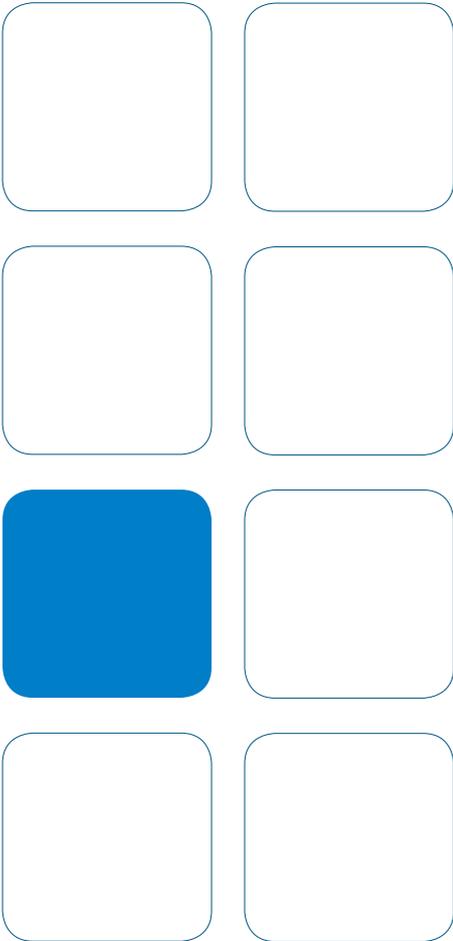
When you move, muscles contract and relax in alternating pairs.

MS affects the coordination between muscles.

This causes some muscles to contract too much. Walking or moving can feel stiff and painful. This inhibits movement.

Another, related symptom is spasticity, meaning involuntary muscle contractions. This happens when a muscle receives





signals to contract, but not to relax. This can lead to the arm or the leg being pulled into strange positions. Unexpected movements occur as well, such as leg twitches during movement or when the bottom of the foot is touched. A full bladder, constipation or bedsores can make these symptoms worse. Heat or tight clothing can also activate an affected nerve unexpectedly, resulting in cramps or odd movements.

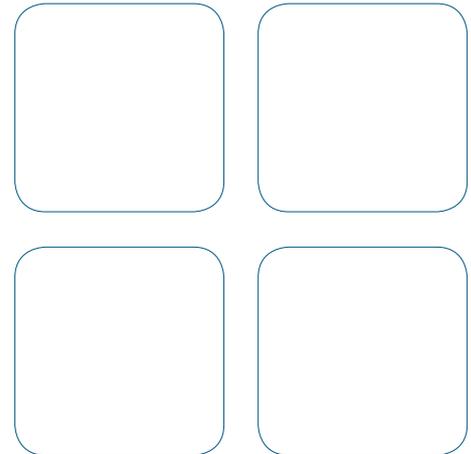
What to do?

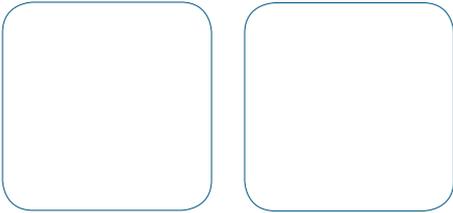
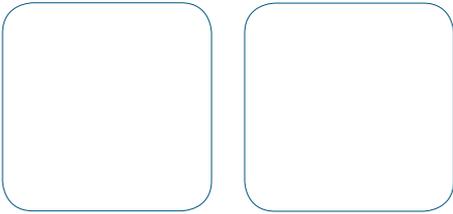
- One way to keep the symptoms under control is by doing the exercises prescribed by the physiotherapist.
- You can try to avoid quick movements and stick to calmer, slower movements whenever possible. Relaxation exercises can also be helpful in this context.

- Keep the intestines going with a high fibre diet and plenty of fluids. It's better not to delay bathroom visits.
- If you experience severely limiting symptoms your doctor can prescribe muscle relaxants.
- Stiffening of the muscles can eventually cause deformity of the joints. The physiotherapist can give you advice about exercises and tools to prevent this.

2.5 Walking, balance and coordination

Walking is usually something you “just do”; you literally do it without thinking. Even so, keeping the body in the right position while moving one foot in front of the other requires a complex interplay of balance, rhythm and strength. This choreography involves a large number of nerves in the brain, and disruptions in the conduction of signals in the brain can have a significant effect on movements.





About two thirds of people with MS have difficulty walking. Some people are not affected very much, while others will eventually need a walking stick or other device to get around. Sometimes it also becomes more difficult to execute smaller movements that require coordination and balance, like pouring a cup of tea.

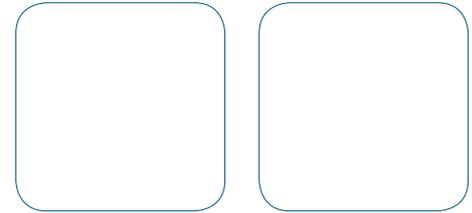
What to do?

- The physiotherapist or rehabilitation physician can explain how you can keep moving despite the symptoms.
- For example, walking with a wider gait and taking smaller steps may help postpone the use of a walking stick or wheeled walker.
- If necessary you can (have someone) install grab bars and support structures in the shower, toilet and other places around the house.

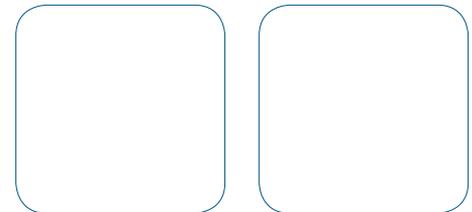
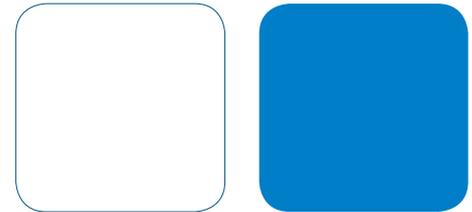
- Remove loose rugs, thresholds and other things you could trip over.
- If you start to experience severe trembling of the head, you can ask for a soft, firm neck collar.
- Medications are sometimes prescribed to improve walking and coordination. Your doctor can tell you more about this.

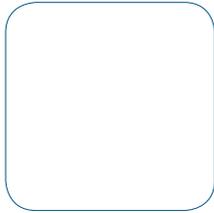
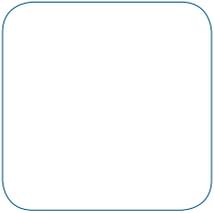
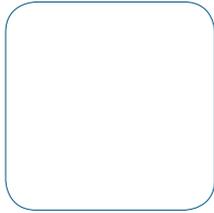
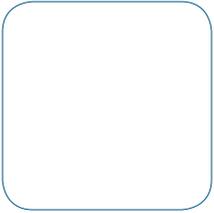
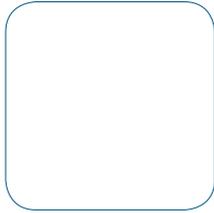
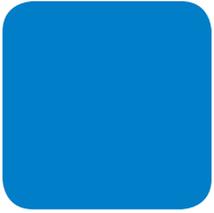
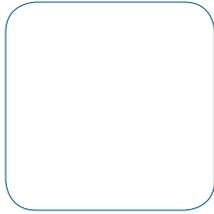
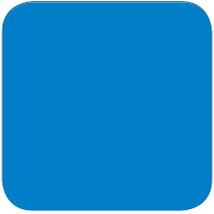
2.6 Pain

Like fatigue, pain is a very common symptom of MS that is difficult to accept. There are many kinds of pain and everyone has their own pain threshold. We distinguish between intermittent pain, acute and subacute pain and chronic pain.



