



Living well with MS as you grow older

A guide for older people with multiple sclerosis (MS) on managing the condition alongside the effects of age.

This information is also useful for younger people with MS who are thinking ahead as well as carers, family members and friends.

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Introduction

About this guide

This guide is for people with multiple sclerosis (MS) aged 65 and older. It will also be useful to people under 65 who are thinking about their future years, as well as friends, family and carers of people with MS.

Here, you can learn about the positive steps you can take to protect your health, wellbeing and independence as you get older.

Each section has tips on ways to actively manage your health and wellbeing. We also list online resources where you can find more information, advice and tools.

We hope this guide supports you in having a positive experience of getting older with MS and reduces any fears about the future.

***‘My MS pushes me to enjoy myself
and my life as much as I can.’***

RANIA FROM TUNISIA, DIAGNOSED IN 2010

Why focus on MS at older age?

Of the 2.8 million people living with MS across the world, about 1 in every 10 is at least 65 years old. Most of these older people with MS have lived with the condition for 20 years or more.

MS symptoms tend to progress over the years. As they get older, people with relapsing remitting MS will have fewer periods where their symptoms come and go. The disease usually becomes secondary progressive MS over time, meaning that symptoms steadily worsen.

As we get older our bodies change, which can bring new challenges for living with MS. We also become more likely to develop additional health conditions.

For these reasons and more, people with MS are increasingly interested in how they can maximise their physical and cognitive abilities, manage their MS well, and get the most out of life as they get older. This is sometimes called 'healthy ageing'.

'The most important thing of all is that, regardless of MS, we can enjoy our lives, with dignity, with quality, and being as happy as we can be.'

LUIS FROM SPAIN, DIAGNOSED IN 1997

Experiences of older people with MS

The good news is that getting older can bring the experience and wisdom to better manage MS.

In a study, many older adults with MS said they had gained confidence in managing their condition and had a better quality of life now than previously. In another study, Canadians with MS in their 80s reported less fatigue and stress than those in their 60s.

However, older people with MS face some increasing challenges. In a survey, people over 65 years old with MS said they faced challenges with things like bathing, dressing and getting around the house or community. Common concerns included:

- being less mobile
- becoming a burden to family and friends
- requiring more care.

'Be proactive in planning your future needs.'

MARIE FROM CANADA,
DIAGNOSED IN 1996



Secrets to living well with MS at older ages

What general approaches help people to live well with MS as they age? Based on a survey, connecting with others, attitude, lifestyle choices and healthcare are all important. We give more detail in the graphic below.

Encouragingly, most themes people found helpful are things we have the power to change. You'll see these themes pop up often in this guide.

Secrets to living well with MS at older ages

Based on a survey of almost 700 people aged 55 or older in Canada



Social Connections

- Friends and family
- Communities and groups
- Caregivers



Attitude & outlook on life

- Positive thinking
- Being determined & persevering
- Accepting limitations



Image Source: Ageing Better



Lifestyle choices & habits

- Healthy diet and exercise
- Managing medicines
- Self-care and rest



Health care

- Being able to get high quality care
- Good relationships with healthcare providers
- Being heard

Additional factors some people find important are:



Spirituality & religion



Independence



Finances

How age, MS and other conditions can affect your health

As you get older, your body and brain health will change. Some of these changes may overlap with your MS symptoms. You might also get symptoms from other health conditions.

In this section, we look at:

Overlapping symptoms of getting older and MS

Common health conditions in older people

How other conditions might affect your MS and treatment options



How our bodies change with age

As we get older, our bodies change in many ways. For example, our muscles become weaker, we may tire more easily, our cognitive abilities (thinking, learning and memory) can decline, bladder control can weaken and vision can change. If you have MS, some of these changes may sound familiar because the condition can affect these aspects of your health too.

This overlap can make it hard to know whether problems you're experiencing are related to your MS, are signs of growing older or both. We show examples of this overlap on the next page.



Image Source: Ageing Better

Overlaps between of the effects of age and MS

	Older Age	MS
Energy levels	Tiring more easily	Fatigue
Movement	Reduced muscle tone, strength, and flexibility, slower movement, an increased risk of falls	Reduced mobility, strength, coordination and balance, an increased risk of falls, speech difficulties
Bladder	Greater urgency and frequency of urination, reduced bladder control, more frequent infections	Greater urgency and frequency of urination, reduced bladder control, more frequent infections
Digestive system	Less appetite, indigestion, constipation	Constipation
Sex	Altered sex drive or enjoyment, vaginal dryness, difficulty keeping an erection	Altered sex drive or enjoyment, vaginal dryness, difficulty keeping an erection
Vision	Poorer near vision, reduced night vision	Blurred or double vision, blind spots, jerky vision
Cognitive function	Slower to process information, reduced attention, reasoning, and memory	Slower to process information, reduced attention, learning, memory, and reasoning
Mental health	Depression	Low self-esteem, depression, anxiety, mood swings
Bones and joints	Weaker bones, stiffer joints	Weaker bones

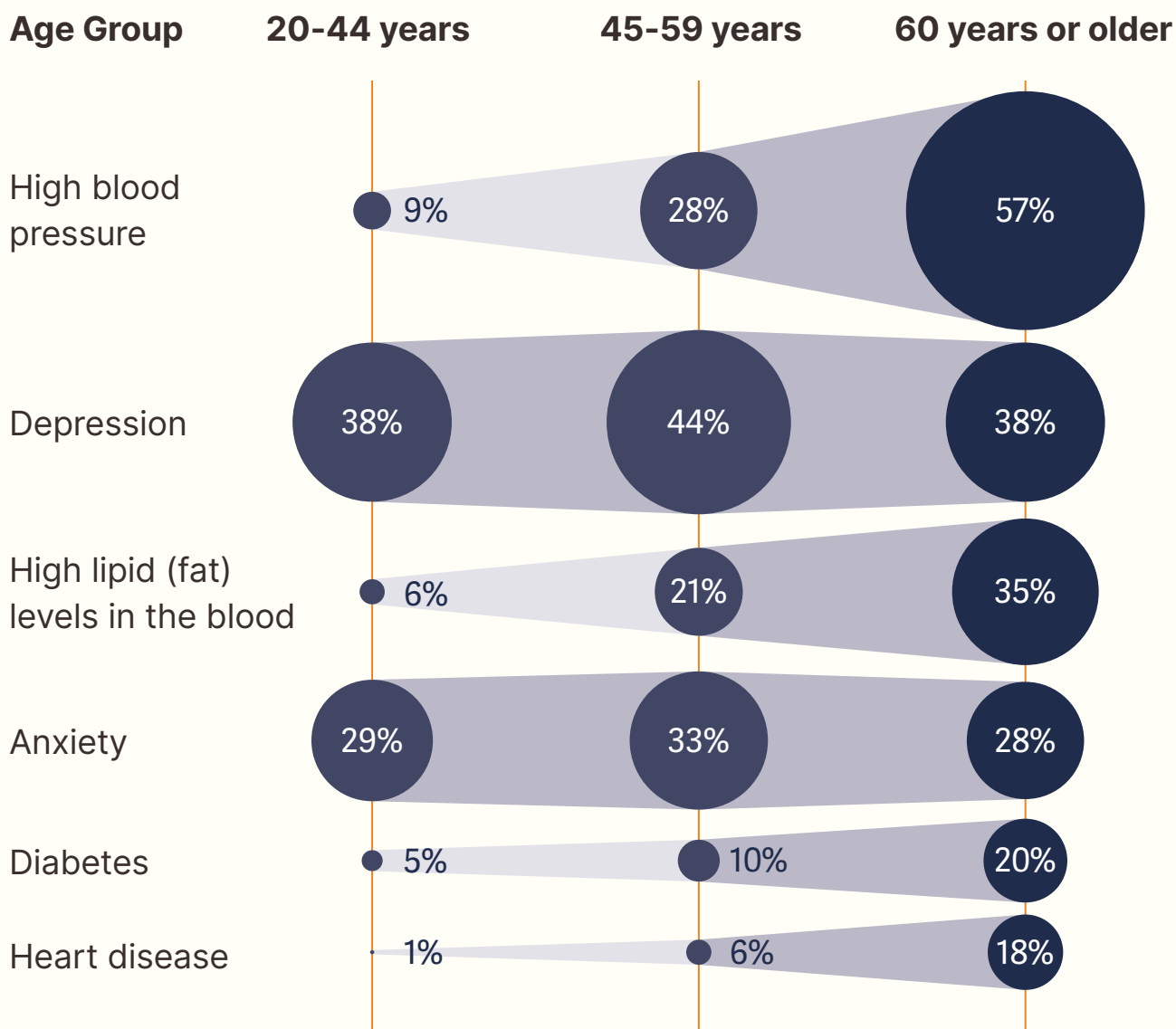
Common health conditions in older adults

