Progression in MS

Multiple Sclerosis Trust

MS

March 2025

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Contents

Introduction

The traditional classification of MS into three subtypes – relapsing remitting, secondary progressive and primary progressive – is being challenged. New imaging techniques and the use of blood biomarkers have shown that chronic inflammation and neurodegeneration occur even in the early stages of MS. This is leading to new ways of thinking about MS, and an increased understanding of the underlying biology which will hopefully lead to better treatments for progression.

This book is for anyone with MS who is experiencing progression or who wants to learn more about progression in MS.

It looks in more depth at why how we think about MS is changing, the terms that are being introduced to describe these new concepts and how the ageing process can affect MS.

It covers the psychological impact of living with progression and the effects it can have on your family, social and work life. It also discusses lifestyle changes that can help you live well with progression and approaches to reduce the risk of complications.

The book includes information on the range of options for treating and managing progression, both disease modifying drug therapies and symptom management approaches, as well as the health professionals who may be involved in your care. It also discusses the options for care and support in the future if your symptoms begin to have a more significant impact on your life.

Finally, it looks at research strategies to target progression and how new and more efficient trial designs could potentially speed up the process to find more effective treatment options for progression in MS.

1 Progression and MS

The way that MS is thought and talked about is starting to shift. Advances in imaging techniques and markers that have been identified in the blood and cerebrospinal fluid (biomarkers) are shedding new light on our understanding of the underlying biology that contributes to relapses and progression.

In this chapter we look at how the different patterns of MS are currently classified and how this is changing. We also introduce some of the newer terminology that you might increasingly encounter when reading about progression or talking to your MS team.

Some of the newer terminology is quite technical. If your neurologist or MS nurse is using terms you're unfamiliar with, or you don't understand, ask them to explain what they mean. Or you could use this chapter as a reference source when needed.

Historical descriptions of MS

MS has historically been divided into three types with different disease courses.

- **Relapsing remitting** – acute attacks of symptoms (relapses) followed by full or partial recovery (remission).
- **Secondary progressive** – initial relapsing remitting course followed by gradual worsening later in the disease course.
- **Primary progressive** – gradual worsening of symptoms from the start.

These descriptions are based on what can be seen and measured in the clinic and by MRI. Your MS can be further described to include what's happening at an individual level, at a specific point in time in terms of MS activity and progression.

- **Active** or **not active** – used in relapsing remitting and progressive forms of MS to describe whether you're having relapses or not and/or if new lesions can be seen on an MRI scan.
- **Worsening** or **stable** – used in relapsing remitting MS to describe whether symptoms have worsened or returned to the same level following a relapse, i.e. if there has been partial or full recovery from a relapse.
- **With progression** or **without progression** – used in progressive forms of MS to describe if symptoms have increased or stayed stable over a period of time.

We use the term relapsing MS to include people with a diagnosis of relapsing remitting MS and those with progressive MS who still experience relapses. And we use progressive MS to include anyone with a diagnosis of secondary progressive or primary progressive MS.

These descriptions have simplified communication between clinicians and individuals with MS when it comes to talking about the condition and informing care decisions. They've also given researchers a way of ensuring that clinical trial participants are comparable. Additionally, they're the basis on which the disease modifying treatments for MS have been approved by the regulatory authorities.

How MS is defined is changing

Traditionally, the relapsing remitting stage of MS has been linked to inflammation in areas of the brain which contain nerve axons (white matter). This type of inflammation is described as acute and focal, meaning it happens suddenly, worsens quickly (acute), and occurs in specific areas (focal). If the focal areas of inflammation occur in particular sites, they will be recognised as relapses. Some areas of

inflammation (active lesions) can be detected by MRI even if they don't lead to relapses. In contrast, progression is explained by a different process – the gradual loss of nerve cells (neurodegeneration).

These processes were previously considered to happen independently from each other, with a switch from one to the other being the explanation for why many people with MS initially diagnosed with relapsing remitting MS later transition to secondary progressive MS. However, it is now recognised that separating the relapsing and progressive types in this way isn't a true reflection of what is happening in MS at the biological level.

It's becoming increasingly accepted that both acute inflammation and neurodegeneration can occur at the same time, even in the early stages of the condition. This has marked a move towards thinking of MS as a single condition with continual ongoing biological changes, rather than as three separate types falling under the MS banner.

So, why is there so much variation seen clinically amongst people with MS if it's a single condition with both inflammation and neurodegeneration happening from the start? It's likely because there are varying degrees of inflammation and neurodegeneration within the same individual over their lifetime with MS, and this variation will be different and unique to every person living with the condition.

How progression might be described

Alongside this novel way of thinking about MS, there is an array of new terms being used to describe the underlying biological processes that lead to worsening or progression. Although they are being used more frequently, not everyone in the MS field is using them in the same way – some terms are still evolving, with a fixed definition yet to be agreed. This is because these biological processes, and how they link to symptoms, are still not fully understood.

Work is ongoing in this area and shows much promise in helping to identify what exactly leads to the irreversible disability seen when progression becomes established. For example, although progression doesn't seem to be driven by acute focal inflammation (relapses and lesions), there may be another type of inflammation at play in the

progressive phases. This inflammation is less strong and more diffuse throughout the brain and spinal cord. It is sometimes described as chronic inflammation, where chronic means that it develops slowly and worsens over a period of time.

The hope is that with better understanding, treatments can be developed to tackle progression more effectively. But this way of thinking will take time to evolve and fully integrate into clinical practice, research and the drug licensing framework. So, even though there is a shift to a new way of thinking, it is likely that you will continue to hear the terms relapsing remitting, secondary progressive and primary progressive MS for some time, and we continue to use these terms in this book where appropriate.

Emerging terminology

The following are some of the newer terms you may come across in the future.

Relapse-associated worsening (RAW)

A relapse is where new symptoms reappear, or old symptoms become significantly worse for at least 24 hours. Relapses can last for varying lengths of time and recovery can vary widely too. Some symptoms may go away completely, but others may only partially improve, remain unchanged or become permanent. If you don't recover completely and have some lasting effects following a relapse, this is now routinely being referred to as relapse-associated worsening or RAW. RAW describes the acute loss of myelin (demyelination) and loss of nerve cells (neurodegeneration) which occurs as a result of acute focal inflammation. This damage can leave you with lasting difficulties following a relapse.

Progression independent of relapses (PIRA)

One of the typical signs of progression is worsening function in the arms and legs, making walking and other daily activities more challenging. PIRA is the term used to describe a gradual worsening of disability which is unrelated to relapses but could be attributed to neurodegeneration and chronic inflammation. PIRA can be measured using clinical measures including the Expanded Disability

Status Scale (EDSS), the Timed 25-Foot Walk Test (T25-FWT) and the Timed 9-Hole Peg Test (9-HPT). You can read more about these measures in chapter 9.

Smouldering MS/silent progression/smouldering-associated worsening (SAW)

A large number of people with MS, despite being relapse free and showing no activity on an MRI scan, report a more subtle worsening of symptoms. You may find you can no longer walk or run quite as far, or for as long, as you used to even though your walking isn't impaired. Similarly, you may notice fatigue, difficulties with 'brain fog', or bladder problems gradually become more of an issue.

These changes often can't be detected by the clinical scales which are used to measure PIRA, and many clinicians wouldn't consider they fulfil the criteria for progressive MS. Terms such as smouldering MS, silent progression, and smouldering-associated worsening or SAW, are being used to describe these changes.

Different clinical tests may be needed to detect these more subtle changes, including fatigue and mood scales, and cognition tests such as the Brief International Cognitive Assessment for MS (BICAMS) and the Symbol Digit Modalities Test (SDMT). Patient reported outcome measures, questionnaires that directly collect health outcomes from you, may also have a role. You can read more about these different measures in chapter 9.

More advanced imaging techniques can now detect biomarkers that can be measured on a scan, or in the blood or cerebrospinal fluid (CSF), as well as lesions which are associated with this subtle progression.

As mentioned previously, there is currently no agreement on the terms being used to describe the progression that occurs as a result of widespread neurodegeneration and chronic inflammation. Some experts consider SAW as an umbrella term that incorporates PIRA. Others haven't embraced this terminology at all, and we expect it to continue to evolve.

Lesion types in MS

MS can be notoriously difficult to diagnose. The symptoms seen are common to many other health conditions. A diagnosis is made using a combination of medical history, neurological examination, lumbar puncture and MRI scans, alongside a set of guidelines known as the McDonald criteria (named after the MS neurologist Ian McDonald) to help neurologists to accurately diagnose MS. The criteria continue to be updated as we learn more about MS alongside advances in imaging techniques and research.

MRI is routinely used as part of the diagnostic process to look for evidence of lesions that are characteristic of MS. MS lesions typically occur in different parts of your brain and spinal cord (the central nervous system or CNS) at different times. Lesions can happen in other conditions and are also associated with the normal ageing process. This can make the diagnostic process more challenging.

The most recent revisions to the criteria that have been proposed will see more use of MRI biomarkers to help accurately identify MS. These are discussed below.

Central vein sign (CVS)

MS lesions in the white matter often have a blood vessel running through the middle of them which can be seen on MRI scans. This is known as the central vein sign (CVS) and can be used as a biomarker for MS. Detecting lesions with the CVS on MRI can help differentiate MS from other conditions with similar symptoms or lesions which are due to ageing.

Chronic active lesions (CALs)

The inflammation that is associated with relapses and acute active lesions on an MRI scan usually subsides. But there is mounting evidence that a considerable number of lesions remain active beyond the initial attack. These chronic active lesions are present in all types of MS but are found more often, and in higher proportions, in people with progressive MS. They are thought to be a factor in ongoing demyelination and progression.

Chronic active lesions (CALs) are known by many names including **mixed active/inactive lesions**, **slowly expanding lesions (SELs)** and **smouldering lesions**, so you may come across these terms too.