You can use handy practical tools like grab bars and support structures to improve your balance.





Intermittent pain

Intermittent pain is also called “paroxysmal pain”. The most common type in MS is facial pain. This is a sharp, “electric” pain shooting down the face. This pain can be elicited by movements of the mouth while talking, chewing or swallowing. It is probably caused by irritation of the facial nerve.

The same type of pain sometimes occurs in the arms and legs as well. The pain lasts anywhere from a few seconds to a couple of minutes, and often occurs several times a day. The pain is usually not caused directly by MS, but by minor inflammation of the nerve which causes the nerve to be more sensitive to stimuli. This is why even relatively minor stimuli such as cold (brushing your teeth, drinking) can cause pain.

What to do?

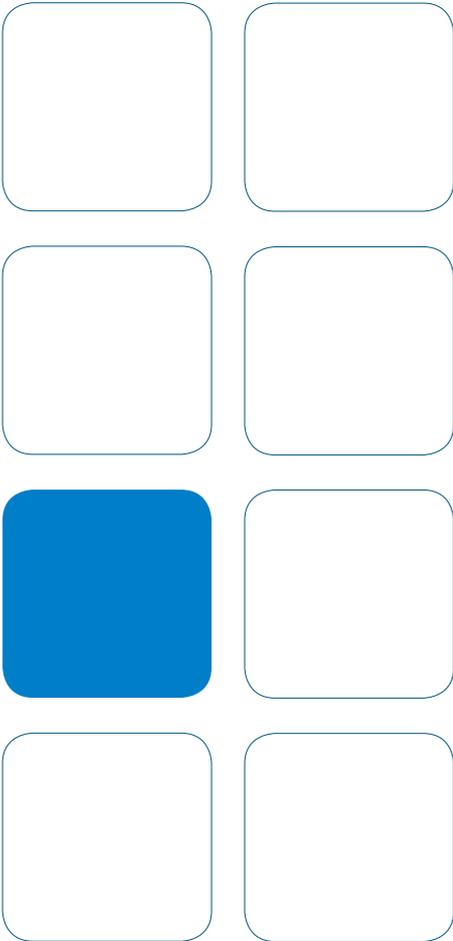
- Pain medication makes the nerves less sensitive to stimuli.
- There are special treatments where tiny electric shocks are sent through the affected area. Your doctor or physiotherapist can tell you more about this.

Acute and subacute pain

A fairly common acute symptom is pain behind the eyes. This could be caused by inflammation of the optical nerve. The pain can be treated with medications. If you experience pain behind the eyes you should contact a doctor.

Bladder cramps can be a source of pain as well. The cramps are caused by damage to the nerves that control the bladder. This may lead to a urinary tract infection. If you experience this type of pain you are advised to consult a doctor. One approach would be to prescribe antibiotics to treat a urinary tract infection that might be causing the pain.





Acute pain can also be caused by pressure on certain nerves. MS patients who use a wheelchair are particularly prone to this pressure pain. If the lower arm is frequently placed on the armrest, for instance, this may cause pressure on the nerve in the lower arm, resulting in a pins-and-needles sensation. Improved posture and modification of the armrest can provide relief.

Chronic pain

The three most common types of chronic pain in MS:

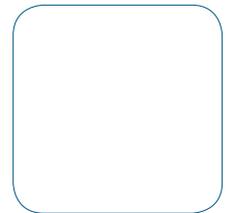
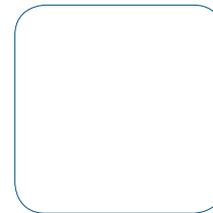
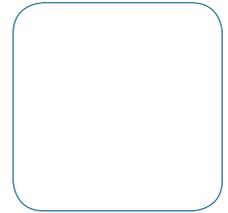
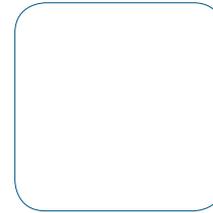
- painful tingling in arms or legs;
- pain in the lower back;
- painful cramps due to spasticity.

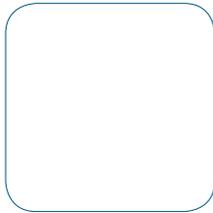
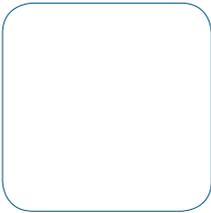
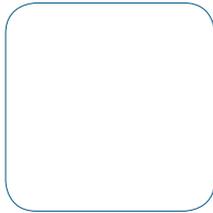
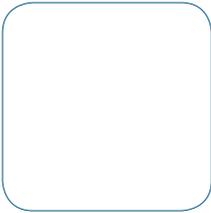
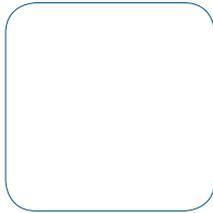
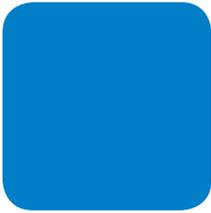
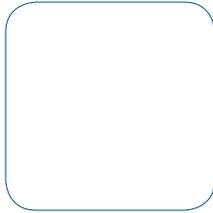
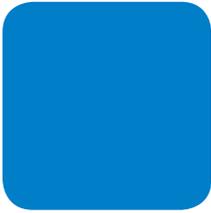
Painful tingling in arms or legs

This is usually a persistent burning, tingling, achy or throbbing sensation. The pain often gets worse when it gets dark and when the weather changes.

What to do?

- Unlike acute pain, this chronic pain responds to heat. A lukewarm bath, icepacks or “cool packs” from the pharmacy are often very effective.
- Compression stockings sometimes change the painful tingling into a not-unpleasant sensation of pressure and support.
- Psychological counselling focused on learning how to deal with pain.
- You can take pain medication if necessary.





Pain in the lower back

Pain in the lower back develops when the back muscles become too weak to keep the spine in position as a result of MS. Other muscles try to straighten out the spine, which results in pain and stiffness. Eventually it may become more and more difficult to find a pain-free position.

What to do?

- Don't wait until you experience symptoms; start focusing on proper posture right away. Your doctor or physiotherapist can help you with this.
- If you start experiencing symptoms despite these efforts, physiotherapy is the recommended route.
- You can take pain medication if necessary.

Painful cramps due to spasticity

Spasticity-related pain is usually worse at night. The mantra

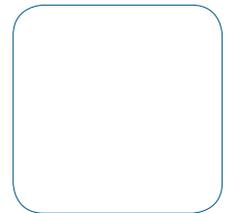
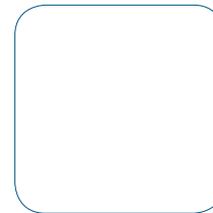
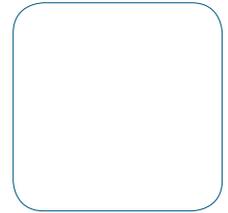
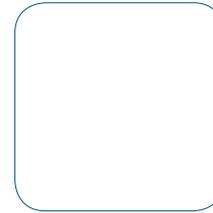
for this type of pain is: relax, no matter how hard it seems. When you are tense you feel more pain, which makes you more uptight - literally.