As you get older, it becomes increasingly likely that you'll have additional health conditions to your MS. These are sometimes called 'co-morbidities'. People with MS are as likely to get other health conditions as the general population.

About 5–6 in every 10 people over 60 with MS have high blood pressure. More than 2 in every 10 have high levels of lipids (fats such as cholesterol) in the blood, and a similar proportion have a chronic (long-term) lung disease. Some health conditions become more likely as we get older (see graphic).

People with MS are as likely to get other health conditions as the general population.

The percentage of people with MS who have additional health conditions



Graphic reproduced and adapted from 'Why manage comorbidities in people with multiple sclerosis?', with permission from Oxford Health Policy Forum. (<https://www.msbrainhealth.org/healthcare-professionals/why-manage-comorbidities-in-people-with-multiple-sclerosis/>)

Women may also experience problems during and after menopause. These can include bladder problems, changes to sex life, sleep problems and depression. You can learn more about MS and menopause on the MSIF website: www.msif.org/living-with-ms/ms-and-menopause/

If you have another health condition, some of its symptoms may overlap with those of your MS. Your doctor can help to unpick the cause of any new problems you experience. They can also give you advice on how to manage the two conditions together.

While you're experienced at managing your MS, learning to manage new health needs can feel a challenge. In a study, older people with MS said they were more concerned about their other health conditions than their MS.

Managing your other health conditions well is important. This will help to reduce any impact they might have on your MS, general health, cognitive abilities and quality of life.



Can other conditions affect your MS symptoms?

Some health conditions may worsen or add to your MS symptoms, especially if they are not well controlled.

For example, studies suggest:

- People who have a cardiovascular condition at the time they're diagnosed with MS are likely to need a cane to walk sooner than other people with MS.
- People with MS with higher levels of cholesterol (a type of fat) in their blood have more disability and more brain shrinkage than those with lower cholesterol levels.
- People with MS who are depressed or anxious do not always take their MS medicines (disease-modifying therapies) as prescribed and some stop taking them altogether. This is important because if you don't take your medicines as prescribed, your MS might not be controlled properly.

Some health conditions don't affect MS directly. However, they may add further challenges to your everyday life. (For example, some medicines given to reduce cholesterol levels).

Your doctor will be able to explain which treatments are suitable for you, and why.



Image Source: Shutterstock

Can other conditions affect your MS treatment options?

Treatments are available to manage MS (known as disease -modifying therapies) and its symptoms. If you have certain other health conditions, some MS treatments might be less suitable for you. This can be for a variety of reasons, including:

- Certain medical conditions increase the risk that an MS treatment could cause serious side effects. For example, if you have certain cardiovascular problems (such as a recent heart attack or stroke) or are taking beta-blockers or calcium channel blockers for high blood pressure, the MS treatment fingolimod (and some similar medicines) will not be suitable for you.
- Some treatments for MS can affect the way other medications act in your body, and vice versa. This is known as a drug–drug interaction. For example, the MS treatment teriflunomide can affect how quickly your body processes some statins - which are medicines given to reduce cholesterol levels. This might mean the statin dose has to be reduced.

Your doctor will be able to explain which treatments are suitable for you, and why.

Basic steps to managing your health

To live well with MS as you get older, you'll need to stay on top of your overall health and wellbeing.

In this section, we look at four simple steps you can take to manage your health:

Be alert to and report new symptoms to your doctor

Have screening tests for other health conditions

Diligently follow health advice

Keep physically active



Spotting new symptoms

New symptoms could be related to MS or your age. They could also be a sign of a new health problem.

If you have any new symptoms, share them with your doctor. By finding the exact cause, health professionals can give you the right treatment and advice. For example, fatigue caused by a sleep disorder or by thyroid disease might be treated differently to fatigue caused by MS.

Sometimes, multiple things may contribute to your symptoms. You might need to see a few different healthcare professionals before they can work out the causes and determine the best treatments for you.

Your primary care doctor (family physician) is best placed to help with health changes due to age, while your neurologist can help you to manage your MS. They may refer you to other specialists to help you to manage other conditions.

You can find more information on MS symptoms and their management on the MSIF website:

<https://www.msif.org/about-ms/symptoms-of-ms/>

Having screening tests for other conditions

As well as looking after your current health, consider having any screening tests you're offered.

Screening tests check for risks or warning signs of other conditions. Spotting these early means you can take steps to reduce your risk or manage a condition at an earlier stage.

Depending on your country, age and sex, screening available to you might include checks for bowel cancer, diabetes, an enlarged blood vessel in your abdomen (aneurysm), depression, cervical cancer, breast cancer and weak bones (osteoporosis).

'We will all get old, but it may be more of a challenge for those of us living with MS. Don't be too hard on yourself and accept your limitations. Seek out support to help with activities that you can no longer do, or modify the activity. Every day, my husband and I walk and roll around the block with our dog, we have done so for the past two years.'

MARIE FROM CANADA, DIAGNOSED IN 1996

Following health advice

Doctors, nurses and other health professionals can provide regular checks, advice, treatments and support. However, only you are in the position to protect your health and wellbeing every day. So, save some time and energy each day to devote to your health.

It can be hard to stay focussed and follow health advice every day. However, some age-related changes and other health conditions may add to your health problems. Unhealthy habits such as smoking can also worsen MS.