Some CALs have a distinctive dark rim around their edge on certain MRI scans. This is caused by immune cells which roam the central nervous system cleaning up damaged cells and pathogens. These cells are activated by inflammation but can become overactive, which could be how chronic lesions get started. These lesions are known as **paramagnetic rim lesions (PRLs)**. It's thought that the immune cells nibble away at the edges of lesions, enlarging them and causing further damage which contributes to progression. PRLs tend to be larger than slowly expanding lesions that don't have this dark rim. The presence of PRLs can also be used to help exclude MS mimics in the diagnostic process.

Biomarkers for progression

There are a number of biomarkers that have been proposed to help identify and monitor smouldering MS and progression. The following are showing promise in helping us understand progression better.

- **Neurofilament light (NfL) chain** – levels of this marker increase during relapses and when there are acute active lesions present. But higher levels also correlate to neurodegeneration so NfL may also be helpful in predicting long-term disability.
- **Glial fibrillary acidic protein (GFAP)** – levels of GFAP may be used to predict the amount of atrophy (brain shrinkage) in the grey matter of the brain (the tissue made up of the nerve cell bodies). Levels aren't related to relapses so they may be able to be used to monitor progression.
- **Chitinase 3-like1 (CHI3L1)** – it is thought that higher levels of this marker may reflect the chronic inflammation seen in smouldering MS. Higher concentrations of CHI3L1 are also linked to an increased risk of disability worsening and progressive MS.

- **Immunoglobulin M (IgM)** – high levels of this marker in the cerebrospinal fluid of people with MS are associated with a worse prognosis, especially if there are also high levels of NfL.

It's important to note these tests are still being developed and validated. They are not yet routinely available in clinics. But the hope is that better imaging techniques and understanding the significance of the levels of biomarkers will lead to a greater understanding of the processes involved in progression and lead to more effective treatment options in the future.

2 Coming to terms with a progressive MS diagnosis

Hearing the term progressive being used to describe the pattern of your MS, whether you've recently been diagnosed or have been living with relapses, might have been a shock. Here we discuss how a progressive MS diagnosis may affect you emotionally, and the steps you can take to help yourself adjust and begin to come to terms with the diagnosis.

Initial feelings

Everyone will have their own response and way of dealing with a potentially lifechanging diagnosis. There's no right or wrong way to react.

You may feel a sense of relief that you finally have a name to put to the cause of your symptoms. If you suspected you had MS, or you'd noticed a change in the pattern of your MS, you may feel a sense of closure. Alongside these feelings though, a progressive MS diagnosis can still be potentially devastating and leave you in a state of shock. You may feel anger, fear, sadness, anxiety or even guilt. You may find you're uncertain of what you're feeling, or that your feelings fluctuate. All these reactions are normal.

Stages of grief

It's natural to need time to come to terms with the diagnosis. Being diagnosed with a long-term condition has been compared to experiencing grief after loss. There are different emotional stages to work through. There's no set time for working through this process – it'll be different for everybody.

- **Denial** – you may feel shock initially and refuse to believe the diagnosis. You may try to ignore your symptoms and bury your head in the sand.

- **Bargaining** – you may wonder about the what ifs. Could I have done anything differently to avoid getting MS? Would things have been different if I'd seen a doctor sooner? You may find yourself feeling guilty, like it's all your fault.
- **Anger** – you may feel angry and think, why is this happening to me? This isn't fair. Your anger may be directed at yourself, your doctor, family and friends, or the world in general.
- **Low mood** – you may feel extremely low and want to withdraw from those around you. You may have anxiety about the future.
- **Loss of self** – you might look at yourself differently and feel a sense of loss for roles you had before, particularly if you have to give up activities that are important to you.
- **Re-evaluation** – this involves reassessing your goals in life and deciding whether you need to make changes about your aspirations for the future. This may be in your personal life (relationships, family and social life) as well as professionally.
- **Acceptance** – you might not ever feel fully OK about the diagnosis, but you are able to accept it and move forward in a positive way. You can acknowledge that the future is uncertain and challenges may arise as you move forward in your life with MS.

You might not go through these emotional stages in the order we've listed them. There can also be some overlap. You may find you move from one stage onto the next and then back again, or experience some emotions at the same time. Equally, there might be some emotions you don't feel at all. Undoubtedly some days will feel harder than others, but only once you've gone through this process are you able to move on and begin the process of redefining yourself.

Being diagnosed with a condition like MS is not a one-time event. The unpredictable nature of MS can act as an unwelcome reminder of the changes it has led to in your life. This can bring up fresh feelings of grief all over again, but it doesn't mean you can't process these

feelings and get to a better place. You might find it helpful to talk about the changes, any sense of loss, or the impact of your feelings with someone you trust. By talking to others and learning ways to manage the wave of emotions, you'll build a personal toolkit you can use whenever life or MS throws you off balance.

Adjusting to a new diagnosis

So, what can help you adjust and begin to cope with a progressive MS diagnosis?

- Use the people around you. Supportive relationships with family members, friends and professionals are incredibly useful in helping you cope with the challenges of MS. It's easy to think you might overwhelm someone if you tell them how you feel. However, usually the people closest to you will know when you're upset and will feel relieved if you open up to them. They can then offer their support.
- You may prefer to talk through your concerns with people outside your family or circle of friends. MS support groups offer the opportunity to share ideas and concerns with people who have had similar experiences. Different people will prefer different types of groups. Some may like the sociable side of attending meetings and get-togethers, others may prefer the distance and anonymity offered by online groups.
- Psychological support can give you practical strategies to help you adapt, understand your emotions, and continue living your life while managing a long-term condition. Therapies such as cognitive behavioural therapy (CBT) and acceptance and commitment therapy (ACT) can be particularly helpful for people with progressive MS. Speak to your MS team or GP about a referral to a talking therapy service. Or you can find your local service on the NHS website and refer yourself.

- Get answers to your questions. If there are things you're unsure about, speak to your MS team for more information. Alternatively, you can call the MS Trust helpline (0800 032 3839), and we can help you find the information you need. Once you're informed, you're in a better position to make decisions going forward.
- Some people find it helpful to explore available options, resources and services in case more support is needed in the future. This is called advance care planning (ACP) – see chapter 8 for more on this. Not only does this mean your family and professionals know your thoughts, preferences and wishes, it can also make it less stressful should a crisis ever arise.

Worries about future disability

There are lots of difficult questions you may worry about when you're diagnosed with progressive MS. One of the initial concerns that might arise is anxiety about what your future might look like.

- How quickly will my MS progress?
- Will I become very disabled?
- Will I have to stop work?
- Am I going to lose my independence?
- How will I manage and cope?

Unfortunately, it isn't easy to answer these questions as everyone is affected by MS differently. It's not possible to predict how your MS will develop. Although progression does mean that disability will continue to increase over time, it does not mean that you'll inevitably experience a rapid decline in your health. As with people who experience relapses as part of their MS, there is considerable variation seen in the course of progressive MS from person to person.

Whilst for some people progression can happen quickly, for many the rate at which disability increases is very gradual. You may notice

slow, subtle changes in your symptoms that steadily increase over many months. These changes may only become apparent when you compare your symptoms to previous years. You may also experience periods of stability where you find your symptoms remain the same for a while. Occasionally, you may see temporary periods of improvement. For more on the variability of progression, see chapter 3.

Readjusting to progression after living with relapses

If the pattern of your MS has changed to progressive after living with relapses for many years, it can feel like being diagnosed all over again and bring back a range of emotions. For others, this gradual change may feel less significant. You've gained a new label for a condition you're already used to living with, but which may now bring some new challenges as your symptoms progress.

Although you may be dealing with fewer relapses and less of the unpredictability this brings, the gradual worsening of symptoms you may see over time with progressive MS can be equally challenging to live with, manage and accept. Try to be kind to yourself during this transition and talk to those you trust for support. It's normal to go through a range of emotions at this time.

Sometimes there's an assumption that the change to progressive MS means your MS has become worse. This is not necessarily the case. Comparing the different patterns of MS can be unhelpful. People will have better or worse experiences depending on the nature of their symptoms and the impact these have on their lives, regardless of what terminology has been used to describe the clinical pattern of their MS.

Changing your mindset

We have a natural tendency to worry about uncertainties and things that are out of our control. But this can end up causing us a great deal of fear and concern about the future. Whilst acknowledging and accepting the uncertainty of the future is important, it can also be helpful to shift your mindset. Try looking at things from a different perspective by asking yourself: what *can* I control right now?

This can help you feel more grounded in uncertain or unpredictable situations, such as when dealing with the challenges of living with a long-term condition.

There are many aspects of your health that are still in your control.

- Explore treatments that can help manage your symptoms – these options can reduce the impact your symptoms are having on your daily life (see chapter 4).
- Talk to your MS team about whether a disease modifying drug (DMD) is an option for you (see chapter 4).
- Keep up to date with the latest MS research (see chapter 9).
- Consider getting involved in a clinical trial.
- Take steps to look after your body – for instance, working on your fitness and activity levels so your body is best prepared to face any future challenges MS may bring (see chapter 5).
- Look after your brain – keep your brain healthy by maintaining a healthy weight, reducing alcohol, avoiding smoking, and doing creative activities (see chapter 5).
- Prioritise your mental health and wellbeing – make time for the things you enjoy, schedule some self-care time, and practise mindfulness and relaxation techniques.
- Learn about your condition – become an expert on your MS and what's normal for you. That way, if anything changes you can be proactive and discuss things with your MS team early.
- Seek support – connect with people in the MS community to share experiences and gain emotional support from others facing similar challenges.
- Plan for setbacks – having a plan in place for if your symptoms worsen can provide some reassurance and peace of mind as you know what the next steps are if your situation changes.

- Follow treatment and management advice from your MS team – make sure you're taking any medications as prescribed and keeping up with any exercises, activities or strategies recommended by a rehabilitation professional. This'll ensure your MS symptoms are being managed as well as possible, and your MS is kept under control.

How do other people with MS cope with uncertainty?