What to do?

- Physical and mental relaxation; yoga, a massage, a bath, read a book.
- Massage of the affected area to make the muscle warm and relaxed.
- Contact with other MS patients for a listening ear and mutual mental support.

Vision problems

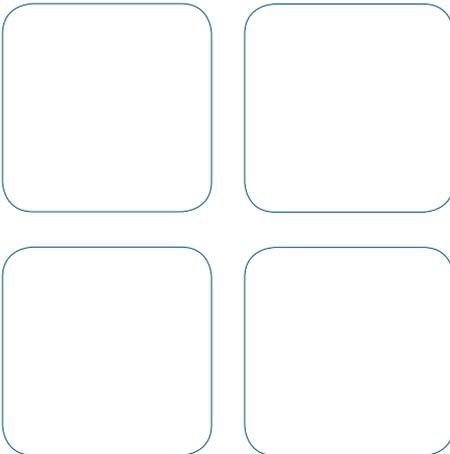
Vision problems are often one of the first symptoms of MS. They usually disappear after a few weeks, but not always. Vision problems in MS are caused by inflammation of the optical nerve. Whether one eye or both eyes will be affected depends on





the location of the inflammation. The symptoms can vary widely: blurred vision, double vision, loss of depth perception, seeing dark spots, loss of ability to see certain colours. This may be accompanied by pain and itching. Drooping eyelids sometimes occur as well. A particular symptom is “nystagmus”: quick involuntary movements of the eye.

Blurred vision may come back during periods of stress, fatigue or fever. This does not necessarily mean you’re having a relapse.



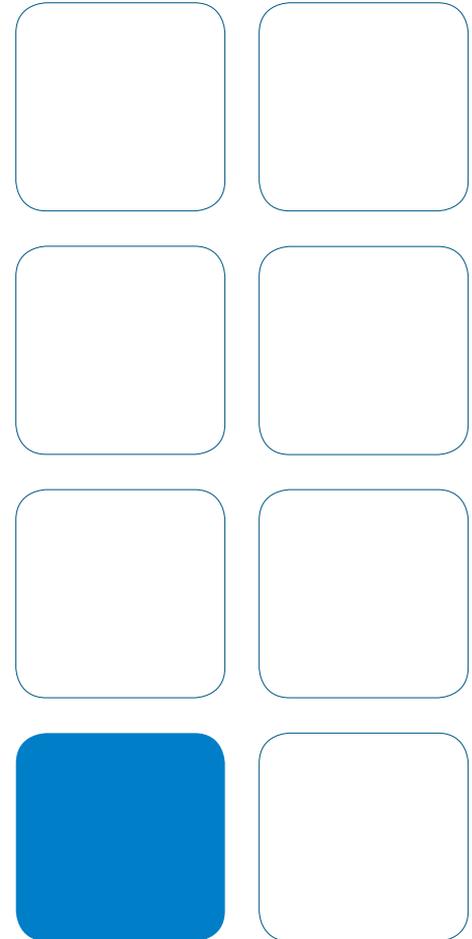
What to do?

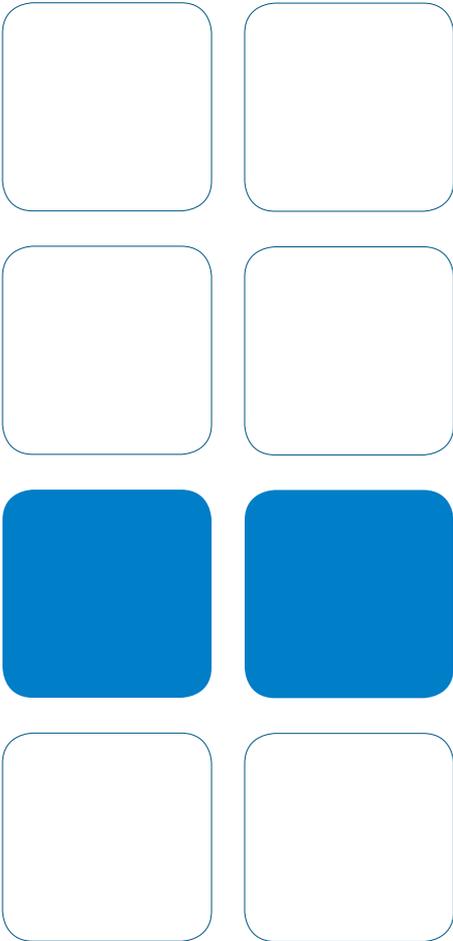
- Report the symptoms to your doctor and ask for a referral to an ophthalmologist.
- If you are seeing double, you can cover one eye with an eyepatch while reading or watching television. Don’t do this too often, or the brain will not be stimulated to compensate for double vision.

- If you are experiencing nystagmus, placing a ruler underneath the lines makes reading easier. In severe cases it sometimes helps to cover one eye with a patch.
- Anti-inflammatory drugs may help in rare cases.

2.8 Bladder problems

Bladder problems are very common - even in people who do not have MS. About three-fourths of all MS patients will experience bladder problems at some point. This usually does not happen for quite some time. The bladder problems that eventually occur are due to the fact that the bladder is “controlled” by three different parts of the nervous system that are far away from each other. These areas are connected by long nerve pathways. These pathways are vulnerable in MS. When these connecting pathways are affected, it can result in disruption of the signals to and from the bladder.





This can lead to a variety of symptoms, such as:

- Excessive urge (urge incontinence), urine loss during physical exertion (stress incontinence), frequent urination of small amounts, inability to hold in urine.
- Urinating as soon as you feel the urge.
- Difficulty starting the urination.
- Difficulty emptying the bladder completely (retention problems). This increases the risk of bladder infections.

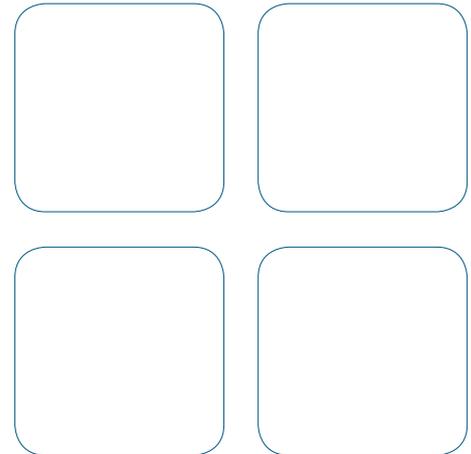
What to do?

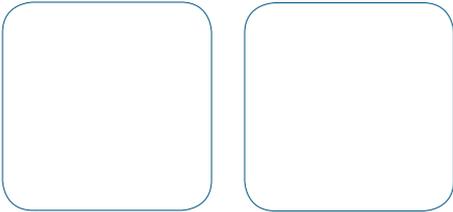
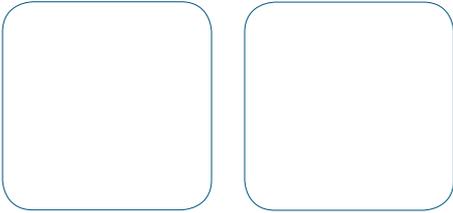
- Urge and stress incontinence: treatment with medications that inhibit the excessive urge. Nightly urine production can also be inhibited with certain medications, antidiuretic hormones. Incontinence products may also provide a greater sense of security.
- Exercises for the pelvic floor muscles prescribed by the physiotherapist.