It will pay off if you can find routines and approaches that help you to stay on track.

We give some general tips at the end of this section. In the next section, we look further at approaches you can take to manage your MS, health and wellbeing within your overall life (self-management).



Keeping physically active

For older people with MS, being more physically active can improve walking and physical function. Being regularly active may have additional benefits including:

- better cognitive function
- reduced MS symptoms
- slower disease progression
- help with depression
- improved cardiovascular fitness.

Whatever your age and fitness level, there are ways to keep active. You'll need to find the right type of activity and intensity for you. **Check with your doctor before starting a new physical activity plan.**

You may need to be at least moderately active to get the benefits listed above. Examples of moderate activity are faster walking, gardening, swimming and cycling.

Lighter physical activity — including strengthening exercises, posture work and stretches — are possible seated.

'Living with MS for over 20 years has definitely been a challenge, but it is always manageable. The mantra I tell myself to keep me going when I face challenges is: If I rest, I rust.'

GOPI FROM INDIA, DIAGNOSED IN 2002

Succeeding in being regularly physically active is about mindset as well as strength and stamina. You're more likely to keep physically active if you set yourself goals and have confidence in your ability to achieve them.

Ways to ensure success include:

- find activities you enjoy
- make plans with others to exercise together
- use an app to track your activity
- join local physical activity groups
- speak to your doctor or nurse about services to help you.



TIPS

looking after your health & wellbeing

- **Note down changes** to your physical and mental health in a diary or app so you can discuss them with your doctor or nurse.
- Be open to **hearing from friends, family and carers** if they notice a gradual change in your health that you might have overlooked.
- Have a **set routine** for taking medications. A pill box, calendar or reminders on your smartphone may help.
- If you're struggling to stay motivated or to fit your health needs into your daily life, ask your doctor or nurse what programmes or **specialist support** is available to you.
- Take up invitations for **health screening**. If you're unsure what's available, contact your family doctor's clinic or insurer to ask.



Additional resources

Online information and tools

General information resources on MS symptoms (various languages)

<https://www.msif.org/resource-topic/ms-symptoms/>

Fatigue – an invisible symptom of MS (booklet)

<https://www.msif.org/resource/fatigue-an-invisible-symptom-of-ms/>

Managing spasticity (booklet)

<https://www.msif.org/resource/managing-spasticity-in-ms/>

Managing MS and other health conditions (webinar)

<https://www.youtube.com/watch?v=gTMIDJMMqpQ>

Managing MS and other health conditions (booklet)

<https://www.msif.org/resource/lifestyle-tips-for-managing-ms-other-medical-conditions/>

European MS Platform: home exercise programme (video series)

<https://www.msif.org/resource/keep-moving-with-ms/>

Living well with progressive MS (webinar)

<https://www.msif.org/resource/ask-an-ms-expert-living-well-with-progressive-ms/>

Stretching & strengthening (video)

<https://www.msif.org/resource/wellness-break-stretching-and-strengthening/>

Exercise as part of everyday life (booklet)

<https://www.msif.org/resource/exercise-as-part-of-everyday-life/>

Wellness discussion for people with MS and their healthcare providers (booklet)

<https://www.msif.org/resource/wellness-discussion-for-people-with-ms-and-their-healthcare-providers/>

Taking control of your health (self-management)

Self-management is a set of approaches to manage (and improve) your physical health, mental health and wellbeing within your overall life. It can help you to:

- feel confident and positive about managing your MS
- feel in control of your life and future
- cope with your MS symptoms
- improve your quality of life.

In this section, we look at:

What self-management involves

How self-management can improve with age

Six ingredients of self-management

How to stay positive and turn around negative emotions

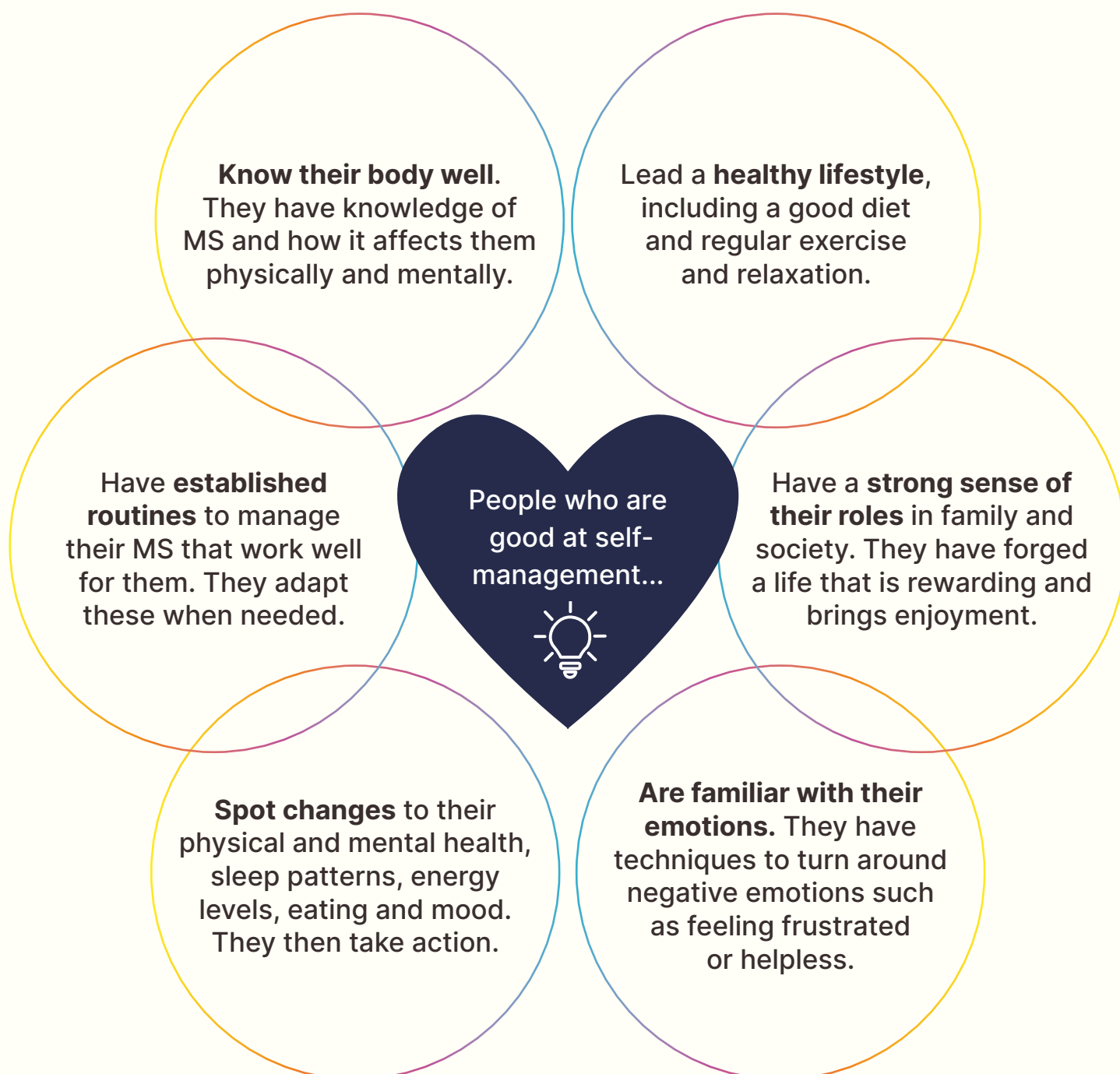


What is self-management?