Everyone will have different coping strategies that work for them when it comes to living with a long-term, progressive condition. Here are some more approaches to mindset that other people have found useful.

- Give yourself lots of time to process the diagnosis.
- Practise remaining present and not dwelling too much on the future.
- Focus on what you can do.
- Show yourself care and compassion.
- Accept the future is uncertain, but don't let that overshadow your life today.
- Prioritise looking after yourself physically and mentally.
- Don't let MS define you – instead, take the time to learn who you are now.

Your mental health

Living with a long-term, progressive condition puts you more at risk of developing depression and anxiety. This risk seems to be greater around diagnosis and at times of significant change in your condition. At these times, difficult and powerful feelings may emerge and feel harder to cope with. Feelings of uncertainty, loss, helplessness and stress can all contribute to depression and anxiety, as can other MS symptoms (like pain and fatigue) and drug side effects. Anxiety and depression can also be directly caused by MS damage (lesions) in certain areas of the brain.

It's important to be aware of your mental health and reach out to a health professional for support if life is ever feeling unbearable. There are treatments, such as psychological therapies and medications, available on the NHS to support you through these difficult times. If you're feeling depressed or anxiety is overwhelming you, talk to your GP or MS team. You are not alone.

Find out more

Our website resources

Anxiety
mstrust.org.uk/anxiety

Depression
mstrust.org.uk/depression

MS and your emotions
mstrust.org.uk/information-support/wellbeing-ms/ms-and-your-emotions

MS Trust Facebook Group
mstrust.org.uk/fb-group

Psychological therapies
mstrust.org.uk/a-z/psychological-therapies

Support groups
mstrust.org.uk/support

Wellbeing and MS
mstrust.org.uk/wellbeing

Other organisations and support

Find an NHS talking therapies service
nhs.uk/nhs-services/mental-health-services

3 Variability of progression

Living with progression doesn't mean that you will inevitably experience a rapid decline in your health or abilities. Although progression does mean that your level of disability will continue to increase over time, the rate at which this occurs varies. For many people it happens slowly over many years. There may be periods where your symptoms remain stable for a while and are easier to manage.

Temporary worsening of symptoms vs progression

It's possible to experience a temporary worsening of symptoms when you live with progression. This is often due to external factors, such as an increase in fatigue levels, a period of stress, an infection, or temperature sensitivity – such as an increase in body temperature when exercising, or in response to much hotter or colder weather. These can all have a negative impact on symptom severity, so it may not necessarily be an indication that your MS is worsening if any of these circumstances are present. Once the external trigger has improved or resolved you will have a clearer picture as to whether you've experienced further progression or not.

Factors that can affect the rate of progression

The rate at which you might experience progression will depend on many contributing factors. These include:

- the number, type and location of your lesions
- how efficient your compensatory mechanisms are at repairing damaged axons and rerouting messages around damaged areas (brain plasticity)
- your age and how long you've lived with MS
- lifestyle factors such as how active you are, your diet, whether you smoke and how much alcohol you drink.

Higher numbers of chronic active lesions have been linked to worse physical and cognitive outcomes in progressive MS. Some lesions may be in an area of the central nervous system that doesn't lead to obvious symptoms, whereas others may have a more significant impact.

The extent to which you're able to remyelinate damaged nerves is thought to be influenced by the location of lesions, your age, genetic factors and how long you've lived with MS. More remyelinated lesions equates to slower progression. But as you get older, compensatory mechanisms, including remyelination and the ability of the brain to reroute messages around areas of damage, are more likely to fail. For more information on how ageing can impact on progression see chapter 7.

You can't alter some of the above factors, but there are some aspects of your life that you can modify that could have a positive effect. A lack of physical activity, poor diet, and smoking are all thought to have a negative impact on the rate of progression. Chapter 5 of this book looks at steps you could take to help you live well with progression.

4 Treating and managing progression

There can sometimes be a misconception that there aren't any treatments available for people with progressive MS. In reality, there are many treatment options, management strategies and health professionals that can help you with your symptoms. The options discussed in this chapter may not all be needed in your care – it depends on your MS and how it affects you personally.

Treating and managing progressive MS may include several approaches.

- Reducing relapses/acute inflammation and slowing progression with a disease modifying drug (DMD).
- Improving and controlling symptoms through a combination of:
  - rehabilitation therapies, and
  - drug treatments.
- Preventing complications that may worsen or trigger symptoms.
- Adopting self-management strategies and becoming an expert on your MS.
- Taking care of your general health and wellbeing.

You can read about preventing complications, lifestyle and wellbeing, and self-management in chapter 5. Here we focus on DMDs and symptom management approaches.

Can a disease modifying drug help me?

There are a small number of DMDs available to treat those diagnosed with progressive MS.

- Ocrevus (ocrelizumab) for early, inflammatory primary progressive MS.
- Mayzent (siponimod) for active secondary progressive MS.

These drugs can reduce disease activity and slow down disability progression. However, you may only benefit from (and be eligible for) these drugs if you still experience relapses or your MRI scans show signs of acute inflammatory activity. This means that only a small number of people with progressive MS are eligible for these drugs.

Currently there aren't any DMDs available for those with progressive MS who no longer experience relapses (non-relapsing) or do not show signs of acute inflammation on MRI scans (non-active).

However, there are drugs in development that are showing signs of promise for progressive MS, specifically in slowing down disability progression and treating chronic inflammation (smouldering lesions). Some of these drugs are at the final stages of large clinical trials with initial positive results being reported. The hope is that more drugs will become available to alter the course of progression for all people with progressive MS in the not-too-distant future (see chapter 9 for more on this research).

Stopping DMDs

With time, you may no longer experience relapses as part of your MS (if these have been a feature before) but you may notice your symptoms progressing. At this stage, your diagnosis may change from relapsing remitting MS (RRMS) to secondary progressive MS (SPMS).

When this transition happens, your MS team may advise you to stop your current DMD (if you're taking one) as it may no longer be benefiting you, or the risks may start outweighing the benefits. The DMDs used to treat relapsing MS aim to stop acute focal inflammation from happening and the subsequent disability that lesions and relapses can cause. As this type of inflammation is seen

to a lesser extent in progressive MS, the DMDs have a limited effect on the gradually worsening disability that happens independently of relapses. These DMDs therefore often aren't suitable or effective for people with progressive MS.

However, if you transition to secondary progressive and acute inflammation is still present, then switching your DMD to Mayzent (siponimod) may be an option.

Large studies have been done to see what happens when people with MS who have been free of relapses for several years stop their DMDs. The majority of people remain free from disease activity. However, in the small number who do show some return of disease activity after stopping their DMD, it's likely they would be eligible to restart treatment.

Stopping a DMD doesn't mean there are no other treatment strategies available for you. Instead, treatment is likely to focus on managing your individual symptoms.

Symptom management approaches

A major part of treating progressive MS involves symptom management. This is usually done through a combination of rehabilitation therapies and drug treatments.

Rehabilitation therapies

Rehabilitation therapies aim to help you live life as fully as possible, despite the physical, psychological or social challenges that MS may bring. These therapies can maintain and improve your physical function, comfort and quality of life. Typical examples are physiotherapy and occupational therapy.

Rehabilitation generally takes place alongside other treatments. For example, you may be given a drug to reduce muscle stiffness in combination with stretching exercises from a physiotherapist. These treatments complement each other and help you see better improvements.

Drug treatments for symptoms

There are a range of medications used for managing individual symptoms. There are drugs available to reduce the impact of:

- muscle stiffness (spasticity) and spasms
- pain
- fatigue
- bladder and bowel problems
- depression and anxiety
- mobility issues
- sexual difficulties.

When there are no effective medications, or where medication can only manage a symptom to a certain degree, rehabilitation therapies may be used as a complementary approach.

As new drugs become available and guidelines frequently change, we've decided not to list the drugs that are used to treat symptoms here. These are covered in more detail on our website (see links in Find out more at the end of this chapter). Instead, we focus on the different health professional teams that can provide support with symptom management and advice on what medications are the most suitable for you.

Who can help me manage my symptoms?

As you may experience a range of different symptoms, it's common for someone with progressive MS to be supported by a multidisciplinary team who has expertise in different areas.

Knowing which health professionals are available to support you can be helpful if your symptoms worsen or new symptoms arise. Having this awareness can encourage you to be more proactive in your care and give you the confidence to push for the support you need.

Here we go through the health professionals that may be involved in your care.

Neurologist

Neurologists are part of your core MS team. They are usually supported by an MS nurse(s). Your neurologist will review your MS over time and assess how well treatments work for you. An appointment with your neurologist may involve a discussion about your symptoms, a neurological examination to assess disability progression and, on some occasions, referral for an MRI scan.

Neurologists can advise you on what medications and rehabilitation therapies may benefit you and refer you to relevant services for support. Some treatments, like DMDs and certain drugs that treat symptoms, can only be prescribed by an MS specialist, such as a neurologist.

Some neurologists support people with a wide range of neurological conditions whilst others specialise in MS. If your diagnosis was made by a general neurologist, you might want to consider transferring your care to an MS specialist neurologist.

MS specialist nurse

MS nurses are often the first point of contact for discussing any symptoms that are bothering you and guiding you through treatment options (both symptomatic ones and DMDs). They also have a role in referring you to other specialists as appropriate and liaising with your GP.

In some areas, once you're diagnosed with MS, you can contact your local MS nurse directly (by phone or email) without a referral. In other areas, you may need to be referred by your GP or neurologist first. When you contact your MS nurse, you usually have to leave a message and they will get back to you.

Whilst most areas are covered by an MS nurse, if there isn't one in your area then your GP will become your first point of contact.

GP

Your GP can support you in managing your symptoms, either through prescribing medications or referring you to other specialist services.

GPs aren't experts in MS, so they may need to liaise with your MS team for advice before prescribing some symptomatic treatments or if

symptom management becomes more complex.

If you contact your MS team with a problem that they do not think is related to your MS, they may ask you to consult with your GP.