- With retention problems, the urine that remains in the bladder increases the risk of bladder infections. For this reason it may be necessary to use a catheter to empty the bladder on a regular basis. Not only is a bladder infection unpleasant in and of itself, it also activates the immune system. This can have the opposite effect of provoking an MS attack.

2.9 Intestinal problems

Intestinal problems may occur as well, although they are less common than bladder problems. There is less information about these problems, which means the treatment options are more limited as well. Control of the intestines – by the voluntary and the involuntary nervous system (see section 2.1 in booklet 1) – may become disrupted, not just as a result of nerves affected by the disease, but sometimes also as a result of medications, lack of physical activity and eating habits.





Possible symptoms mainly consist of gas, diarrhoea, constipation or difficulty holding in bowel movements. Severe constipation may be accompanied by episodes of diarrhoea.

What to do?

- A high fibre diet and plenty of fluids (at least two litres a day) are important for regular bowel movements. Eat plenty of raw fibres, fruit, green vegetables, dried prunes. A dietician can give you advice if necessary.
- If the problem cannot be controlled with diet, you can discuss the use of a laxative with your doctor.
- Severe constipation may also be accompanied by episodes of diarrhoea. This has to do with the fermentation of faeces that remain in the bowels too long. Surprisingly, the treatment for this type of diarrhoea is more laxatives.

2.10 Cognitive symptoms

MS can affect certain brain functions, the “cognitive functions”. This includes memory, the ability to concentrate and the ability to think. These functions may diminish somewhat over time, making it more difficult to process and retain information, for example. Planning and keeping track of things may become more difficult as well.

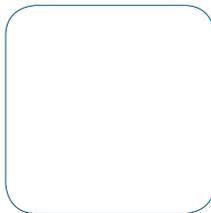
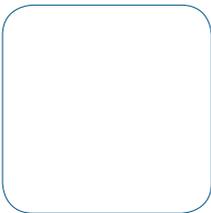
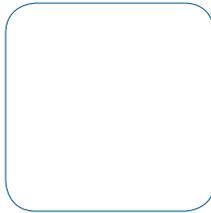
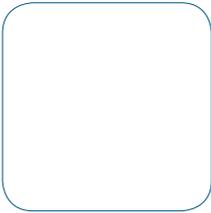
However, stress, fatigue and discouragement can also affect concentration and memory; this applies to people without MS as well. This can lead to a vicious circle: you become less interested and involved in your environment, so you notice less of what goes on around you, which further diminishes your interest and involvement.

(See also the section on mood changes.)

For more information on cognitive function see booklet 5.

The terms “**intelligence**” and “**cognition**” are often used interchangeably, but they mean different things. In a nutshell, cognition is a set of skills, like memory, concentration, reasoning ability, language use, and orientation.

Intelligence is the ability to use your knowledge and experience to solve problems, like a math problem or a crossword puzzle. MS does not affect your intelligence.



- MS does not lead to dementia.
- Deterioration of cognitive functions can be reduced with medications, among other things.

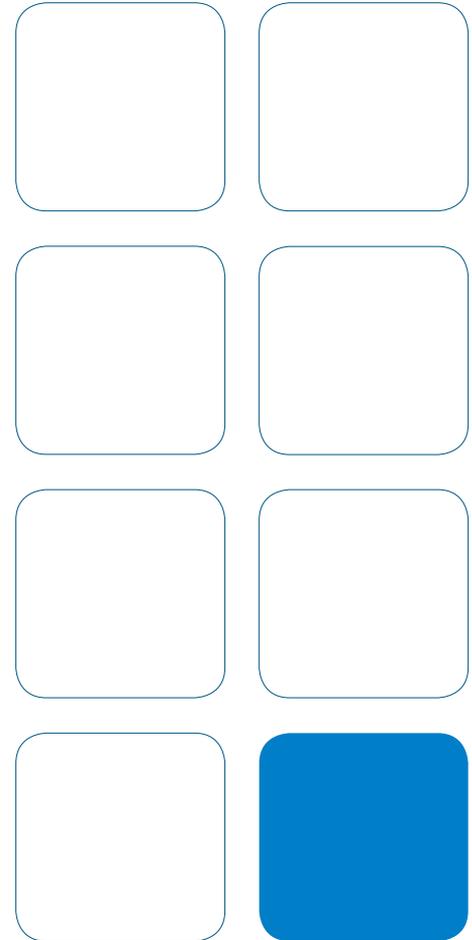
What to do?

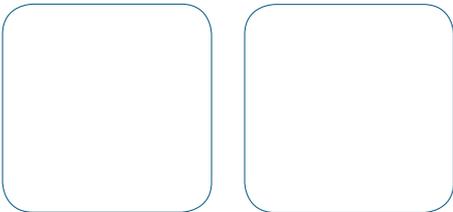
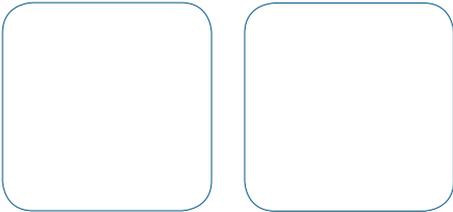
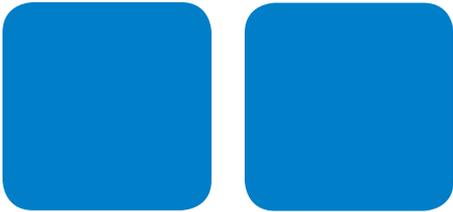
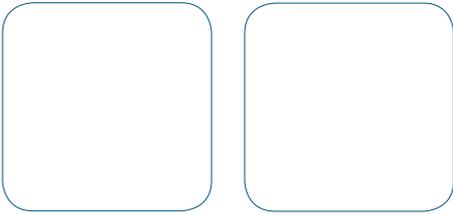
- Try to identify the source of the symptoms. They may point to an MS attack or to stress, fatigue or feelings of anger or sadness.
- Specifically make time for things that interest you and energise you. Forgetfulness or poor execution of a task may also be due to lack of motivation and interest.
- Talk about it with your partner and people around you.
- Discuss it with your doctor.
- Discipline yourself to use a day planner or make lists.
- Memory training can sometimes be helpful.

2.11 Mood changes

MS can have far-reaching effects on your daily life. The disease also creates uncertainty because its course is so unpredictable. Dealing with that is not an easy task. You may feel anger, fear, frustration and uncertainty about daily life and the uncertain future.

This is why feelings of sadness are more common in people with MS. If these feelings overshadow the whole day and last longer than two weeks, you may be dealing with depression. This is also relatively common in MS. Depression is like a heavy weight. This is complicated by the fact that some symptoms, like fatigue, insomnia and forgetfulness, mimic those of MS. This makes it even harder to get a grip on these symptoms, so it is important to seek professional help as soon as possible. There are all kinds of treatment options.





What to do?