Self-management is a valuable skill and can be very rewarding. It involves managing various aspects of your life to help you meet your goals. You can tailor approaches to match your personality, qualities, experiences, abilities and desires. You probably do more self-management day-to-day than you realise.

We give a summary of what good self-management looks like in the graphic below.

What does good self-management look like?



Why do people get better at self-management with age?

Many people with MS feel they've become more able to manage their condition and symptoms as they've got older.

In studies of living well with MS at older ages, some people explained that it took them almost 10 years to understand their MS. Once confident in how to predict and manage their MS symptoms, they were able to cope better and focus on the parts of their lives that were important to them.

Several wished they could have learnt about their MS and gained that confidence earlier. Generally, people who are living well with MS in older age are adaptable in their mindset.

In one study, many people felt that their ability to live well with MS as they got older was due to:

- gaining wisdom
- creating meaningful activities and relationships
- being able to deal with their changing capabilities.

Another study found that individuals with MS reported that, over time, their disease felt more predictable. They got used to their symptoms and how their bodies functioned with MS. Critical to their quality of life were:

- socialising
- access to health care
- healthy lifestyle habits
- being independent at home.

On average, women with MS might be better able to adapt to growing older than men. Older men with MS can feel less resilient, might participate in things less, and can view their health as poorer. These are all things that self-management can help you to improve.

How to self-manage

The ingredients of successful self-management can be broken down into six skills. These are shown in the graphic and more detail is provided in the following text.

Six skills of self-management



01
Problem solving



02
Decision making



03
Using resources



04
Communicating with
healthcare professionals



05
Taking action



06
Self-tailoring

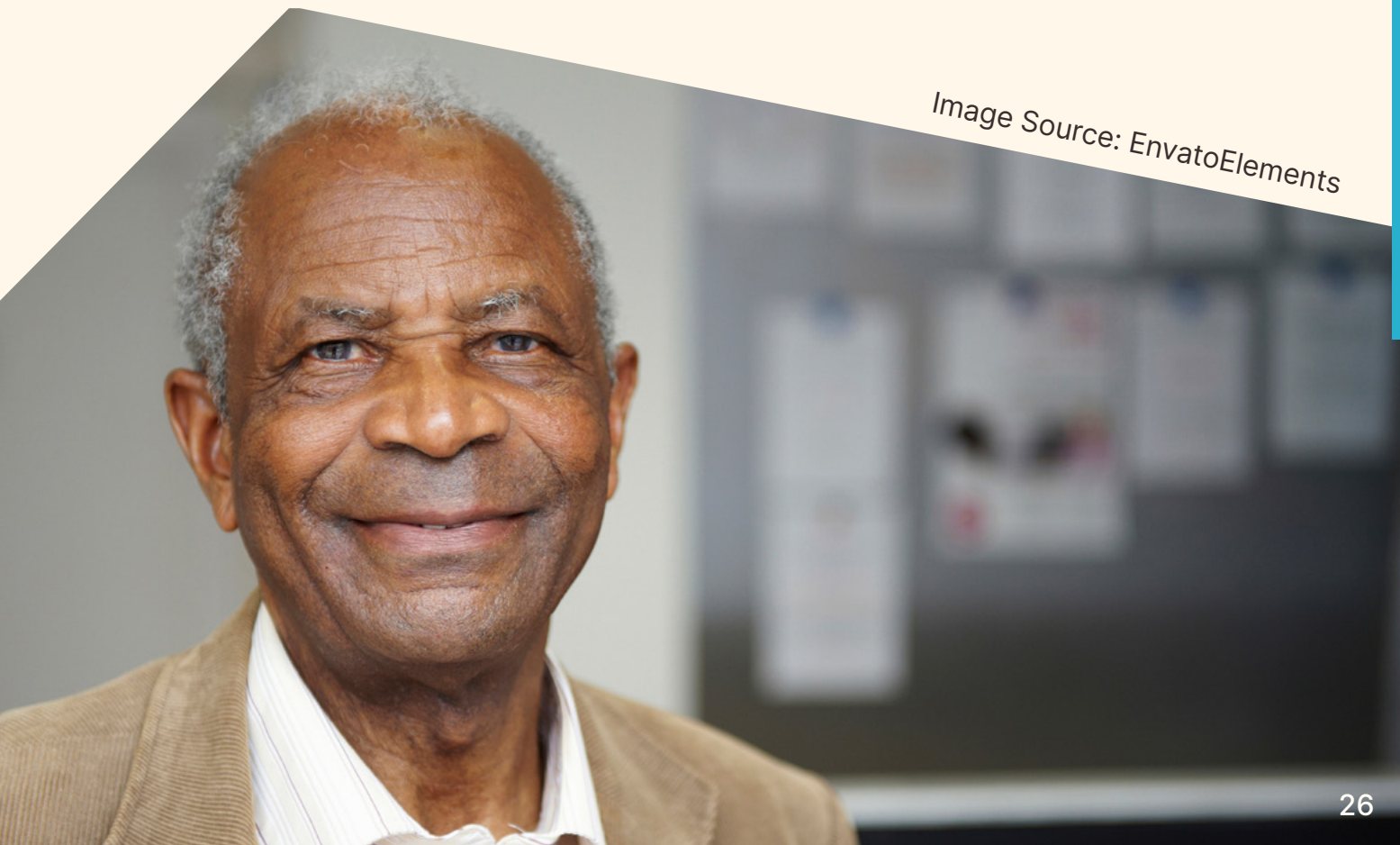


Image Source: EnvatoElements



1. Problem solving

To problem solve, you first need to spot and understand the problem. You can then work out possible ways to solve it and choose the best solution. For example, you may find that standing and cooking meals is taxing. To problem solve, you could identify ways to reduce the time you spend cooking. You could then try out these different ideas, such as making enough food for two meals, trying simpler recipes, or eating out on certain days of the week.



2. Decision making

Decision making can involve working out what is most important to you and deciding how to manage your daily activities. For example, when faced with a busy day that might be too fatiguing, you could list the activities in order of priority. What do you most want to do? What must be done today? Can you postpone activities that are lower priority? For example, you might prioritise having coffee with a friend and doing some strengthening exercises but delay a trip to choose home furnishings.



3. Using resources

Resources are anything you use to help you complete a task, such as technology, transport, the help of others, or a strategy. You also have your own resources, such as your time and energy.

Good self-management involves organising yourself efficiently using the resources you have available.

For example:

- You could group chores together to save time and energy. An example would be to combine exercise and grocery shopping by walking to the shops and getting a bus back.
- You could set up online banking so you can avoid some trips to the bank.