Physiotherapist/neurophysiotherapist

A physiotherapist can help you maintain and improve movement and function if MS has affected your mobility. There are some physiotherapists who specialise in treating people with neurological conditions like MS (known as neurophysiotherapists). Others specialise in managing specific symptoms, such as muscle stiffness (spasticity) and breathing problems (respiratory).

After an initial assessment, a physiotherapist may recommend a range of approaches, such as:

- tailored exercises to strengthen specific parts of your body
- stretches to maintain flexibility in your muscles and joints
- advice on appropriate physical activity
- education on posture in various positions and walking pattern (gait)
- manual therapy (e.g. massage)
- advice on using walking aids (e.g. a walking stick, walking frame or wheelchair)
- spasticity management options and techniques (including stretches, exercises, posture and positioning advice, trigger factors and medication)
- advice on the prevention of falls.

Physiotherapy can improve the following MS symptoms: walking difficulties, problems with movement and coordination in the hands and arms, muscle stiffness and spasms, weakness, tremor, balance issues, dizziness, bladder and bowel problems, speech and swallowing problems, musculoskeletal pain, and breathing problems.

Your GP, MS nurse or neurologist would usually need to refer you to a physiotherapist. Some physiotherapists work in GP practices, so you may have the option to see the physiotherapist directly without having to see your GP first.

As waiting lists for physiotherapy can be long, some people opt for physiotherapy in a private setting instead. If this isn't an option for you, you may want to check if your employer provides occupational health services including physiotherapy. Alternatively, there are charities called Neuro/MS Therapy Centres around the UK that offer physiotherapy sessions (as well as other complementary therapies) at a reduced cost.

Physiotherapists will often work closely with occupational therapists.

Occupational therapist

An occupational therapist (OT) can help you overcome barriers that may be interfering with your daily activities. If your MS is making daily self-care, your working life or leisure activities more difficult, an occupational therapist can find practical solutions to help you remain independent for longer and continue doing the things that are important in your life. This often involves looking at how an activity (or the environment where it takes place) can be adapted or carried out differently to make it easier for you.

After an initial assessment at your home or workplace, an OT may:

- source equipment to help you with daily activities at home – such as a grab rail in the bathroom or a perching stool so you can sit while preparing food in the kitchen
- offer advice on how you can change the way you do certain everyday tasks to make them easier
- suggest changes at your home to ensure safety and accessibility
- talk with your employer to help them understand how MS affects you and what reasonable adjustments you may need

- recommend mobility equipment – such as a stick, walker or wheelchair (and refer you to an NHS wheelchair service if one is required).

Occupational therapy can support in the management of: fatigue, walking difficulties, problems with movement and coordination in the hands and arms, balance and risk of falls, thinking and memory problems (cognition), muscle stiffness and spasms, swallowing problems, tremor and weakness. They can also support you with managing your MS at work (see chapter 6).

OTs, often in partnership with a physiotherapist, can be particularly helpful in supporting you with fatigue management. Some OTs deliver courses on this topic. They can work through practical strategies to help you build up energy levels and use your energy more effectively.

There are OTs that work in the NHS and some of them specialise in MS. Speak to your GP or MS team for a referral. There are also OTs that work within adult social care, although they do not tend to specialise in specific conditions. You can contact these OTs through your local council.

Orthotist

An orthotist can provide external devices (orthoses) that support your bones and joints. These devices can help you maintain and improve mobility and function in various parts of your body. For example, a brace that supports your ankle and foot can help with walking difficulties like foot drop, or a resting splint can be useful to achieve better hand and wrist positioning if you experience muscle contractures (see chapter 5 for more information on contractures).

Orthotists usually work closely with OTs and physiotherapists. You can be referred to an orthotics service by your GP or MS team.

Bladder and bowel specialist(s)

Nurses and physiotherapists who have received specialist training can help people with continence problems. Bladder and bowel specialists can support you in a variety of ways depending on the nature of the problem(s).

They can:

- suggest exercises to strengthen your pelvic floor and improve bladder and bowel control
- prescribe medications (such as those which can reduce bladder accidents or improve constipation)
- suggest devices that may be helpful on a daily basis (such as catheters to help you empty your bladder or transanal irrigation to flush out your bowel)
- advise on lifestyle and diet
- offer incontinence products (such as pads and pants).

You can usually contact your local bladder and bowel service without a referral. If not, your GP or MS team can refer you. These services offer appointments in the clinic as well as home visits if you can't attend a clinic.

Psychologist/neuropsychologist

A psychologist can assess your psychological and emotional wellbeing, and support you if you feel low, anxious or depressed.

There is a range of psychological therapies they can offer, depending on your needs. Low mood and anxiety may be treated with approaches such as cognitive behavioural therapy (CBT) or acceptance and commitment therapy (ACT). In some areas you can self-refer to a talking therapy service (see link to NHS website in Find out more section at the end of this chapter).

A neuropsychologist has more expertise on how MS physically affects your brain and the impact this can have on your thinking and memory (cognition) as well as your mood. After a cognitive assessment, a neuropsychologist may offer cognitive rehabilitation and suggest compensatory strategies to minimise the impact of any difficulties.

Your GP or MS team can refer you to a psychologist or neuropsychologist.

Speech and language therapist

A speech and language therapist (SLT) can assess problems affecting your communication and swallowing.

For speech problems – such as slurring, volume issues and difficulties finding words – an SLT may:

- provide you with strategies to improve your speech
- suggest exercises to improve the volume or clarity of your voice
- advise on technology that can support your communication
- give you compensatory strategies to use in situations when you find communication difficult.

For swallowing issues, an SLT can provide advice on:

- posture when eating and drinking
- the consistency of food and drink
- how to create an appropriate eating environment at home (for example, making sure the environment is free of distractions and allows for good positioning)
- exercises to strengthen the muscles involved in swallowing.

You can be referred to an SLT by your GP, MS nurse or neurologist.

Pharmacist

Pharmacists can provide useful information on prescribed medicines, such as side effects and possible interactions (if you take multiple drugs – known as polypharmacy). Some local pharmacies offer a medication review service where a pharmacist looks at all the medications you take, assesses whether there are any interactions, identifies problems and suggests ways to improve their effectiveness.

Increasingly, there are MS pharmacists that work as part of your MS team. They have expertise in the prescribing and dispensing of MS medications, as well as ongoing monitoring, managing side effects,

advising on interactions, and ensuring newly available drugs can be prescribed. They can also answer questions about vaccines and the safety of medications during pregnancy or breastfeeding.

Pharmacists generally work behind-the-scenes and provide advice to other health professionals, such as your MS nurse and GP, so you may not have contact with them directly, but your MS team can draw on their expertise.

Dietitian

A dietitian can assess your nutritional needs and provide advice on your diet. You may benefit from seeing a dietitian if your MS symptoms have resulted in significant weight loss or weight gain, or if eating has become difficult. Changes in your weight can be due to a range of factors, such as reduced mobility, loss of appetite, or difficulties eating or preparing food. Dietitians can also provide advice on different food consistencies and suggest alternative methods of eating if swallowing has become difficult. Your GP or MS team can refer you to a dietitian.

Taking control of your care and navigating NHS services

People with progressive MS can sometimes feel like they've dropped off the radar of MS services and end up not seeing their MS team as often as they should. This can happen for various reasons.

- As progressive symptoms tend to happen gradually, you may have adapted to the changes without realising and you may think that it's unnecessary to contact your MS team for support.
- If you stopped taking a DMD because you no longer experience relapses, the monitoring appointments may have stopped. This means that you don't have the opportunity to see your MS nurse as often as before.
- You may not have regular MRIs scheduled. This can leave you feeling like changes in your MS aren't being monitored as closely.

- As there is a limited number of DMDs targeting progression, you may feel that nothing can be done for you and be less inclined to reach out for support with your symptoms.

Keeping in touch with your MS team when you have progressive MS is important. As discussed in this chapter, there is a wide range of treatment options and management strategies to support you with your symptoms. Regular communication with your MS team will help you access a wider range of health professionals who can support you in many ways.

If you feel that your symptoms have worsened and they're increasingly affecting your daily life, contact your MS team for advice. It's recommended that all people with MS see an MS specialist (such as their nurse or neurologist) *at least* once a year to review their symptoms and treatments options. You can reach out to your MS nurse more often than this if your symptoms worsen and become more difficult to manage.

How can you be proactive in your care and treatment?

- Know how to contact your MS team and have their contact details on hand for when you need them (see link to our Map of MS Services in Find out more section at the end of this chapter).
- Keep a list of all the medications you take – this can be useful for the variety of health professionals involved in your care.
- Set reminders to ensure you take drug treatments when you're supposed to.
- Keep up with any exercises or other management strategies that have been recommended to you by a health professional (such as a physiotherapist or bladder and bowel specialist).
- Be aware of the health services available to support you and how the referral process works – including the cases when you can self-refer without the need to see your GP or MS nurse first.

- Prepare for appointments beforehand to ensure your most important issues are discussed.
- Ask your MS team about clinical trial opportunities and new research that may impact the management of your MS.
- Look after your physical and mental health as far as possible so you're in the best position to deal with any problems MS may bring (see chapter 5 for more on self-management, lifestyle and wellbeing).

Complementary therapies

Alongside conventional drug treatments and rehabilitation therapies, some people choose to use complementary therapies to relieve certain symptoms and improve their general wellbeing. These therapies can include yoga, Pilates, massage, meditation, reflexology, mindfulness and acupuncture.

Although these therapies fall outside conventional medicine, they are largely accepted as improving physical and mental wellbeing. Complementary therapies are generally considered safe, but if you're uncertain, speak to your MS team before starting a new therapy.

One drug doesn't fix all

As this chapter makes clear, treating and managing progression in MS isn't solely about drug treatments. Medications can indeed go some way to managing and improving certain symptoms, but it's often a combination of management strategies – including rehabilitation therapies and looking after your health more generally – that benefit you the most.

