



Living Life with MS

There are a number of ways you can adapt to living with MS. Through talking with others, making small changes to your daily activities, and recognizing steps you can take to ease symptoms, you can work towards maintaining your lifestyle.

This booklet gives you advice on how to talk to friends and family about your MS, changes you can make to your day-to-day activities, and offers guidance on controlling some common MS symptoms.

Communicating about MS

How do I talk about MS to my friends and family?

Talking about MS to friends or family can be a daunting task, however, communicating your feelings is an important step in living with MS.

Through communication, others can understand how you are feeling and how they can support you.¹

Consider these tips for talking to your friends and family:

- Don't feel you need to tell everyone.
- Only talk about MS when you are comfortable in doing so.
- Plan what you are going to say.
- Work out what ways of talking work best for you. You may find shorter conversations easier than sharing everything at once.
- Let others know how they can help you.
- Talk to others in your situation.

THINGS TO CONSIDER

Take your time – discuss your thoughts and feelings when you feel ready. There is no single 'correct' way to talk about your MS, find out what works best for you.



What if MS is affecting my relationships?

MS can put strain on relationships, impacting how you feel about yourself and how you relate to those close to you.¹



Let others know that you understand they may be anxious about your condition and are trying to make sense of your MS. Try to work through these feelings together.



Consider that those close to you may need time out for themselves.



You may need to ask for help from different people.



If MS is affecting your relationships, consider talking with a counsellor.

“A relationship is about being part of a team; I couldn’t work without him and he wouldn’t work without me. We faced my diagnosis together. I would argue his snoring is more of an inconvenience to our relationship!”

- Ellen M

What if I'm a parent with MS?

Looking after children can be stressful and tiring for anyone. Living with MS and raising children can create new challenges that you wouldn't otherwise face. There is no shame in asking for help to maintain and enhance family life as you live with MS.

If you have children consider the following tips:



Take time to talk to them about your MS and give them straightforward descriptions using age-appropriate language.



Let them know that you understand they have feelings and anxieties about your MS and work through these together.



Reassure them that, despite your diagnosis, you are still their parent and they can have trust and confidence in you.



Let them know that at times any one of you may be feeling upset, but that it's normal and these feelings are not due to them.



Different children will want to learn about MS in different ways – some might prefer to read a book, whereas others might want to ask questions or watch a video.



Keep them involved with everyday things, such as helping out around the house or walking the dog.



Talk to other people about helping out with your children. Also talk to family members about how they can help your children understand and cope.

Day-to-day living

Daily activities – what can I do?

If you have just been diagnosed with MS you may not need to make any immediate changes to your daily activities, but discuss with your MS team based on how you are feeling. If certain activities are proving a little more difficult, there are some simple changes that can make things a bit easier.



Shopping

- Shop with a friend or carer and at a time of day when you have more energy.
- Consider using home delivery services and ordering your shopping online.



Cooking and housework

- Consider sitting down to prepare meals and using electronic aids such as food processors.
- If you have children, encourage them to put away their own toys and involve them in daily tasks.
- Try spreading tasks over a period of time, rather than trying to do everything at once.



Personal care

- Consider sitting down while washing or showering and using an electric toothbrush.
- Consider spreading personal care tasks out throughout the day or week so your routine doesn't become exhausting.



Going out

- Keep going out and enjoying yourself.
- Plan ahead. For example, before going out, call and ask about the closest place to park.
- When going to a restaurant, you may want to ask for a table that is easily accessible and close to the entrance or bathroom.



Exercise

- A regular but simple exercise routine that suits your lifestyle can be beneficial in improving your mobility and common symptoms of MS.²
- Listen to your body and how it responds to your activity level. With MS, every day can be a bit different from the next, so don't worry if you have to adjust your exercise plans.
- If you already exercise, you may need to adjust your routine to suit how you are feeling.

Do I need to make any adjustments around the house?

There are a number of ways you can make changes in your house to make accessibility easier and generally improve your environment if needed:



You could start using aids such as ramps or walking aids, and install handrails on the stairs, bath and shower



Look out for trip hazards



Make sure floors are not slippery, and put non-slip pads underneath rugs



Consider replacing furnishings with ones that are easier to move or keep clean



Consider speaking to an occupational therapist, who will be able to advise on changes that could work for you



See these adjustments as a positive step in helping you continue with your day-to-day life

Will MS affect my work?

You can keep working as long as you feel well enough. Work can help with your self-esteem and well-being.³

You are not obliged to disclose your diagnosis to your employer unless a medical exam is a condition for employment (for example, if you are a pilot or firefighter). However, doing so may allow them to make changes to suit your needs.

Talk to an occupational therapist or a legal or job counsellor about when and who to disclose your diagnosis to at work.

Useful tips for work

Some small adjustments to your workspace could help with any difficulties you may face.



