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 booklet, 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

Living well with MS as you grow older

www.msif.org/resource/living-well-with-ms-as-you-grow-older/
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?

- **Know their body well.** They have knowledge of MS and how it affects them physically and mentally.
- **Lead a healthy lifestyle,** including a good diet and regular exercise and relation.
- **Have established routines** to manage their MS that work well for them. They adapt these when needed.
- **Spot changes** to their physical and mental health, sleep patterns, energy levels, eating and mood. They then take action.
- **Have a strong sense of their roles** in family and society. They have forged a life that is rewarding and brings enjoyment.
- **Are familiar with their emotions.** They have techniques to turn around negative emotions such as feeling frustrated or helpless.

People who are good at self-management...
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
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. Here 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
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<thead>
<tr>
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<th><strong>What it looks like</strong></th>
<th><strong>What to do about it</strong></th>
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<tr>
<td><strong>Denial</strong></td>
<td>• Ignoring a change in your health, an upsetting feeling, or a difficult situation.</td>
<td>• When you have a quiet moment, acknowledge and think through the problem.</td>
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<td>• Delaying the action needed to manage a situation.</td>
<td>• Plan a course of action and then take the steps you need to stay healthy.</td>
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<td><strong>Self-defeating thoughts</strong></td>
<td>• Unhelpful thoughts that get in the way of you achieving what you want to.</td>
<td>• Take note of all the positives of a situation.</td>
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<td>• Dwelling on a negative detail.</td>
<td>• Identify the things you have the power to change and the resources or support that can help you.</td>
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<td>• Feeling hopeless or angry that things are not the way you feel they ‘should’ be.</td>
<td>• Set goals that are realistic and believe in your ability to achieve them.</td>
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<td><strong>Worrying</strong></td>
<td>• Thinking about the possible negative outcomes of a situation repeatedly.</td>
<td>• Learn to turn your concerns into action. For example, reflect on a symptom, recognise its patterns, and discuss them with your doctor.</td>
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<td>• Focussing on the worst-case scenario rather than the best or likely outcome.</td>
<td>• Adapt your goals or approach when needed.</td>
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<td></td>
<td></td>
<td>• If anxiety is affecting your daily life, talk to your doctor.</td>
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<td>• Don’t avoid thinking about issues – this isn’t a solution.</td>
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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)

Low self-esteem (various languages) (video)

National MS Society (USA): Living well with MS
https://www.nationalmssociety.org/Living-Well-With-MS
This is a section from the guide ‘Living well with MS as you grow older’. Download the full guide here:

www.msif.org/resource/living-well-with-ms-as-you-grow-older/