This obviously involves an aspect of self-management, such as staying motivated to carry out exercises suggested by a physiotherapist, changing your lifestyle, and taking drug treatments as recommended. We explore what self-management involves and how to live well with progressive MS in the next chapter.

Find out more

Our website resources

Bladder problems
mstrust.org.uk/bladder

Bowel problems
mstrust.org.uk/bowel

Disease modifying drugs
mstrust.org.uk/DMD

Equipment
mstrust.org.uk/equipment

Fatigue
mstrust.org.uk/fatigue

Map of MS services
mstrust.org.uk/map

Making the most of appointments
mstrust.org.uk/appointments

MS Therapy Centres
mstrust.org.uk/a-z/ms-therapy-centres

Muscle stiffness and spasms
mstrust.org.uk/spasticity

Pain
mstrust.org.uk/pain

Speech problems
mstrust.org.uk/a-z/speech-problems

Swallowing problems
mstrust.org.uk/swallowing

Talking therapies
mstrust.org.uk/a-z/psychological-therapies

Thinking and memory
mstrust.org.uk/thinking

Treatment finder
mstrust.org.uk/treatment-finder

Walking difficulties
mstrust.org.uk/a-z/walking-difficulties

Weakness
mstrust.org.uk/weakness

Our publications

Disease modifying drugs (book
mstrust.org.uk/90

Living with fatigue (book
mstrust.org.uk/204

Managing your bladder (book
mstrust.org.uk/429

Managing your bowels (book
mstrust.org.uk/430

Managing spasticity and spasms (book
mstrust.org.uk/400

Other organisations and support

Find an NHS talking therapies service
nhs.uk/nhs-services/mental-health-services

5 Living well with progression

Being diagnosed with a long-term, progressive condition means that life may not turn out quite how you'd anticipated. You may feel like you've lost a part of yourself. It's normal to grieve for the life you'd expected – both at diagnosis and if things change significantly. But a diagnosis of MS doesn't mean that you can't still live a good life. Hopefully, in time, you will reach a level of acceptance. This doesn't mean giving up and being resigned to what life will bring. Rather it's about taking ownership of your condition and seizing control.

Sometimes an MS diagnosis can provide you with an opportunity to assess your life and consider whether there are changes you'd like to make. This might be big life decisions such as changing career, moving house, or starting/extending your family. It could be lifestyle changes such as stopping smoking, eating more healthily or increasing your levels of physical activity. You may also want to equip and empower yourself with the knowledge and skills that'll prepare you for any future challenges MS brings.

In the following chapter we look at some of the steps you can take to help you live well with progression.

Comprehensive assessment

Living with progression often means living with wide-ranging and changing needs, some of which may be complex. The NICE guidelines recommend that you should be offered a comprehensive review at least once a year by a health professional with expertise in MS. Ideally, it should be carried out by a health professional already involved in your care – such as your neurologist, an MS nurse or physiotherapist. It should cover both your physical and mental health needs and any concerns or worries you have.

The review should include the chance to talk about any significant changes you've experienced over the past year. Any medication you're taking should be reviewed to check that it's still appropriate,

that you're taking it in the way intended and that the dose is working for you. It's also an opportunity for you to find out about any new treatments and options for your care. The assessment can identify any unmet needs you have and how they can be addressed – including any other health professionals who need to be involved to support you.

You should also be aware of who to contact within the MS team, and how best to get in touch, if you have any MS-related problems. You can ask during the review if you're not sure.

In some areas, particularly where there is a community MS nurse or practitioner in the team, you may be offered a more in-depth assessment that also covers any social or spiritual wishes that you would like to be taken into consideration. This is known as a holistic assessment, where the focus is on you as a person – not just on your MS. Unfortunately, this is not available to everyone.

The following are some of the things that might be covered in a holistic assessment where available.

- **Symptoms and physical issues** – these could be MS-related or about any other health conditions that you're living with.
- **Emotional concerns** – such as dealing with uncertainty, worries about the future, feeling lonely, anxious or depressed. Do you have a good support network? Do you have people you can rely on if you need help? If not, let the health professional carrying out the assessment know, so they can help you find this support.
- **Practical concerns** – this might be around being able to look after yourself and your home, especially if you live alone. You could be worried about taking care of others or your pets. Any equipment needs you may have can be explored. You could raise any issues about driving, parking or using public transport.
- **Financial worries** – any job or money worries, such as balancing work and treatment, paying bills, applying for benefits or any other financial help available.

- **Spiritual concerns** – any aspects of your faith or spirituality that are important to you. Or if you feel at odds with any strongly held cultural beliefs or values. What is important in your life? Do you have a hobby or something that makes you feel positive and gives meaning to your life?
- **Information that can support you** – this might be around lifestyle choices, complementary therapies, support groups or planning for the future.

The assessment can be used as a starting point to look back over the past year as part of your annual comprehensive review. It will help record how things may have changed – whether that is positively or negatively. You'll be able to see how you've adjusted to your MS and made changes that have helped you manage your condition. You can also bring up any other concerns that you want to share. The assessment is there to help you and is a chance to raise whatever issues are important to you.

If your area has the capacity to carry out a holistic assessment, it can be shared with all the teams involved in your care, avoiding unnecessary duplication.

Self-management

On average, people living with long-term health conditions only spend at most a few hours a year with the health professionals involved in their care. This means that most of the time you'll be managing your own MS. Self-management, also known as self-care, doesn't mean going it alone. Rather it's about having the tools in place to give you the confidence to manage your MS between appointments or your annual review.

Having a good understanding of your MS can empower you to ask questions and work in partnership with your healthcare professionals. You can learn to identify 'red flags' specific to how MS affects you. This helps you to be in control of your MS and be more proactive in how you manage your condition. It can also give you the confidence to recognise when you need to seek help.

It's important to be able to advocate for yourself or have a trusted person who can do that for you. Knowing what to do – when and where to get help if your symptoms are getting worse – can help reduce the risk of serious complications.

Choose what's right for you

As you live your life with MS you'll become the expert of your condition. You'll also have your own set of beliefs and values that shape who you are. Along with the knowledge you gain about MS, and the self-management skills that you learn, these will give you the confidence to advocate for what is right for you.

Know where to find reliable information

Some people with MS choose to live one day at a time, taking life as it comes. Others prefer to read anything and everything about MS. Whatever your approach, the most important thing is knowing where to find reliable health information if, and when, you need it. Information from charities and the NHS are usually a good starting point.

Be aware of the resources available that could help support you in making the right decisions. Learning more about MS, and the options available, can give you an increased sense of control and leave you better prepared to deal with everyday challenges. It can help reduce any anxiety if you have a better understanding of why something is happening and how it can be managed. It can also give you an idea about what you might do if things aren't going well. Setbacks can be easier to deal with if you feel more knowledgeable about what the next steps might be.

Learn skills to help manage your health

Self-management strategies and techniques can help improve your health. It's important to look after your physical and mental health for your overall wellbeing. This might be through embracing better lifestyle choices, learning techniques to help manage stress, adopting a problem-solving approach or setting goals.

All these skills can help you live a better life on your own terms. They may also have a positive impact on your MS.

Lifestyle and wellbeing

We're all encouraged to manage our physical and mental wellbeing through staying active, eating well and reducing stress. But looking after your general health is especially important when living with a long-term condition like MS. By making sure your general health is as good as it can be, you'll be in a better position to manage your MS and any challenges it brings.

Worsening symptoms can be a prompt to think about how you're living your life and if there are any changes you want to consider. Although it's tempting to make lots of changes at once, be realistic about what's most important to you and what'll fit into your way of life. It's more likely that you'll maintain changes in the long term if you choose one area to focus on at a time.

Sometimes small or simple changes can make a big difference to help keep your body and mind as strong as possible. The following are some aspects of your life where you could consider making changes.

Eating well

Living with MS can make it harder to maintain a healthy weight as there are a number of factors that can contribute to weight changes. If you have fewer opportunities to exercise or have reduced mobility, this can contribute to weight gain. Weight gain can also be a side effect of some medications. If you have difficulties preparing food, it can leave you more reliant on convenience foods that are often higher in fat, salt and sugar.

Symptoms such as stress, depression, or fatigue can be a factor in weight gain, whilst for some people they can lead to a reduced appetite and weight loss. Difficulties with swallowing might mean it's not easy to get enough nutrients and energy from food to maintain your weight.

If you're struggling with your weight, you certainly won't be alone. Ensuring your diet is well-balanced can be an active part of self-management. You may find a good diet helps with some of your symptoms or reduces the impact of MS on your life. It can also offer you a sense of control when life with MS feels unpredictable.

Diet is a very personal thing. You'll have your own likes and dislikes. It can be difficult to stick to anything that is too prescriptive (or restrictive) over the long term. You'll be more successful if you find something that fits your budget and lifestyle, is easy to prepare and doesn't exclude foods that you enjoy. The best approach to any dietary changes you make is to try it and see. It can be helpful to keep a food diary to monitor not only what you're eating and when, but how it makes you feel and whether there has been any effect on your MS.

So, what is a healthy diet? The NHS advice on a healthy diet is a good place to start. This diet is based on reducing your risk of heart (cardio) and blood vessel (vascular) disease and some cancers. It includes foods from all the food groups and can help you get a good balance of all the nutrients you need to keep as active and healthy as possible. A good diet can help with managing symptoms like constipation, fatigue, pain, weakness and depression. Drinking plenty of fluids is important too to keep you hydrated and help your bladder and bowel function.

If you've gained weight, losing even a little bit could have a positive impact on a wide range of symptoms, reduce pressure on your joints and make mobility problems easier to manage. It can also boost your mood, self-esteem and confidence.

If you're underweight, eating well can help ensure you're getting more of the right nutrients. This is important to reduce your susceptibility to malnutrition, other illnesses including osteoporosis and cardiovascular disease, and pressure ulcers. Being well nourished also contributes to muscle strength and can improve memory and thinking skills.