If typing is difficult, consider using voice-activated programmes and dictation software



Try a keyboard with larger keys



Use a trackball instead of a mouse



Use a screen magnifier or a larger monitor to make things easier to see



Working in an office at a comfortable temperature may help



Make lists and use diaries, calendars or reminder apps



Rest at lunch time



Sit in a chair with arm rests and good back support, and make sure that it is at the right height



Arrange your desk so that frequently used things are within easy reach



Make sure that you have good lighting over your work area



See if you can have a parking space close to the entrance

Symptom control

Fatigue

MS-related fatigue is associated with an overwhelming sense of tiredness that comes on very quickly and is out of proportion to any activities undertaken. Fatigue is common in people with MS and can cause frustration as it is not visible and can therefore be difficult for others to understand.

You should speak to your MS team if you are experiencing fatigue. There are also some actions you can take that might help:⁴



Getting good quality sleep



Managing your temperature – some people find that extremes of temperature can bring on fatigue



Addressing low mood – exercises such as mindfulness or talking issues through with others may help



Managing stress



Eating a healthy, well-balanced diet



Regular exercise



Keeping a fatigue log to help you identify any patterns in your fatigue



Taking time to relax

Sleep changes

People with MS tend to suffer more with poor sleep. Reasons behind poor sleep can be linked to the symptoms you may be experiencing. Many of these symptoms are treatable, and your MS team may be able to help you in managing these.

There are also some tips you can follow to improve your sleep quality:⁵



Try to be physically active during the day, but allow time to wind down before bedtime.



Avoid getting overtired, this may make it more difficult to get to sleep.



Get some sunlight in the day but avoid bright lights in the evening. Consider wearing an eye mask or using blackout curtains.



Avoid caffeinated drinks or other stimulants, especially within four hours before going to bed.



Try and stick to a sleep routine.



Try to avoid activities such as using mobile devices or watching TV in the bedroom. Prioritize the bed as a place for sleeping.



Try relaxation activities such as meditation, stretching, yoga or listening to music.



Keep the bedroom temperature comfortably cool.

Bladder and bowel control

Bladder and bowel problems are common in people with MS. The good news is that there are lots of things you can do to help yourself:



Stay hydrated and adjust the amount of water you drink to suit your environment, symptoms and activity levels.



Don't have too many caffeine containing drinks, such as coffee, tea, cola and energy drinks.



Eat plenty of fibre-rich foods such as fruit and vegetables.



Keep as active as you can – some exercises can help with bladder control.



If you are out, become familiar with the location of the nearest toilet.

THINGS TO CONSIDER

Discuss any issues about your bowel and bladder with your doctor or MS nurse – they may have tips for you, can review your current medications, or offer you medications specifically for the problems.



Changes to thinking and memory

You may experience some changes to your thinking and memory. Changes might include difficulty finding words, shorter attention span or difficulty concentrating, reduced problem-solving ability, forgetfulness, or poor decision making. Lifestyle modifications may help manage some of these symptoms.⁵

It is important that you speak with your MS team if you or your family notice any changes to your memory or thinking to help manage these changes.

There are some things you can try to help keep your mind fit:



Organize yourself by using a calendar or diary to schedule activities, important appointments and treatment.



Eat healthily and incorporate exercise into your daily routine.



Minimize fatigue by staying active but ensuring you get plenty of rest.



Maintain a social network of family and friends and keep them informed of any changes that are occurring.



Try mindfulness as a technique to help you improve your mental wellbeing.

Resources and support

Who are the experts that can support me?

Different experts can provide you with advice on changes you can make to enhance your daily life. You may not have access to all of these experts, but this page can act as a guide to who can help you and how.

You can add in their contact details in the spaces provided to keep them all in one handy place:

MS nurse

Advice on any issues or concerns

Doctor

Advice on any issues or concerns

Local MS society

Advice and support on living with MS

Local MS support group

Direct support for living with MS

Local/national MS helpline

Immediate advice on issues or concerns

Exercise physiologist or physiotherapist

Advice on exercise

Dietitian/nutritionist

Advice on diet and healthy lifestyle

Occupational therapist

Advice on practical tasks

Bladder and bowel specialist

Advice and support for questions regarding bladder and bowel difficulties

References

1. Canoe. Talking to Friends and Family about MS. Available at: <http://chealth.canoe.com/healthfeature/gethealthfeature/talking-to-friends-and-family-about-ms>. Accessed May 2020.
2. Briken S, et al. Effects of exercise on fitness and cognition in progressive MS: a randomized, controlled pilot trial. *Mult Scler J*. 2014;20(3):382–390.
3. Dorstyn DS, et al. Employment and multiple sclerosis: A meta-analytic review of psychological correlates. *J Health Psychol*. 2019;24:38–51.
4. MS Trust. Living with fatigue. Available at: support.mstrust.org.uk/file/Living-with-fatigue-2018.pdf. Accessed July 2019.
5. Rahn K, et al. Cognitive impairment in multiple sclerosis: a forgotten disability remembered. *Cerebrum*. 2012;2012:14.