4. Communicating with healthcare providers

Working in partnership with healthcare providers is an important part of self-management. In one study, older people with MS said it was more helpful when they had a two-way conversation with their healthcare providers rather than simply being told what to do. One way to take ownership of your health is to prepare for healthcare visits by noting issues in a journal. Also write down discussions and outcomes. Share what's important to you and your goals.



5. Taking action

Often, taking planned action is the most difficult step in self-management. For example, you might say 'I intend to eat better' but this is not an action. Developing new habits is the tricky bit! By following your new plan often and consistently, you'll find it soon becomes the norm. For example, to improve your diet you could write down your goals, plan meals for the week, and then keep track of your progress.



6. Self-tailoring

Self-tailoring means modifying the things around you to suit your own needs and the resources you have available. Using this skill, you can find ways to make your health needs fit into your schedule. For example, if commitments (such as work or childcare) mean that you're not getting sufficient sleep, you could build rest periods into your day to catch up when it's convenient. It's a good idea to check any changes with your nurse or doctor.

Continuing to adapt

Self-management is a continual learning process. To live well with MS as you get older, you'll need to find ways to manage varying symptoms and challenges. By **adapting your routines**, you can reduce the impact of your MS and do the everyday things that matter to you.

Sometimes, changes in your life or health mean that an approach that worked well before no longer does. You might begin to feel weighed down by the demands of living with MS or the routines you put in place. **Learning new approaches to self-management or changing tactic can help.**



Staying positive

Developing positive and useful ways of thinking can help you to succeed in self-management. As you start to feel the benefits of self-management, this can make you feel more positive and confident too. **People who are good at self-management reflect on their own thoughts and feelings often.**

Ask yourself:

- How are you feeling physically and emotionally?
- What are your strengths and are you making the most of them?
- Do you have a plan of action and are you following it?
- Do you need help, and who can provide it?

Of course, none of us feel positive all of the time. It's normal to have times where it's harder to see a way forward or to motivate oneself. On the next page are some feelings you might experience from time to time, along with **ways to get back on track**.

'Nowadays I live my life as retired and it is a good life. I am involved in my MS organisation (Neuro Sweden) both locally and regionally, which I find very stimulating. In my spare time I like to paint, and I have participated in several local exhibitions. I can do basically everything I want, but not all at the same time. It's important to allow yourself to take a break now and then.'

MARIA FROM SWEDEN, DIAGNOSED IN 2010

	What it looks like	What to do about it
Denial	<ul style="list-style-type: none"> • Ignoring a change in your health, an upsetting feeling, or a difficult situation. • Delaying the action needed to manage a situation. 	<ul style="list-style-type: none"> • When you have a quiet moment, acknowledge and think through the problem. • Plan a course of action and then take the steps you need to stay healthy.
Self-defeating thoughts	<ul style="list-style-type: none"> • Unhelpful thoughts that get in the way of you achieving what you want to. • Dwelling on a negative detail. • Feeling hopeless or angry that things are not the way you feel they 'should' be. 	<ul style="list-style-type: none"> • Take note of all the positives of a situation. • Identify the things you have the power to change and the resources or support that can help you. • Set goals that are realistic and believe in your ability to achieve them.
Worrying	<ul style="list-style-type: none"> • Thinking about the possible negative outcomes of a situation repeatedly. • Focussing on the worst-case scenario rather than the best or likely outcome. 	<ul style="list-style-type: none"> • Learn to turn your concerns into action. For example, reflect on a symptom, recognise its patterns, and discuss them with your doctor. • Adapt your goals or approach when needed. • If anxiety is affecting your daily life, talk to your doctor. • Don't avoid thinking about issues – this isn't a solution.

Getting support

Although self-management is about taking charge of your own health and life, this doesn't mean you have to manage things alone. Indeed, making good use of the help and resources available to you is a fundamental part of self-management.

Take some time to work out what help healthcare professionals, friends, family or carers can give you. Be willing to accept help when it's offered.

'Don't give up. Find loving and supporting people to walk the journey with you.'

EVANGELOS FROM GREECE, DIAGNOSED IN 2002





'Age is just a number, it does not define me or my MS. I believe living well with MS is possible with self-management.'

NEELIMA FROM INDIA, DIAGNOSED IN 2007

Resources

Online information and tools

Finding MS support near you

<https://www.msif.org/living-with-ms/find-ms-support-near-you/>

Guide for support partners (booklet)

<https://www.msif.org/resource/a-guide-for-support-partners/>

Advanced MS – a carer’s handbook (booklet)

<https://www.msif.org/resource/advanced-ms-a-carers-handbook/>

A guide for MS caregivers (various languages) (booklet)

<https://www.msif.org/resource/guide-for-ms-caregivers/>

Optimising mobility (video)

<https://www.msif.org/resource/optimising-mobility-free-from-falls-program-3/>

Low self-esteem (various languages) (video)

<https://www.msif.org/resource/low-self-esteem-and-ms/>

National MS Society (USA): Living well with MS

<https://www.nationalmssociety.org/Living-Well-With-MS>



Your independence and identity

Loss of independence is a common concern for people with MS as they get older. Losing some independence can also affect your sense of identity (how you feel that others perceive you) and sense of self (the person you feel you are).

In this section, we look at:

The help you might need as you get older

Who might provide that help

Protecting your identity and boosting your self-esteem



What help might you need?

Compared with younger people, those with MS who are over 65 years old say they have more difficulty with:

- bathing, dressing and going to the toilet
- getting out of bed or around a room
- taking medication
- shopping and getting around the community.

The services they find most important to staying healthy are shown in the graphic below.

Services that help older people with MS to stay healthy

Based on a survey of people over 65 years old



In a 2021 survey by the Danish MS Society, about two-thirds of people with MS over the age of 65 said they need some help from others.

Many people with MS do not progress to the point of serious disability. However, the effects of MS and getting older may mean you need to consider some **adjustments to your lifestyle** and level of independence.

You might need help due to physical limitations or changes in your cognitive function (thinking, learning and memory).

Who will provide your care?

Help and support from a partner, family member or friend is invaluable to many older people with MS. Often, this is unpaid.

Many older people with MS have help from professional carers too, which might be funded personally, publicly, through insurance, or a mix of these. People living alone are more likely to use professional help.

'I think it is important to be open to those little things that can really give us happiness: a grandchild's kiss, a shared lunch, listening to music, reading a good book, a smile from our caregivers or the hug of a loved one. These things can help us protect our identities.'