There are several diet plans which are advocated for MS that claim to improve symptoms or even cure MS. Diet is a notoriously difficult area to research, and dietary information is often conflicting. There is currently insufficient evidence to recommend any specific diet for anyone with MS, aside from for general health.

If you do decide to try one of the MS diets, there are a few things to be aware of.

- They often include expensive ingredients or dietary supplements, so is it affordable?
- Do you have time for, and can you manage, all the preparation that might be involved?
- Will you still be able to eat with friends and family when you're at home or out for a meal?
- If some food groups are restricted, is it still nutritionally balanced?

If you're thinking of making big changes, it can be helpful to speak to a health professional, like a dietitian or your GP, to make sure you won't be missing out on essential nutrients that could impact on other aspects of your health.

Sometimes MS symptoms can make preparing food more difficult. It could be that you struggle with fatigue or can't stand for long periods. You may find it difficult to chop vegetables or lift heavy pans due to dexterity problems, altered sensations, weakness or tremor. It can be helpful to talk to an occupational therapist if you're struggling. They may be able to suggest strategies or gadgets that can help you in the kitchen. Also, consider how you might be able to make things easier for yourself. For example, buying tinned, fresh or frozen vegetables that are already chopped to save you time and effort.

If you're really struggling, consider asking for a referral to a dietitian or a speech and language therapist (SLT) for their input and support. They may be able to suggest appropriate supplements, advise on the consistency of foods, or look at alternative methods of feeding that could help.

Staying active

Staying as active as possible when you live with MS can have a positive effect on your symptoms. Being more active can help you:

- maintain your weight
- increase your general fitness
- reduce fatigue
- improve your balance, strength, flexibility and mobility
- improve your bladder and bowel function
- maintain good bone health.

The benefits of exercise on mental health are also being increasingly recognised, particularly outdoor activities where you're connecting with nature and stimulating your senses.

There are lots of options when it comes to exercise. What is best for you will depend on factors such as your current fitness level, what you enjoy doing and accessibility. There are now lots of online resources that allow you to carry out exercises at home. These can be a good option if it's difficult for you to get out to a class or a gym, or if exercising around others is not your thing.

Activities such as yoga, Pilates and Tai Chi can be a good option if you want to try a gentler approach. These activities focus on strength, flexibility and balance. The exercises can often be adapted or be done sitting or lying down. A good instructor or a personal trainer at the gym should be able to advise you on suitable adaptations if needed. If you're looking to improve your cardiovascular health then you might choose something like walking, running, swimming, cycling or dancing.

Any weight bearing exercise will help with strength and bone health. This might include lifting weights in the gym, or exercising with small hand weights, but activities such as climbing stairs, squats and lunges, yoga, aerobics and walking are also classed as weight bearing. So, it is possible for most people to include some weight bearing activities in their life.

If these traditional types of exercise aren't your thing, perhaps consider options such as joining a local Green Gym – a free outdoor volunteering initiative where you're having a positive impact on your community as well as getting active. Activities include weeding, pruning, digging and planting. You choose what (and how much) you want to do and how often you want to go, so you don't have to worry if you're having a bad day.

There might be things you've done in the past but need to approach in a different way to be able to carry on enjoying them. Many activities can be adapted, such as horse riding and sailing, giving you more options to explore.

When it comes to staying active, the most important thing is to choose something that you enjoy as you're more likely to commit to doing it regularly. For your chosen activity, don't only think about the 'what', also think about the 'where', 'with who' and 'how'.

Does time outdoors in the fresh air give you an extra boost to your mental health or are you more likely to duck out if the weather is bad? Do you prefer to exercise alone or with others? Being with other people can add a social element and make you more committed. But if having an exercise buddy makes it feel too competitive or forces you to exercise out of your comfort zone, then maybe you'd be happier going it alone – perhaps with some music or a podcast for company. Can the activity be done in a position that you can manage better? For example, you may find working on raised beds in a garden easier than kneeling on the ground.

Sometimes having MS can mean there are barriers to participating in even the gentlest of exercise. This is where it can be helpful to think about functional activity rather than exercise in the traditional sense. The focus here is simply on trying to carry out day-to-day activities like getting up and down from the sofa, reaching for things in a cupboard, lifting the laundry basket, or walking up stairs. These activities can help you maintain some strength and flexibility which is still valuable, for example in helping prevent falls. Carrying out breathing exercises can also be beneficial as they can make you less susceptible to chest infections.

On days when just getting out of bed feels daunting, even the smallest amount of physical activity can have benefits. Try to do a little bit and see how it goes. For example, rather than trying ten reps of an exercise, aim for two. Setting achievable goals will help you feel a sense of satisfaction and give you something to build on. You can always stop if it feels too much or count it as a win if you achieve more than you thought you would. Don't be too hard on yourself if you've not done as much today, or this week, as you'd hoped – there's always another time.

Boosting your brain health

Keeping your brain active can help maintain your cognitive skills such as concentration, memory, learning, and planning. It can also boost your cognitive reserve – this is your brain's ability to improvise or find a different way to carry out a job. Increasing your cognitive reserve will help you maintain your thinking and memory skills for as long as possible.

There are lots of activities that stimulate or challenge the brain by encouraging abstract thinking, problem solving, strategy development, sequencing and organisation. Just as with physical activity, the key is finding something you enjoy. The following are some ideas you might want to explore.

- Reading for pleasure or keeping a journal.
- Learning a new language or revisiting one you've studied previously.
- Playing board or card games.
- Solving puzzles such as Sudoku, crosswords and word searches.
- Brain training games and apps.
- Finding a TV quiz show you enjoy and trying to answer the questions before the contestants.
- Listening to music, singing or playing a musical instrument.

- Art and craft activities such as drawing, painting, sculpting, knitting or sewing.

Boosting your brain health may improve your brain's ability to compensate for some of the damage MS has caused. It can help your brain reroute messages or adapt healthy areas to take on new functions.

Stopping smoking

People with MS who smoke have been shown to progress at a faster rate than those who don't. If you do smoke, you can reduce this risk by stopping.

Giving up isn't easy, especially if you don't really want to. But it could have a significant impact if you can quit. There's a range of support programmes and products available to help you stop. If you're not sure where to start it can be helpful to speak to a pharmacist, your GP or a local Stop Smoking Service for advice and encouragement. It's common for people to try and quit a number of times before they succeed for good. Don't feel embarrassed if you need to seek support again if you aren't successful at first.

Some people consider vaping to help them stop smoking. This is where an electronic device is used to inhale nicotine in an aerosol, or vapour, instead of smoke. It's generally seen as being less harmful than smoking as e-cigarettes don't contain cancer-causing tobacco or many of the toxic chemicals found in cigarettes. But this claim isn't supported if you have MS. The blood-brain barrier (BBB) separates the blood from the cerebrospinal fluid (CSF) and acts as a barrier to some cells, particles and large molecules entering the brain. It is thought vaping could allow more cells to be able to breach the BBB which may trigger neuroinflammation. Like smoking, vaping is also thought to irritate the cells lining the lungs. So, nicotine replacement products such as lozenges or patches may be a better option if you choose this route to help give up.

Drinking sensibly

Sensible drinking means not drinking alcohol to excess to reduce the risks of harm to your health. It's about knowing your limits and being aware of how much you're drinking. Current guidelines for men and women recommend drinking no more than 14 units of alcohol a week across at least three days. That's equivalent to around six medium glasses of wine (175ml) or six pints of beer (4% strength).

If you're concerned that you're regularly exceeding these guidelines you might want to consider cutting back. You don't have to stop drinking completely to feel the benefits of drinking less. Having two or three alcohol-free days each week or switching to lower-strength or low-alcohol alternatives are all positive steps. But some people find stopping completely is the best way to avoid slipping back into bad habits.

The following are some more tips to help you drink sensibly.

- If a few drinks in the pub are a big part of your social life, think about other ways to see friends such as meeting for coffee and a walk, or seeing a film.
- If you're in the pub, avoid getting into rounds and don't feel you have to say yes to another drink just because everyone else is.
- If you tend to reach for a drink to handle stress or because you're bored, try to find a healthier activity to occupy you instead.

Alcohol can affect sleep, mood, balance and bone health – all things which can already be affected in MS. So, more good reasons to be extra mindful about how much you are drinking.

Drinking less has a wide range of health benefits. You may notice improvements in your energy, mood and sleep. Plus, it may make managing your weight easier and help lower your blood pressure and cholesterol levels. Drinking less also reduces your risk of cancer, liver and cardiovascular disease.

Reducing stress

Experiencing stress is a natural part of life. Deadlines at work, family commitments, relationship problems or financial difficulties can all lead to you feeling under pressure. Adapting to health issues such as living with MS, and the changes it can bring, can add additional stress.

You might find that when you feel under pressure some symptoms feel worse, or old symptoms return. This can be a good indicator that you need to pull back from, or seek support for, whatever is causing you stress before you become more unwell.

It's not possible to remove all the sources of stress in your life, so the key is finding an approach that helps you manage stress better to reduce its impact. It can help to take a practical approach to managing stress. First you need to identify what is causing you to feel under pressure. Then think about the steps you could take to manage it better. Here are some suggestions to consider.

- Would planning ahead or enlisting the help of others be beneficial?
- Does removing yourself from the stressful situation for a short time help? For example, by going for a walk, carrying out a breathing/relaxation exercise or letting off steam by shouting, dancing wildly or screaming. If work is the main issue, is it possible to be signed off for a while?
- Try taking a step back to see if it changes your perspective on the problem. Give yourself permission to relax or rest without feeling guilty.
- Don't keep things to yourself. Talk it through with someone else. It may show things in a different light, or they may be able to offer support.

There isn't going to be one quick fix or strategy that works for everyone or in every situation. It'll take time to figure out what works best for you. If you've tried some of these techniques but you're still struggling, speak to your GP or MS team. They can refer you for further support.

Improving sleep

Finding it difficult to get to, or stay, asleep can leave you feeling stressed, anxious, tired or sleepy the next day. Low energy levels can make it difficult to concentrate and can affect your memory and mood. Poor sleep can also make other MS symptoms feel worse.

