

Symptoms Management Book

Welcome

This book is for people living with persistent symptoms such as fatigue, pain, brain fog, or movement difficulties. These can arise from a wide range of health conditions, including neurological illnesses and other long-term conditions.

It is designed to help you understand these symptoms and give you practical strategies to manage them in everyday life. It can be used on your own or in discussion with healthcare professionals, family or carers.

This resource provides general, evidence-informed self-management strategies. It does not replace individual medical advice or treatment from your healthcare team

1. Understanding Your Symptoms

Symptoms like fatigue, pain and brain fog can vary in severity and often come and go. They may be invisible to others but still have a real impact on your daily life.

They can affect how you: - Get through the day - Take part in work, leisure or social activities - Think, concentrate and remember things - Sleep, rest and recover

Although different conditions can cause these symptoms, the impact on your energy, mood, and quality of life is often similar—and so are many of the strategies that can help.

In conditions like multiple sclerosis, fatigue can be part of the condition itself and is not always related to activity, sleep, or motivation. It may fluctuate day to day and can be worsened by heat, infection, stress, or doing too much at once.”

2. Activity Management: Planning, Pacing, Prioritising

Many people find they do too much on “better days” and too little on “bad days.” This can lead to a cycle known as boom and bust:

- On good days: doing lots, then crashing
- On bad days: doing very little, fearing symptoms will worsen

Instead, try to: - Plan your day and week. Spread out demanding tasks. - Pace activities. Break tasks into steps and rest before fatigue builds up. - Prioritise. Ask yourself: what needs to be done, what could wait, and what could someone help with?

You may find it helpful to: - Balance physical, mental, and emotional activities - Allow for recovery time between tasks - Keep a stable baseline of activity, even on bad days

Pacing is not about avoiding activity. It is about using energy more sustainably so that important activities can be maintained over time.

3. Making Tasks Feel Easier and More Rewarding

Sometimes tasks feel too difficult, tiring, or not worth the effort—especially when fatigue is high. But research shows that we can reduce fatigue and increase motivation by adjusting either the difficulty or the reward of a task.

Strategies to try:

- **Tiered Goals:** Break activities into levels (e.g. Level 1: get dressed, Level 2: walk to the gate, Level 3: walk to the shop)
- **Chunking:** Divide tasks into smaller parts (e.g. “put shoes on → walk to the door → open the door → step outside”)
- **Reward Framing:** Remind yourself of the *value* of the task—“this helps me stay independent” or “after this I’ll sit with a cup of tea”
- **Reduce Effort:** Adjust when, where, and how you do things. Use aids, do them seated, or simplify steps.
- **Add Meaning:** Link tasks to your values or goals. “Making this call helps me stay connected,” or “Preparing food supports my recovery.”

These approaches are supported by behavioural therapy, motivational psychology, and rehabilitation medicine—and they’re often used in managing fatigue from neurological conditions, post-viral fatigue, and long-term illness.

4. Priorities and What Matters Most

When you're managing symptoms, it's easy to lose touch with the things that give life meaning. Taking time to reflect on what's important to you can help you make choices that feel more satisfying—even when energy is limited.

Below is a list to help you reflect on your priorities:

Things that are important to me:

Spending time with family

Being a good friend or partner

Staying independent at home

Looking after my pet or garden

Listening to music or being creative

Keeping in touch with people I care about

Doing something useful or kind for others

Having some quiet time to myself

Things I have done that I feel proud of: -

What I would like to keep doing, even in small ways: -

You can refer back to this list when you are deciding how to spend your energy. You might not be able to do everything right now—but small steps towards what matters can still be meaningful.

5. Talking to Others About Your Symptoms

Many symptoms that come with long-term conditions—like fatigue, brain fog, or pain—are invisible to others. This can lead to people misunderstanding or underestimating what you're going through.

A helpful image is the duck on a lake: calm and smooth above the water, but paddling furiously underneath. That's often how living with these symptoms can feel—on the outside you may look fine, but it takes real effort to keep going.

Talking openly with people you trust can:

- Help you feel less alone or judged
- Give others a better understanding of what you're managing
- Make it easier to ask for help when you need it

You might want to share this workbook—or parts of it—with your partner, a friend, a carer, or someone close to you. It could help them:

- Understand how your condition affects your daily life
- Know what kind of support is helpful (and what isn't)
- Feel more confident talking about it with you

You don't need to explain everything. Just being able to say, "This is hard right now," or "I'd really appreciate a hand with this" can make a big difference.

6. Using an Activity Diary

Activity diaries help you: - Recognise what types of activity tire you most - Find your baseline (your stable daily activity level) - Track boom and bust patterns - Rebalance your day with a mix of must-do, want-to-do, and restful activities

Try filling in a week like this:

Time	Activity	Score (0–10 effort)
6–9am		
9–12pm		
12–3pm		
3–6pm		
6pm–bed		

7. Sleep and Rest

Getting good sleep supports symptom management, but fatigue is not always solved by more sleep. Some people sleep too much, others too little—or wake feeling unrefreshed.

Tips for better sleep:

- Keep a consistent sleep and wake time
- Avoid screens and caffeine in the evening; turn the TV or video games off an hour before you go to bed and leave your phone in another room.
- Try relaxation exercises before bed
- Create a calm, cool, dark sleep environment

Avoid: - Long daytime naps - Sugary/fizzy drinks or alcohol late in the day - Going to bed very full—or hungry

8. Diet and Hydration

Your diet can affect energy and brain function. When fatigued, you may crave sugar or skip meals. Planning ahead can help.

Try to: - Eat small, regular meals - Choose foods that need minimal prep - Include protein, fibre, fruit and vegetables - Stay hydrated (6–8 cups of decaf, non-sugary fluids a day)

Tip: soft, moist foods are often easier to eat when tired.

9. Emotional and Cognitive Wellbeing

Living with symptoms can affect your emotions and thinking. You may feel frustrated, anxious, low or overwhelmed.

Cognitive fatigue may cause: - Trouble concentrating or following conversations - Slower thinking - Memory slips

Try to: - Break tasks into chunks - Take regular brain breaks - Use memory aids like lists, reminders or calendars

Talking therapies and stress management techniques can also help.

10. Goal Setting

Use the **SMART** goal format:

Specific – What exactly?

Measurable – How will you know?

Achievable – Start small

Relevant – Does it support your wellbeing?

Time-bound – When will you review it?

Example: “I will do a 10-minute walk three times a week for two weeks.”

Set goals around things that matter to you—like social contact, hobbies, or self-care.

BUT DON'T THINK YOU HAVE FAILED IF YOU DON'T MANAGE TO COMPLETE IT - it is important to set goals to give you something aim at; any progress or even any effort is positive

11. Support Plan

Fill this in with your team:

My GP or Consultant: _____

Therapists involved in my care: _____

Emergency Contact: _____

What helps when symptoms flare up: -

What doesn't help:

12. Resources and Next Steps

Useful websites:

www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/

www.mstrust.org.uk

www.parkinsons.org.uk

Remember

- Your symptoms are valid and can be made better.
- You family and friends want to support you: accept that support.
- A flare-up doesn't mean you're going backwards.
- Recovery is not always linear – it can seem to go in 'fits and starts' and there can be flare-ups and setbacks
- Even small changes can make a meaningful difference.

NOTE

When to seek further help:

Speak to your GP, neurologist, MS nurse or therapy team if:

- **fatigue is rapidly worsening or very different from usual**
- **new neurological symptoms appear**
- **fatigue is affecting safety (falls, driving, work risks)**
- **symptoms are causing significant distress, anxiety or low mood**