LUIS FROM SPAIN, DIAGNOSED IN 1997

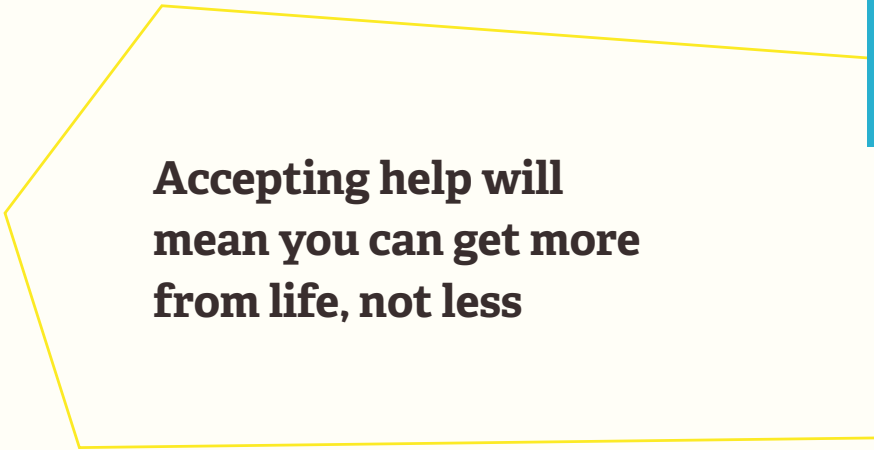
Concerns about needing more help

It's natural to want to keep your independence. Becoming more dependent on others can feel a threat to your freedom to do what you'd like at the times you'd choose. It can also make you feel vulnerable. **However, accepting help will mean you can get more from life, not less.**

People living alone or away from friends and family may worry about getting sufficient support. Conversely, it's common for those living with a partner, friends or family to worry about being a burden.

If you currently provide care to others – for example, older relatives or grandchildren – needing to take a step back can have practical and emotional impacts. Changing your roles in the family might alter your sense of identity or self, which we discuss below.

Receiving care from a partner, friend or family member can alter both of your lives in many ways. It can also alter the dynamics of your relationship. To keep your relationship healthy, **talk openly** about how you're both feeling and your needs.



**Accepting help will
mean you can get more
from life, not less**

Protecting your identity and boosting self-esteem

Changes you make to your life as you adapt to growing older can alter how you view yourself, including:

- how you feel others perceive you (your sense of identity)
- the person you feel you are (your sense of self)
- how valuable you feel (your self-esteem).

This could have a knock-on effect on your mood and mental health. Find activities, roles and friendships that support you in knowing who you are.

It can help to **connect with others** through groups or family. Charities supporting people of older ages can also be a great source of practical and emotional support. Many provide advice and tips on dealing with big changes in later life such as retirement, becoming a grandparent, losing a loved one, or changes to independence.

To **work through your feelings**, you might find a counsellor's help useful. If loss of identity or low self-esteem is affecting your mental health, speak to your doctor or a mental health professional.

TIPS

protecting your independence and identity

- **Plan ahead.** Think about what help you might need in the future. Make realistic plans with others about how you'll get this support. Planning will help you to feel more in control and less threatened by what the future may bring.
- **Research professional care services.** Look into the local options for professional help. Even if your partner, friends or family usually provide your help, it is good to know which professional services you could call on in an emergency or if they would like a break.
- **Adapt your home.** Simple changes to your home could make it easier to do some daily tasks independently. Examples are installing handrails on stairs and in bathrooms, using electric devices (such as an electric toothbrush or can opener), and chairs or stools for the shower or gardening.
- **Use assistive devices.** A wide range of devices are available that could help you to stay mobile. These include leg braces, canes, walkers, wheelchairs and scooters, and shoe inserts. Ask your doctor what is suitable for you.
- **Connect with others.** Conversations with others can help you to identify your feelings, needs and what's important to you. Being part of groups – including MS groups – can also strengthen your sense of identity and self.
- **Do things that bring you joy.** Identify the things you find most rewarding, enjoyable and that maintain your sense of identity.
- **Work on relationships with caregivers.** If your partner, family member or friend is caring for you, this could affect your relationship. Talk openly about each of your feelings. Doing activities you enjoy together can help you to protect your relationship.



Image Source: Ageing Better

Resources

Online information and tools

Finding MS support near you

<https://www.msif.org/living-with-ms/find-ms-support-near-you/>

Adapting your lifestyle: A guide for people with MS

<https://www.msif.org/resource/adapting-your-lifestyle-a-guide-for-people-with-ms/>

Optimising mobility (National MS Society)

<https://www.msif.org/resource/optimising-mobility-free-from-falls-program-3/>

Seven principles to improve quality of life

<https://www.msif.org/living-with-ms/what-influences-quality-of-life/seven-principles-to-improve-quality-of-life/>

Moving well with MS: For people with MS and their caregivers (MS Society UK)

<https://www.msif.org/resource/posture-and-movement-for-people-with-ms-and-the-people-around-them/>



Your cognitive health

MS and growing older can both affect your brain health. This is the way your brain cells grow, change, function and recover. Brain health can affect your cognitive function (thinking, learning and memory), emotions, mental health, behaviour and some body functions.

In this section, we look at cognitive health including:

How it can be affected by age and MS

How cognitive difficulties might impact your daily life

Whether you can prevent or slow cognitive decline

Tips for improving your cognitive health



How do age and MS affect cognitive function?

Just like a computer, your brain takes in information, stores it, processes it, and makes outputs. This is your cognition.

Many people – both with and without MS – experience some changes in their cognitive abilities as they get older. In one survey, more than half of people with MS aged 45–88 years old said they had cognitive difficulties that interfered somewhat with their daily life.

Some of the ways that age and MS might affect your cognitive function are shown on the next page.

**Your brain takes in information,
stores it, processes it, and
makes outputs.**

Image Source: Shutterstock

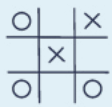


Common effects of age and MS on cognition function

Older Age



Taking longer to process information



Finding it harder to hold thoughts (your working memory)



Finding it harder to make decisions, plan or solve problems



Less able to focus (or divide) your attention

MS



Taking longer to process information



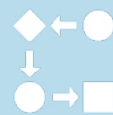
Difficulty concentrating or focussing your attention



Struggling to find a word



Poorer memory



Less able to solve problems, or to understand or form complex ideas (abstract thinking)



Problems visualising or estimating the space between objects

The more common cognitive changes in older people with MS are:

- taking longer to process information
- reduced attention
- learning and memory problems.

Some older people with MS have reduced 'executive function'. Executive function is more complex thinking. We use it to make and adapt plans and control our behaviour or emotions.

Your cognitive problems may be more noticeable when you're tired or fatigued. This is temporary and will improve once you're better rested. **Emotions, anxiety, depression, MS relapses and medicines can also affect cognition.**

How might cognitive difficulties affect your life?

Cognitive difficulties might affect your ability to do some daily tasks, hobbies or aspects of your job. We give some examples in the table.

Cognitive difficulties are often 'hidden symptoms' because they are not immediately obvious to others. Family or friends might find them hard to understand and cope with at times. This might affect your interactions with others and make you feel isolated.