Adopting good sleep hygiene techniques, such as avoiding caffeine and alcohol late in the day, establishing a regular bedtime and finding a way to relax, can improve your sleep. A good diet and regular physical activity can help too but try to avoid heavy meals or anything very energetic (with the exception of sex) too close to bedtime as this may stop you from sleeping.

Blue light emitted from screens (like your phone) can hinder sleep, so it's best to turn them off at least an hour before bed. This could mark the start of a winding down routine where you have a warm bath, read, listen to a podcast or some music, or carry out a meditation exercise. Your sleep environment is important too. Usually a quiet, dark, well-ventilated room makes it easier to fall asleep – but it's very individual, so find what works best for you.

Consider the position you lie in. Does your body feel supported and relaxed? If not, tucking a pillow under your legs, or behind your back, may help.

You may be experiencing symptoms that are disrupting your sleep, such as pain, muscle stiffness (spasticity) or spasms, irregular breathing, or needing the loo during the night. If you experience pain, you might find using something that you can heat up whilst you stay in bed, such as an electric hot water bottle, helpful. If you share a bed with a partner, ask them if you move around a lot. Some people experience restless legs or spasms that they're not aware of. Similarly, your bed partner may notice if your breathing is irregular.

Speak to your GP or MS team if you're experiencing any of these symptoms to see if they can be better managed. Also talk to them if the side effects of any medications are making sleep more difficult as there may be alternatives.

Preventing loneliness and social isolation

Strong family connections and good social networks are central to our sense of wellbeing. But we're all affected by loneliness at certain times in our lives where we feel alone or separate from others. You may feel this way if you're spending a lot of time on your own, particularly if you live alone, don't have a close friend or partner, have had to stop working, or you don't get out much socially. It's also possible to feel lonely in a large crowd or even with people you know. It can be a temporary feeling or may be more long-lasting.

Social isolation is different to loneliness. This is where you have a lack of social contacts or fulfilling relationships and don't interact with people on a regular basis. Social isolation can be more likely if you stay at home for long periods of time, if you don't communicate with family or friends, or if you avoid contact with others even when you have the opportunity.

Living with a long-term condition can put you at higher risk of experiencing loneliness or social isolation. They can both have a negative impact on your mental health and leave you feeling anxious, stressed, low or depressed.

There are simple actions you can take to try and prevent loneliness and social isolation.

- Keep in touch. It might feel like everyone is always busy but try to touch base with family, friends and colleagues regularly to feel more connected. Most of us love to hear from others to catch up. If people are at a distance, or it's difficult for you to get out due to caring responsibilities or mobility issues, you could call them for a quick chat, or message them instead. Messaging can be a good option as it means people can respond when it's convenient for them.

- Do things you enjoy. Spend time outdoors in the fresh air, connect with nature, go for a walk, read a book, be creative, listen to music. Whatever gives you joy. This can boost your mood and give your mind something to focus on.

- Connect with others by joining a group. Is there a particular activity you enjoy, or would like to try, that can be done as a group? For example, a book club, dance class, music group or crafting group. Groups could be in person or online. It can be easier to meet and chat to new people if you already have common interests.

- Volunteering. Do you have a particular interest or skill that you could share with others? It could make a real difference to you and your community. It can also help you maintain a sense of worth. It's a great way to give something back, gain experience and build contacts.

- Share your feelings. It's easy to compare your life with others, but this can make you feel lonelier and more isolated. People tend to just share the good bits of their lives, especially on social media. Talking about how you're feeling might let other people feel they can open up too.

Symptom management

Many MS symptoms have the potential to influence your general sense of wellbeing. If bladder or bowel issues, fatigue, pain or spasticity aren't being managed well, it can have a negative impact on how you feel. It's important to keep taking any medications as prescribed, as well as keeping up with any exercises suggested by a physiotherapist or techniques that you've been taught such as cognitive behavioural therapy (CBT), to get the best benefits.

If you have new or worsening symptoms, or your symptoms aren't responding to your current treatment, it's worth exploring other options with your GP or MS team. Unfortunately, some symptoms can't always be completely resolved. It may be a case of managing them as well as possible to reduce their impact on your life.

Mood matters

Looking after your mental health is just as important as your physical health. All the things mentioned in the previous sections – such as feeling in control of your life, eating well, keeping your mind and body active, managing stress, maintaining social interactions, good quality sleep and managing symptoms well – can all have a positive benefit. But, if despite these approaches, you find you're struggling with low mood, anxiety or depression, seek help from your GP or MS team. They may be able to refer you to courses on mindfulness, CBT or other approaches that can help. They can also discuss whether you would benefit from counselling and/or medication.

Preventing complications

Some MS symptoms can make you more susceptible to complications which can worsen your current symptoms or trigger new ones. For example, bladder infections, constipation and pain can all be triggers that make spasticity and spasms worse. As far as possible, anticipating and preventing complications is vital in the management of MS.

Bladder infections can be particularly problematic. Simple lifestyle changes such as drinking more water and good personal hygiene (for example wiping front to back and emptying your bladder after sex) can help reduce your chances of getting a urinary tract infection (UTI). If you're a woman going through the menopause, it may be useful to rule out hormonal causes that may contribute to an increase in UTIs, such as vaginal dryness. If you use a catheter, it's important to be taught a good, clean technique to reduce the risk of infection.

If you do get a UTI, it's important to recognise the symptoms and get treatment as soon as possible to prevent complications. As well as potentially worsening MS symptoms you may be at a higher risk of developing sepsis, which can be life-threatening. If you experience recurrent UTIs you may be offered a testing kit to keep at home to speed up diagnosis and treatment.

Many people with MS live with spasticity. The main symptoms of spasticity are muscle stiffness and spasms which may cause pain and

impair function. Weakness can also be an issue. Some people also experience ataxia. Ataxia is when you're unable to coordinate the movement of your muscles. It can result in clumsiness, unsteady gait, difficulty with moving your limbs and, in some cases, tremor. These three symptoms can all contribute to a loss of function and make it difficult to carry out everyday tasks like eating, drinking, dressing and walking.

Weakness, in combination with spasticity, poor posture and a lack of movement, can lead to a permanent shortening of the muscles known as a contracture. This is where the affected joint remains in a bent position. A contracture can further impair function, such as making it difficult to be seated, or cause additional discomfort and pain. So, it's important to move as much as possible to keep your muscles supple and decrease the risk of a contracture developing. A physiotherapist can teach you stretches, exercises and massage techniques, especially if it's difficult for you to stay active. If you can't carry these out yourself, they can teach someone else how to gently move your limbs for you – this is known as passive movement.

Maintaining the integrity of the skin is an important aspect of self-care. It's important to keep your skin as clean, dry and well moisturised as possible. Eating well will provide your skin with all the nutrients it needs to keep healthy too.

If you notice your skin has red or dark marks, or sore areas, always seek support from your GP, practice nurse or a district nurse. What starts as a minor skin irritation caused by pressure or friction can quickly develop into a pressure ulcer if not managed properly.

You're at increased risk of pressure ulcers forming if you have poor posture, spend a lot of time sitting, or are in bed for a large part of the day. This is because pressure ulcers can develop if part of your body is compressed for a long period, and the blood supply to that area of skin is cut off. It's important to change position regularly to reduce the risk of pressure ulcers forming.

Your MS nurse, a district nurse or OT can also advise on suitable equipment to reduce the risk of pressure ulcers.

Health screening

It's easy to assume that any symptoms or issues you're experiencing are due to your MS. But you're still susceptible to other health conditions, just like everyone else. If you have a health issue, be mindful that it may not necessarily be linked to your MS and do raise any concerns with your GP to rule out other causes.

It's also important to keep up with regular health, dental and eye checks when offered. This could include preventative vaccinations, cancer screening programmes, age-related health checks and bone health assessments. By being proactive, you're giving yourself the best chance of staying healthy.

Attending breast, cervical, prostate and bowel cancer screenings, as well as routine blood pressure and cholesterol checks, increases the likelihood of any problems being caught early. Earlier detection often means less aggressive treatment.

Seeing a dentist for regular check-ups is important so any mouth-related health problems can be spotted early. Some MS medications can cause a dry mouth which puts you at higher risk of tooth decay, gum disease and infections such as oral thrush. If you experience weakness, stiffness or spasms in your hands or arms, you might find it harder to care for your teeth. Your dentist can advise you how best to look after your oral health.

Regular eye tests will detect any changes in your vision over time. An optician can test for eye problems, such as double vision and nystagmus, which are common in MS. They can also check the health of the back of your eye and the optic nerve. Changes to vision can put you at more risk of trips and falls if not corrected, so eye tests also have a vital role to play in fall prevention.

Sometimes having MS can make it more difficult to access routine check-ups. Often adaptations can be made to overcome any barriers. For example, some dentists and opticians offer home appointments. When you book, let people know of any additional requirements you have so you don't miss out.