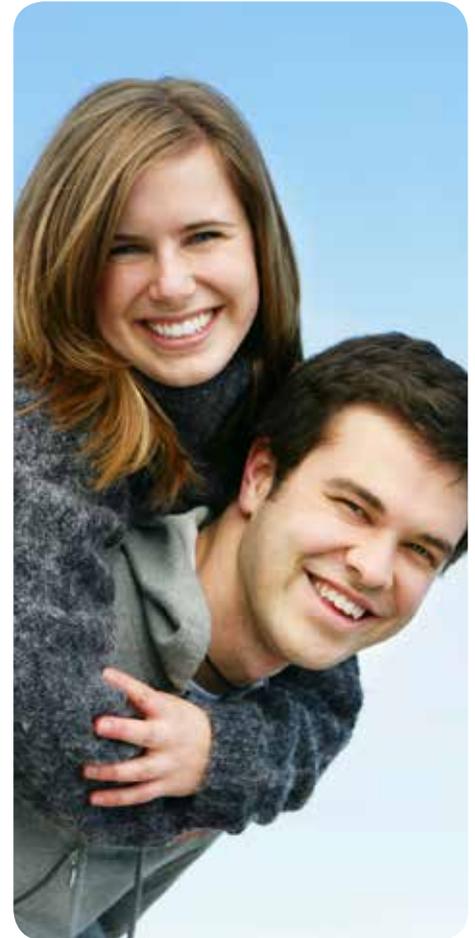
- Share your worries and feelings with people you trust.
- Connect with others who have MS for support and advice.
- Stop fretting about practical problems by asking for help.
- Talk to your general practitioner about options for psychological counselling.
- Try living in the here and now rather than running ahead of yourself to the (distant) future. There are special “Mindfulness” training courses for this.
- Continue to eat a healthy, varied diet. You need all the energy you can get.

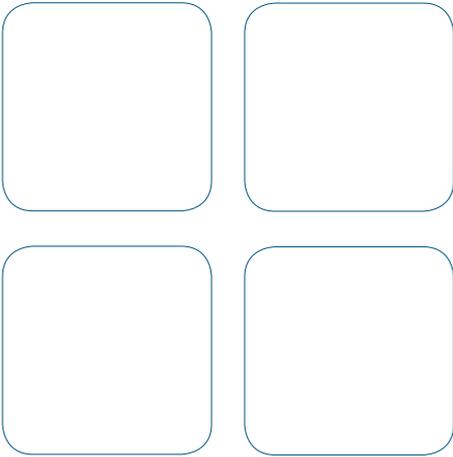
3 Tips for daily life

MS gradually requires more and more adjustments over time. Your relationship with your partner will undergo changes as well. There are all kinds of practical problems that need to be solved. Activities like intimacy, exercise, vacations and sometimes even work can often continue, but some modifications may be necessary. The tips in this chapter will help you navigate different practical challenges you may face in your daily life.

3.1 Sexuality

MS and sexuality are certainly not mutually exclusive, although the disease may affect the way you experience sex over time. You and your partner may have to adjust your expectations. After all, MS does not exactly promote sexual desire. Fatigue can be a factor, but reduced sensitivity of the erogenous zones can play



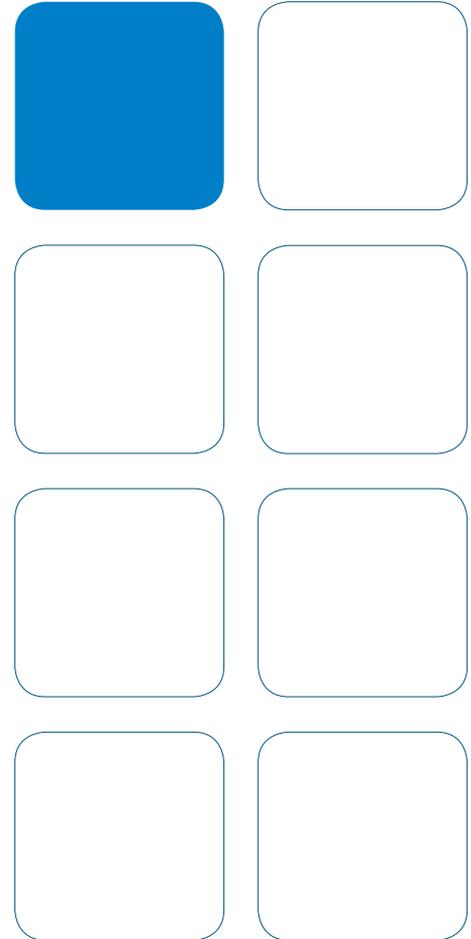


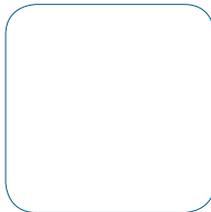
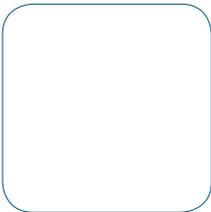
a part as well. Men with MS may find it more difficult over time to get an erection, while vaginal dryness may be a problem for women. Issues like muscle weakness, spasms or unexpected urine leakage may cause feelings of uncertainty. The increasing dependency of one of the partners can also change the couple's relationship, including their sex life.

This may lead to confusion, disappointment and other emotions. Try to talk with each other about desire and limitations, questions and uncertainties. This will give both of you the opportunity to experience intimacy and sexuality in a different way. Intimacy – even if it takes a different form – can be a source of strength and self-confidence. This sense of security can make a big difference in how you feel and what you can do.

A few tips

- Pick a time of day when you have energy for physical intimacy. Make sure you are rested, by taking a relaxing bath for example.
- Set the mood with romantic elements, like perfume, soft music, candle light.
- Let your partner know where you are experiencing pain, or where the skin is numb or hypersensitive.
- Explore together what is enjoyable and which position is the most comfortable; keep pillows within reach for support.
- Keep sex aids and toys on hand for fun and pleasure.
- Ask your general practitioner for a referral to a sex therapist if necessary.





3.2 Pregnancy

MS does not affect fertility. Women with MS can still have children and breastfeed. However, it is wise to give careful thought to the physical and mental demands that are part of having children. There will be periods when you are tired or are not feeling well; it is important that you will have someone you can rely on who can help you. Your personal experiences and circumstances can help you weigh all these factors. It is definitely possible to experience the joy of having a family, especially if you can rely on the help of your partner and family.

Fewer MS symptoms during pregnancy

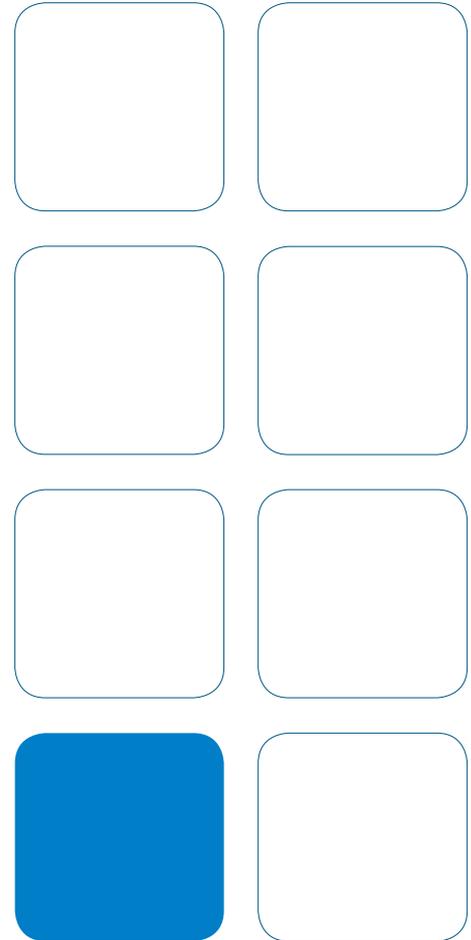
Research has shown that on average, women experience fewer MS symptoms during pregnancy. There are fewer relapses during pregnancy, although the risk of a relapse is slightly higher during the first three months after delivery.