Examples of how cognitive changes can affect your daily life

Taking longer to process information	<ul style="list-style-type: none">• Needing more time to understand and follow an instruction manual.• Taking longer to decide whether to take up an offer.• Struggling to follow a fast-moving conversation.
Reduced attention	<ul style="list-style-type: none">• Finding it harder to split your attention such as packing a bag while talking to a friend.• Not being able to concentrate solely on one thing (such as reading the news in a busy place).
Learning and memory problems	<ul style="list-style-type: none">• Forgetting to set off for a doctor's appointment on time.• Struggling to find the right word.• Not being able to hold a thought (such as a number you just calculated).• Finding it harder to learn a new skill or process (such as setting a new alarm system).
Reduced executive function	<ul style="list-style-type: none">• Finding it harder to organise a day trip.• Being less flexible or adaptable (such as replanning if a train is cancelled).• Having less control over your emotions (for example, crying or getting angry more easily).• Not being able to see someone else's point of view.• Finding it harder to control your behaviour (such as being tempted by unhealthy foods).

How quickly might your cognitive abilities decline?

The effects of MS and age on cognition **differ from person to person.**

MS can begin to affect cognitive function quite early in the disease process. However, some studies suggest that cognitive problems caused by MS worsen no quicker than would normally occur with age.

In general, people with MS experience a fairly slow decline in cognitive function as they get older. This speed of decline is similar to that seen in people without MS.

Can you slow cognitive decline?

Having a **well-stimulated brain** might help to slow or lessen the impact of age and MS on your brain. It's unlikely that you can avoid cognitive changes altogether. However, you might be able to reduce their impact on your daily life.

You can improve your cognitive ability with activities that:

- engage your mind
- make you curious
- spark your creativity
- get you thinking
- challenge your problem-solving skills.

Learning to adapt to cognitive changes can reduce their impact on your life. Physical activity has also been shown to improve cognitive health. Getting sufficient sleep and looking after your mental health can help too.

TIPS

how to look after your cognitive health

- **Stimulate your brain to improve your cognitive abilities.** For example, you could read, write, paint, do craft, puzzles or games, or learn a new language or instrument.
- **Join a club or group.** Talking to and doing activities with others gets your brain active. You could join a book club, support group or faith group, for example.
- **Get sufficient rest and sleep.** Fatigue can reduce your cognitive abilities. Take the breaks you need during the day and get plenty of sleep. Chat to your doctor or look online for ways to improve your sleep.
- **Look after your mental health.** Depression and anxiety can both affect cognitive function. To learn about caring for your mental health, see the next section of this guide.
- **Have formal checks on your cognitive abilities.** It can be hard to spot cognitive changes if they occur gradually. Make use of any formal tests your doctor, MS specialist or cognitive specialist offers you to keep track of your cognitive health.
- **Set up routines that aid your memory.** Have a set place for items you use often (such as your glasses or keys). Use a calendar to keep track of appointments and tasks. Put reminders in places you'll see.

Resources

Online information and tools

Cognitive evaluation and interventions (webinar)
<https://www.msif.org/resource/ask-an-ms-expert-cognitive-evaluation-and-interventions/>

Cognitive symptoms, assessment and strategy (webinar)
<https://www.msif.org/resource/ask-an-ms-expert-ms-cognitive-symptoms-assessment-and-strategy/>

Tips and tricks for sounder sleep (video)
<https://www.msif.org/resource/wellness-break-tips-and-tricks-for-sounder-sleep/>

MS life hacks (infographic)
<https://www.msif.org/resource/ms-life-hacks-infographic/>

Top tips for brain health (video)
<https://www.msif.org/resource/top-tips-for-brain-health/>

Cognition and MS (webinar)
<https://www.msif.org/resource/cognition-ms/>



Your mental health

When living with a long-term condition such as MS, good mental health can make all the difference to your quality of life. Conversely, poor mental health can make it harder to live with the condition and prevent you from living your life fully. For example, depression can make it harder to stay active, eat well and connect with others.

You might feel confident in spotting and addressing mental health problems, or you might feel there is a stigma attached to this. Views on mental health have changed greatly over the years. Younger generations are more aware of their mental health and open to seeking support.

We would like to support older persons with MS in feeling able to discuss and care for their mental health. We hope this information helps.

In this section, we look at:

How MS and age can affect mental health

How depression and anxiety can be treated

How to recognise mental health changes

The mental health of carers

Tips on caring for your mental health

Common mental health conditions in people with MS

Living with MS can sometimes make you feel down, emotional or irritable. It can also affect your self-esteem. As we learnt in the last section, MS can also affect your brain health, which can have an emotional impact.

When issues such as feeling down or anxious go on for a long time or start to affect your everyday life, they are classed as a mental health condition.

Mental health conditions are common in people with MS. For example, about half of all people with MS will get depression in their lifetime. This is a higher rate than seen in the general population. Suicidal feelings are also higher in people with MS than in the general population.

It's possible to have more than one mental health condition. For example, depression and anxiety often occur together in people with MS. In one study of older people with MS, men were more likely to feel depressed, while women were more likely to be anxious.

We show some more facts in the graphic on the next page.



Common mental health conditions in people with MS of all ages

Depression

About 5 in every 10 people with MS have depression in their lifetime.

What is it?

Depression is a low mood that lasts for a long time. It affects your everyday life.



Anxiety

About 3 in every 10 people with MS have anxiety in their lifetime.

What is it?

Anxiety is a feeling of worry, tension of fear. Most people feel anxious at times. It becomes a mental health condition if it affects your ability to live your life fully.



Bipolar disorder

About 1 in every 20 people with MS have bipolar disorder in their lifetime.

What is it?

Bipolar disorder makes you likely to have extremely high (manic) and low (depressed) periods, and possibly times when you are less in touch with reality (psychosis). This impacts your life.



Why does MS affect mental health?

MS can affect your mental health in two main ways:

- MS can affect your brain health. Structural or functional changes to your brain can make mental health problems more likely.
- The symptoms of MS and their impact on your everyday life can affect your emotions, self-esteem and mental health.

Many people find they're better able to cope with MS as they age. However, getting older with MS can sometimes affect mental health negatively.

It may be harder for you to get about, keep social connections with family and friends, and meet new people. Feeling lonely and isolated can sometimes lead to depression and anxiety.

Does the risk of depression change with age?

It's not clear whether the chance of being depressed increases or decreases as people with MS get older. Some studies found that older people with MS were less likely to be depressed than younger people with the condition. Other studies found the opposite.

The chance of getting depressed is likely to differ from person to person and change throughout life. It may be affected by:

- the level of MS disability you have
- how well you cope with challenges.

Your risk of depression can be affected by factors unrelated to your MS too.

Treatments for depression and anxiety

You may feel there is a logical explanation for feeling down or worried. After all, MS can impact your daily life in many ways and bring uncertainties about the future.

This does not mean that depression and anxiety are things you should 'learn to live with'. You can treat them, and this can improve your life. In one study of older people with MS, those whose depression was well-controlled with treatment had a better quality of life, took part in activities more, and led healthier lives than those with symptoms of depression.

Depression and anxiety can worsen other symptoms of MS, such as fatigue, pain, sleep problems and cognitive function. This is another reason to take action.

Depression and anxiety can be helped through:

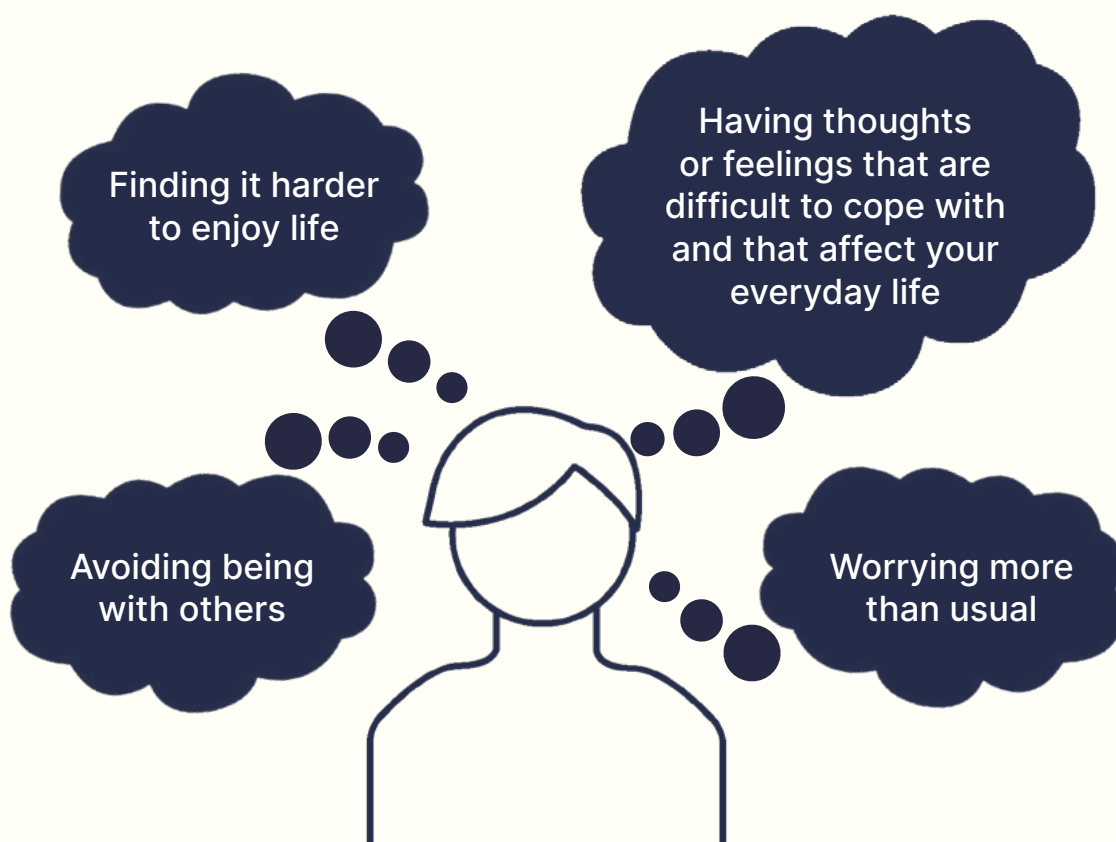
- talking therapies, which involve talking to a trained professional about your thoughts, feelings or behaviours
- self-help programmes to learn to adapt your thinking patterns
- medicines.

Being physically active can also boost your mood and help with depression.

Recognising the signs and asking for help

Depression is not always spotted in older people with MS, especially men. Be alert for the signs. Some of these are shown on the next page.

Some signs of poorer mental health



Some people with depression get physical symptoms too, such as pain, fatigue, or stomach ache. Anxiety can also bring on panic attacks that make you feel that you can't breathe.

If you think you might have a mental health condition, speak to your doctor or nurse. They can refer you to someone who can help.

If talking to a professional is daunting, you might find it easier to talk to a friend, family member, neighbour, carer or a charity advisor in the first instance. Depending on the services available to you, you might be able to see a trained counsellor or get community support or workplace support.

At its most severe, depression can be life-threatening. If you feel you might attempt suicide, contact the emergency services or a mental health crisis team now. If you don't feel able to do this yourself, ask someone to help you.

Connecting with others

If you feel down or anxious, it can be tempting to withdraw from others. It can also be harder to find the courage to make new connections. However, socialising is important for your mental wellbeing.

Older people affected by MS say that socialising is important to their quality of life.

Friendships and family relationships can bring you joy and prevent loneliness. Social connections can also be a source of empathy and support when you need it.

Aim to have regular good-quality time with your loved ones. Be proactive about keeping in touch – even a brief phone call can make all the difference. Seek opportunities to meet new people and connect with others in positive ways.

Connecting with your local, national and international MS communities can be extremely valuable. Through these, you can learn from others and share your own experiences.

Mental health of carers

Being a carer can be very rewarding. It can also be challenging, isolating and emotionally draining at times.

If you're a caregiver, be mindful of signs of depression, anxiety or other mental health conditions. Be active in getting the support and time out you need to care for your mental wellbeing.

If you have people caring for you, ask how they are. Have open conversations together about how each of you is feeling. Support one another.

TIPS

how to care for your mental health

- **Get professional advice and support.** If you think you might have a mental health condition, or want more support dealing with a current one, speak to your doctor or nurse. They can assess your needs and refer you for support.
- **Talk to others.** Speaking to others can help you realise how you're feeling and the effect this is having on you. Support from others can also give you the courage to seek professional help.
- **Have regular mental health checks.** You might not realise how much your mental health is affecting your daily life until you do a questionnaire. You can ask your doctor or MS specialist for a mental health check. Simple ones are also available online: be sure you use a reliable source.
- **Practice relaxation.** Getting sufficient relaxation and sleep is important for your mental and physical health. Relaxing properly takes practice. You can find a variety of ideas and techniques in self-help books, on websites and through apps.
- **Boost your self-management skills.** Mental health problems should not be managed alone. However, good self-management can support your mental wellbeing and improve your sense of control. See the earlier section '[Taking control of your health](#)' to learn how.

Resources

Online information and tools

Finding MS support near you

<https://www.msif.org/living-with-ms/find-ms-support-near-you/>

Depression & anxiety (webinar)

<https://www.msif.org/resource/ask-an-ms-expert-managing-depression-and-anxiety/>

MS and your emotions (booklet)

<https://www.msif.org/resource/multiple-sclerosis-and-your-emotions/>

Yoga for self-care (video)

<https://www.msif.org/resource/meditation-for-self-care-by-mssi/>

Breathing and relaxation yoga exercises for MS (Video)

<https://www.msif.org/resource/breathing-and-relaxation-yoga-exercises-for-ms/>

Taming stress in MS (booklet)

<https://www.msif.org/resource/taming-stress-in-multiple-sclerosis/>

Tips and tricks for sounder sleep (video)

<https://www.msif.org/resource/wellness-break-tips-and-tricks-for-sounder-sleep/>

Rest and self-care for fatigue management (webinar)

<https://www.msif.org/resource/rest-and-self-care-for-fatigue-management-webinar/>

Self-care and wellness for carers (webinar)

<https://www.msif.org/resource/self-care-and-wellness-for-caregivers-webinar/>

Self-care for carers (webinar)

<https://www.msif.org/resource/self-care-for-carers/>





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