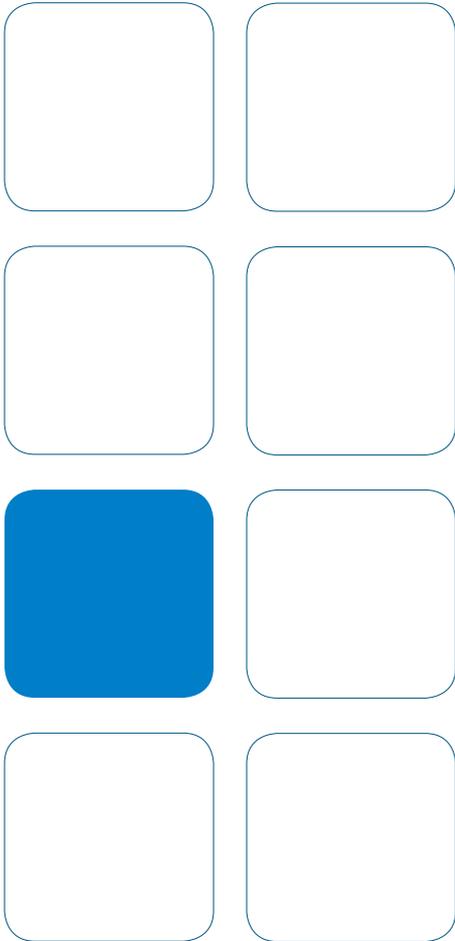
Heredity

Children of a parent with MS have a slightly higher risk of MS, but the risk is still very small. The risk of MS is normally 0.1% (1 in 1,000 people will get it). A child with a parent with MS has a risk of 2-4% (2-4 in 100). Most people consider this a small risk and don't let it stop them.

If you want to have children, talk to your doctor or nurse before you get pregnant. They also know if your medication will have to be adjusted in that case.

Booklet 4: MS, sexuality and parenthood, includes a detailed discussion of this subject.





3.3 Exercise and physical activity

Exercise is always smart, whether you have a chronic disease or not. It's good for your physical condition, your mood, and clarity of thought. Another benefit is companionship and the possibility of making new friends. This gives new energy and confidence.

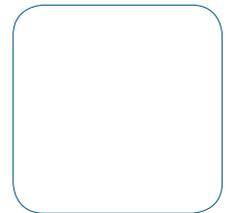
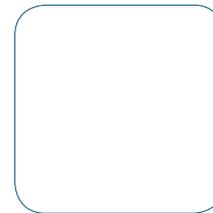
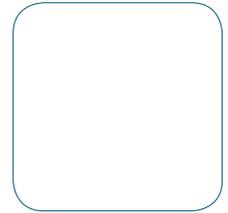
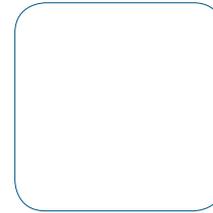
MS and exercise are not mutually exclusive.

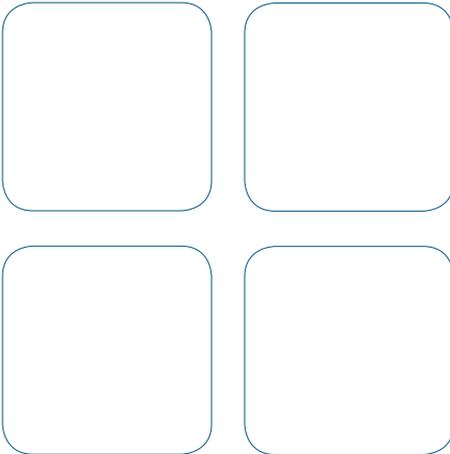
There are many ways to stay active. You can pick a form of exercise you enjoy and which provides a suitable level of intensity. Examples are swimming, walking, Nordic Walking and riding your bike. These are activities that allow you to carry on conversations and adjust the level of intensity. Start with short periods of activity and slowly build up your endurance, preferably in an environment that is not too hot. You might enjoy a lukewarm bath before and after the activity. If you were already very physically active, you can talk to your treating physician or

physiotherapist to determine how you can continue with these activities.

In the long run MS limits your ability to engage in physical activity, but even then you still have a lot of options. Many types of exercise or even (team) sports can be modified to your level of ability, allowing you to enjoy and find satisfaction in the activity even if you have to take things a little slower. If it comes to that, there are clubs specifically for people with a disability.

No matter what you do: do not push yourself to exhaustion, but listen to your body so you can properly recover.





3.4 Vacation

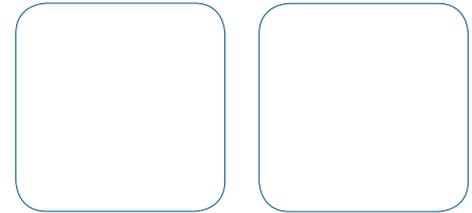
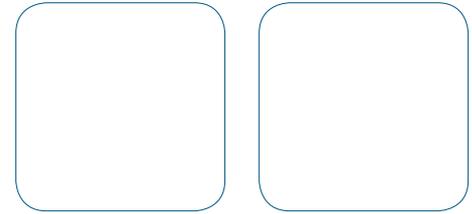
Above all, the point of vacation is to relax and enjoy yourself in a different environment. As long as you don't overextend yourself there is no reason why you can't plan your own vacation. Group travel can be a good alternative as well. The internet offers a large variety of active vacations, art trips and trips just for fun. There are also travel agencies that specialise in travel packages – with just as much variety – for people with more severe functional limitations. Modified vacation accommodations are available as well. An additional benefit of group travel is that you get to connect with people who understand what you're going through (or even have the same condition as you) in a relaxed environment. You can also contact a patient association for help with practical issues. They can tell you, for example, how to keep “cool packs” cold, how to store them when it's hot, and how to get a good night's rest in strange beds.

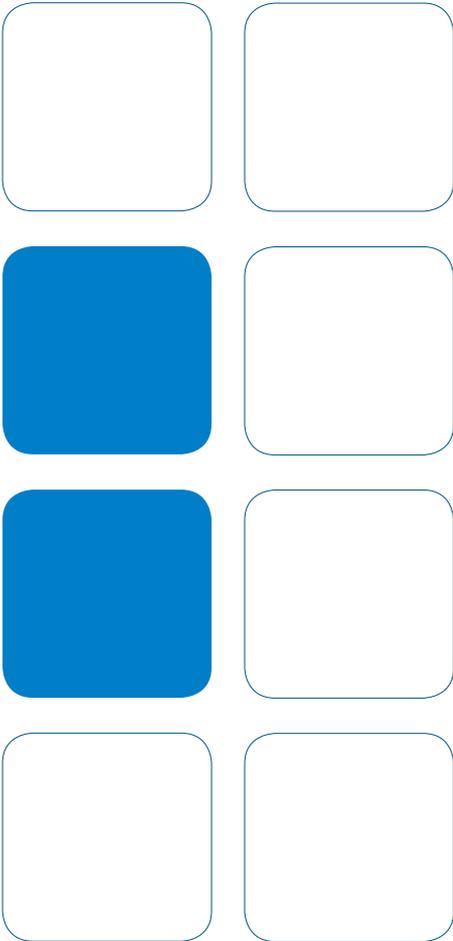
3.5 Tips for every day

Do not let MS take over your life

This is easier said than done, especially at first. Finding out that you have MS is an emotional event. Accepting it and learning how to deal with it takes time. The diagnosis is a shock for your partner and other loved ones as well, which has to be processed.

Emotional adjustment to the new situation is not that easy. It requires a lot of effort and energy. It may seem like it will never happen, but there will come a time when you have come to terms with the disease and you are able to focus on other things again and take up old – or new – interests. You are not your disease; life is more than MS, fortunately.





Make feasible plans

It's frustrating when you're not able to do what you had planned. To prevent too many "disappointments" like this, it is important to set feasible goals. This results in many small moments of satisfaction. This might mean that it would be better to work less or change jobs. This is better than wanting something that is impossible.

Be clear

MS really means: rediscovering your body. Your body has changed (and will continue to change); it takes time to find out what you can do and what you may no longer be able to do. Knowing this creates clarity, which in turn improves your self-confidence. The people who are close to you have to go through this learning process as well. You know best what you can do and what is comfortable for you. You can help yourself and the people around you by communicating these things as clearly as possible. Clear communication enables others to give you what you need.

Stay involved in social activities

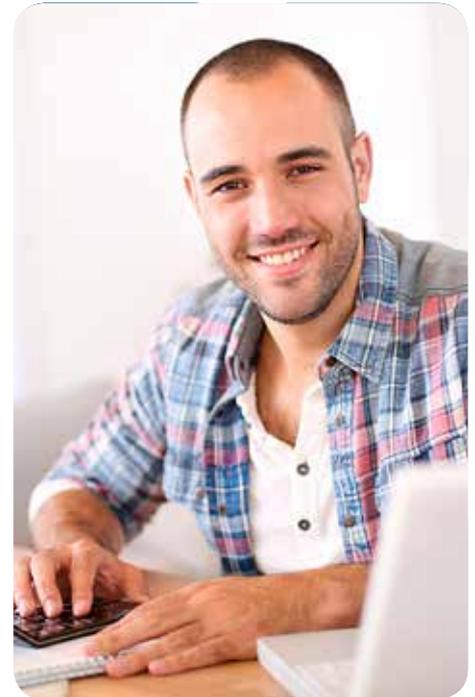
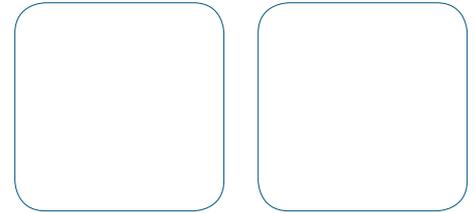
This means: finding manageable tasks and activities that are outside of your immediate sphere, preferably somewhere other than at home.

Living in the moment

When the MS is acting up, there may be days when things don't go as planned. This can't always be avoided, but it's not a reason to not make plans. It's a reason to try and be flexible and adjust your plans to make them feasible.

Humour puts things in perspective

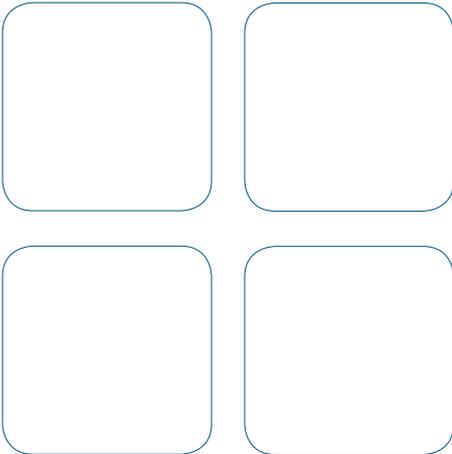
The trick is not to focus on what is no longer possible, but on what is still possible. Physical concerns make it difficult to relax, which in turn affects your mental wellbeing.





Physical activity

It is well known that physical activity improves your mood and helps you think more clearly. Another benefit for MS patients is that it decreases bladder and intestinal problems. Make sure to modify your activities based on what you can handle, though. Start with short periods of activity and slowly build up your endurance, preferably in an environment that is not too hot. You might enjoy a lukewarm bath before and after the activity.



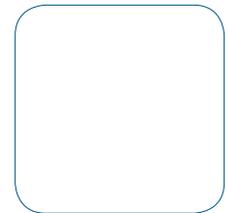
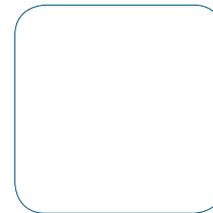
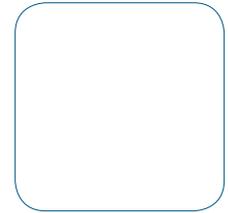
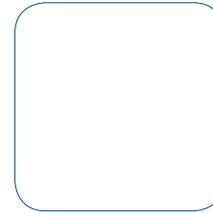
Choose your own doctor

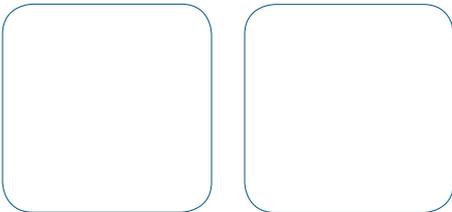
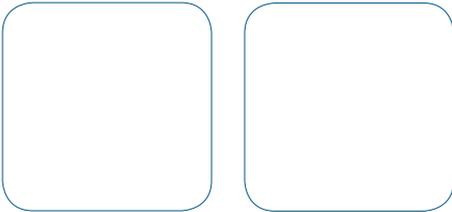
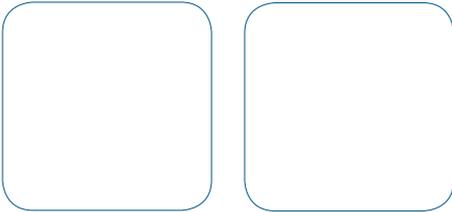
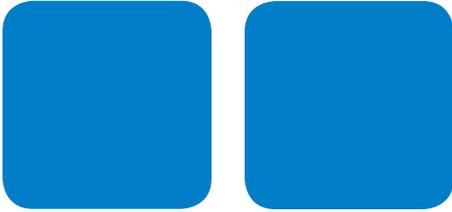
If you think that your neurologist and/or general practitioner are not really listening to your symptoms and concerns, talk to your doctor about whether it might be better to switch to another doctor. You and your doctor don't always have to agree, but you do need to have someone you can rely on, who understands you and whom you can talk to.

Relaxation

Relaxation: everyone needs it to function well, but it can be a difficult task for people with physical and/or mental problems. Symptoms or limitations constantly demand your attention. Help is available if it's hard for you to relax.

Find out if meditation, yoga, Mindfulness or Tai Chi might help you to focus more on the here and now and become more relaxed. Sometimes (temporary) treatment with tranquilizers may help break the cycle of tension and insomnia.





3.6 Tips for the partner

Set limits

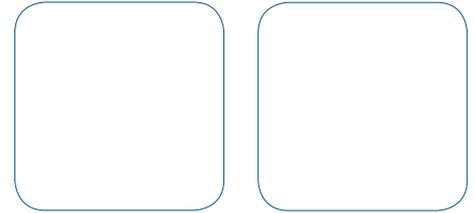
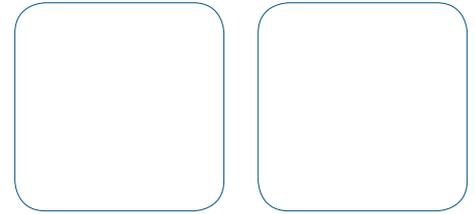
MS also means: discovering new limitations, and setting new limits. This applies to the person with MS, but also to you, the partner. Of course you want to help your loved one the best you can. But you have needs and limitations as well. It is good to verbalise the expectations each of you has about your help.

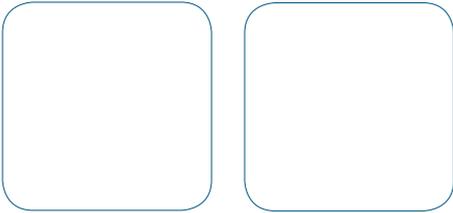
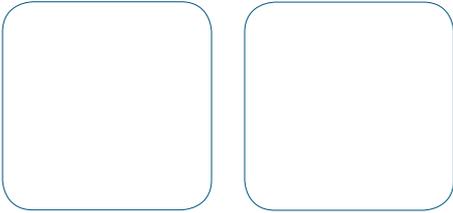
- If you discover at some point that you are reaching a limit of your own, talk about it. Talking about it may help you find creative solutions.
- Decide together what you will and will not do. This might take the form of a division of labour, where you take care of the heavier physical tasks and leave the lighter tasks to your partner.

- Decide together when you are available and when you are not. You need time for yourself as well, without having to feel uncomfortable or even guilty.
- Talk about how you are going to take care of any remaining needs.

Take each other seriously

“And, how are we feeling today?” This classic line from “the nurse” is symbolic for (possibly unintentional) behaviour that can make patients feel patronised or like they are not taken seriously. Humour and perspective are important, but there should be no doubt that you are taking each other seriously.





In conclusion

We hope that this booklet has helped you to continue your daily life and activities the best you can despite MS and the resulting limitations. You may have discovered new ways to integrate MS into your life in your own way.

Booklet 3, “MS and treatment options”, talks about the different types of treatment and medications.

Useful addresses

Stichting MS Research (MS Research Foundation)

Postbus 200

2250 AE Voorschoten

t +31 71 560 0500

e info@msresearch.nl

Nationaal MS Fonds (National MS Fund)

Mathenesserlaan 378

3023 HB Rotterdam

t +31 10 591 9839

e info@nationaalmsfonds.nl

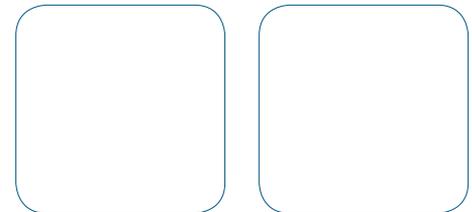
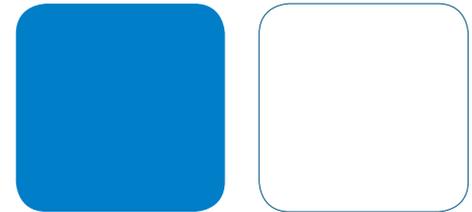
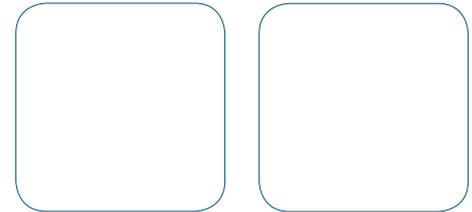
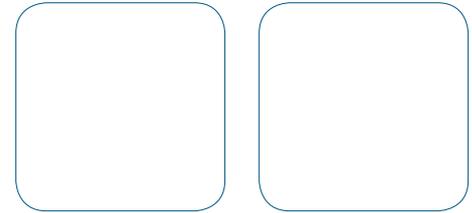
Multiple Sclerose Vereniging Nederland (MSVN, Dutch MS Society)

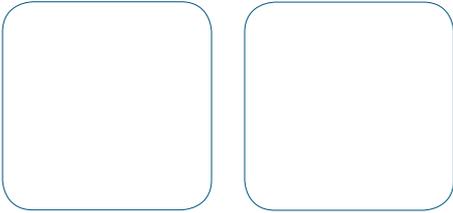
De Corridor 5c

3621 ZA Breukelen

t +31 88 374 8585

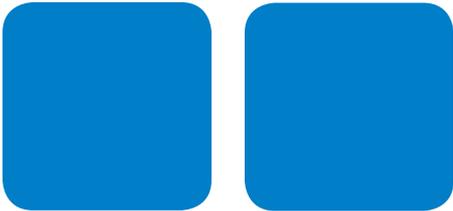
e info@msvereniging.nl



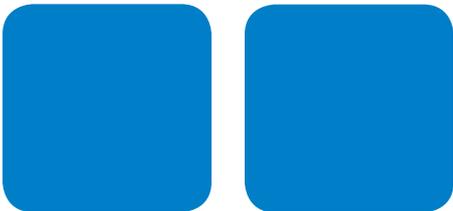
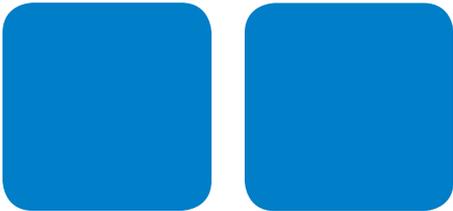


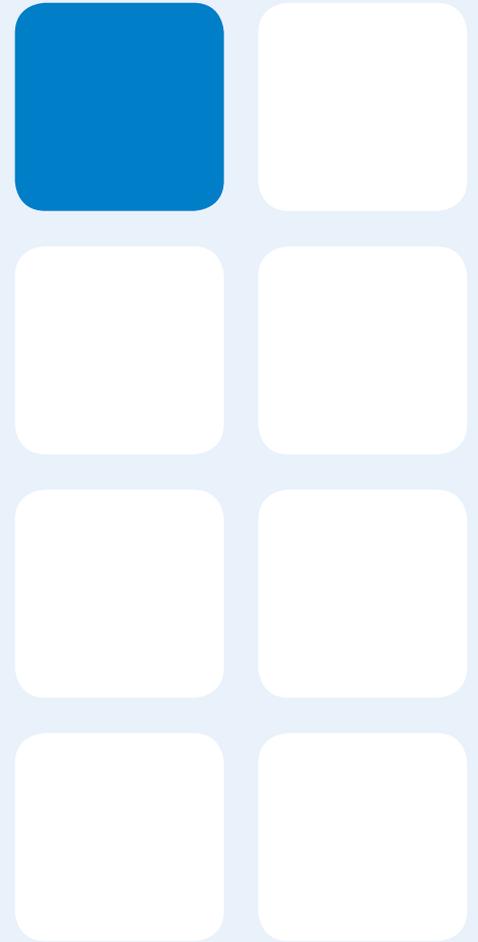
Would you like to know more?

You can find more information about MS at
www.toekomstmetms.nl (in Dutch)



For information about medicines you can consult
www.ema.europa.eu







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