Find out more

Our website resources

Wellbeing

Brain health
mstrust.org.uk/brain-health

Diet and MS
mstrust.org.uk/diet

Diet and MS symptoms
mstrust.org.uk/diet-and-symptoms

Exercise and MS
mstrust.org.uk/exercise

Posture and MS
mstrust.org.uk/posture

Sleep
mstrust.org.uk/sleep

Smoking
mstrust.org.uk/smoking

Stress
mstrust.org.uk/stress

Symptom management

Anxiety
mstrust.org.uk/anxiety

Ataxia
mstrust.org.uk/a-z/ataxia

Bladder problems
mstrust.org.uk/bladder

Bowel problems
mstrust.org.uk/bowel

Depression
mstrust.org.uk/depression

Fatigue
mstrust.org.uk/fatigue

Pain
mstrust.org.uk/pain

Pressure ulcers
mstrust.org.uk/a-z/pressure-sores

Spasticity and spasms
mstrust.org.uk/spasticity

Tremor
mstrust.org.uk/tremor

Weakness
mstrust.org.uk/weakness

Our publications

Living with fatigue (book)
mstrust.org.uk/204

Managing your bladder (book)
mstrust.org.uk/429

Managing your bowels (book)
mstrust.org.uk/430

Managing spasticity and spasms (book)
mstrust.org.uk/400

Other organisations and support

Adaptive horse riding – information from Riding for the Disabled
rda.org.uk

Adaptive sailing – information from RYA Sailability
rya.org.uk/sailability

Alcohol advice – information from the NHS and Drinkaware on how to reduce or stop drinking alcohol
nhs.uk/live-well/alcohol-advice
drinkaware.co.uk

The Eatwell Guide – the NHS guide to a healthy diet
nhs.uk/live-well/eat-well/the-eatwell-guide

Every Mind Matters – information to support your mental health from the NHS
nhs.uk/every-mind-matters

Exercise for bone health – information from the Royal Osteoporosis Society
theros.org.uk/information-and-support/bone-health/exercise-for-bones

Green Gyms – more information from the Conservation Volunteers
tcv.org.uk/greengym

Quit smoking for better health – information from the NHS
nhs.uk/better-health/quit-smoking

Self-Care Forum – national charity working to embed the concept of self-care into everyday life
selfcareforum.org

Staying active – NHS information on staying active if you have a long-term health condition
myplannedcare.nhs.uk/my-health-and-wellbeing/staying-active

6 Adapting to change in your family, social and work life

Progressive MS can have an impact on all aspects of your life and the people around you. Spending time with your family, socialising with friends and having a job that engages and satisfies you are all valuable parts of life that help you to feel fulfilled. They contribute to our overall wellbeing and are connected to our sense of self and identity. They are also important for keeping your brain healthy, whilst reducing the risk of loneliness and social isolation. If MS gets in the way of these areas, it can feel like the normality of your life is disrupted and things may feel more of a challenge than before.

In this chapter, we explore how progressive MS may require you to adapt and make changes to key areas in your life when faced with disabling symptoms. We discuss the steps you can take to maintain your independence at home, in your social life and at work.

Facing new or worsening symptoms and increasing disability

Changes with your MS, such as gradually worsening symptoms, can trigger a whole range of emotions and remind you of the fears you had for the future when you were first diagnosed.

- Am I going to need to use a wheelchair?
- How is this going to impact my relationship with my partner?
- How will I remain independent and maintain my dignity?
- How will this affect family life?
- How will this impact my work life?

If you find yourself feeling very worried and anxious about the future as a result of changing symptoms, give yourself space to work through

these emotions and reach out for support if you need it (see chapter 2 for more on psychological support and coping strategies).

Although none of us knows what the future holds, when symptoms start to have a greater impact on your life, it might be time to begin thinking ahead and planning for the prospect of change in the future. This can help you to feel more in control in unpredictable or uncertain times.

Changing roles at home

MS symptoms may affect your ability to do daily activities. It's possible that you may have to learn how to do certain tasks around the home differently. You may require more support or have to give them up altogether.

If you live alone, it may be that you have to look for external help to keep on top of the household chores. You may need to hire a cleaner or gardener, for example, or use a meal delivery service to make your life a little bit easier.

If you have a family, the roles and responsibilities in the family home may change. Perhaps fatigue becomes more of an issue, so you find it increasingly difficult to complete your share of the chores at home. These tasks may have to be delegated to other family members (or external help as discussed above). This will save your energy levels so you're still able to engage in the more enjoyable aspects of everyday life, like playing with the children or meeting up with friends. In these situations, it can take some time for everyone to adapt to a different way of doing things, including yourself.

It's important for everyone to keep talking to each other and share how they're feeling when roles change. It's easy for feelings to go unnoticed if they're not spoken about. Perhaps your partner is starting to feel overburdened. Or maybe you are feeling frustrated that you can't do as much around the house anymore. Two-way communication can help you work through these issues and be clear about your expectations. Remember to keep talking so you're all on the same page.

If you reach a point in your MS journey where you need more support with daily life at home, you may become dependent on your partner (or another close family member or friend) for some of your care needs. Taking on a caring role can often affect the dynamic of any relationship, so it's important to discuss whether it's something you both want. Often a caring role will involve intimate tasks, such as washing, dressing and toileting. Some families, or people who live alone, may seek support through paid carers instead (see chapter 8 for further discussion of care needs, social care and advance care planning.)

Embracing assistive equipment

The prospect of using assistive equipment in your daily life may feel daunting. You may have a negative view of equipment and adaptations initially. They may act as a reminder of what you were once able to do. You may also feel like they draw attention to you and your disability.

It can help to reframe how you look at aids and equipment, so you see them in a more positive way. Essentially, they're tools to help you keep your independence. They enable you to continue doing the meaningful things in your life.

Walking equipment, such as a stick, frame or wheelchair, may mean you're still able to walk your dog, get out of the house to visit friends, and go to a local community group or fitness class. Household aids, such as a portable frame or grab rails in the bathroom, may mean you can use the toilet yourself or have a bath on your own.

Aids and equipment can break down the barriers caused by MS. They enable you to continue doing daily tasks and the activities you enjoy for longer whilst maintaining dignity and independence.

An occupational therapist (OT) can provide an assessment if you think aids or equipment would benefit you. A physiotherapist can also provide advice on using mobility aids. (See chapter 4 for more on the support an OT or physiotherapist can provide.)

Maintaining your social life

Connecting with people and maintaining friendships can be very important for your mental health and self-esteem. Having a social life can:

- reduce your risk of isolation and loneliness
- give you events to look forward to
- offer a much-needed break from work and family commitments
- give you a different space to be yourself and share stories and experiences.

Friends can offer an extra layer of support that may feel different from the support your family or health professionals provide. You may feel more comfortable discussing certain aspects of your life with them, for example.

Sometimes the symptoms of MS may make it feel harder for you to get out and see your friends. Travelling may be tiring for you, or certain venues may present practical problems around accessibility. It can help to make your friends aware of the extra challenges you face (particularly invisible symptoms, such as fatigue and bladder problems) so social events can be tailored to work for you. It may feel daunting initially, but many people won't know much about MS and may have misconceptions, so you play a key role in educating them and letting people know the barriers you face. Supportive friends who care about you should be accommodating and work with you to find solutions so you can still attend get-togethers.

Overcoming barriers and adapting social events may involve having plenty of notice of any meet ups, planning for easy access to toilets, choosing shorter routes for walks or perhaps suggesting a takeaway at yours instead of going out for dinner. It can also help to set expectations and explain to your friends that sometimes your symptoms (such as fatigue) may mean you have to say no or pull out at the last minute.

There are many ways to stay in touch with people remotely if getting out of the house feels too much. You can chat to your friends over the phone or through a video call. There are also online forums and groups where you can meet new people virtually.

Although maintaining your social life may feel harder when you have MS, with supportive and accommodating friends who understand the barriers you're facing, you should still be able to keep in touch and be involved in social events that are accessible for you.

Support to stay in work

Work is about more than being financially independent. It gives you structure to your day, enables you to make connections with different people, helps you learn new skills, contributes to your brain health, and forms an important part of your identity.

It's difficult to predict how your MS may affect your ability to work going forward. The impact your symptoms have on your working life will be different depending on what your job involves. For example, if you have an office job that requires you to be creative, problems with walking may not be too much of an issue, whilst difficulties with concentration and memory could be more challenging.

In most jobs, you don't have to tell your employer about your MS diagnosis. (There are exceptions to this, such as if you're in the armed forces or drive a passenger or heavy goods vehicle.) However, telling your employer about your MS can help you access support at work. Under the Equality Act, your employer is required to make reasonable adjustments to help you stay in work. This can involve:

- having a parking space closer to the building
- moving your desk to a quieter part of the office
- taking frequent short breaks
- ensuring your workspace is set up to suit your needs
- changing your working hours or pattern.

The government's Access to Work scheme can help to cover the costs of practical support at work beyond reasonable adjustments (see link in Find out more for further information).

It can be useful to seek support if MS is affecting your working life. An occupational therapist, your MS nurse or a union representative (if you have one) would be a good starting point. They can help you in discussions with your employer about how your MS affects you and what support you might need. (See Find out more at the end of this chapter for resources on support at work, including our checklist that guides you through disclosing MS to your employer.)

There are also vocational rehabilitation services available for support in some areas. These specialist services are usually run by a team including occupational therapists and psychologists. They help people with health conditions overcome any barriers they may face in their current job, when returning to work after a period of absence, when seeking new employment or when considering medical retirement. Your GP or MS team can refer you to your nearest service if there is one in your area.

Try not to make any drastic decisions about work during times of significant change with your MS. Instead, wait for things to settle and give yourself some time to think about your options and the potential implications of any decisions you make.

Leaving work

MS symptoms can make it increasingly challenging to stay in work. For some people, choosing to leave work could be the right decision.

It may take some time for you to decide this and come to accept that you can no longer keep going the way you always have. It's important to consider the potential implications of leaving work, both for you and your family. You may also want to look at your options, such as retiring on medical grounds (medical retirement). Talking things through with someone you trust can help with your decision making.

You may wonder how you'll fill your time if you no longer work. The loss of routine and daily connection that work brings can be a difficult adjustment. But stopping work doesn't have to be entirely negative. It may give you the time to do something that you've always wanted to

do, such as take up a new hobby or start volunteering. Maybe you've wanted to spend more time with family or friends, but work got in the way. By pursuing new interests, you may connect with new people and expand your social network.

Leaving work is likely to have financial implications, so it can be worthwhile to explore the support available to you.

Financial support

There is a range of financial benefits that people with MS may be eligible for. They can help to cover some of the extra costs that come with living with a health condition. It can take time and effort to understand what benefits you're entitled to and to go through the application process.

A good starting point is to get a benefits check. This can be done using a benefits calculator online (e.g. Turn2us) or by speaking to a local advice organisation with expertise in this area, such as Citizens Advice (see Find out more section at the end of this chapter). You'll need to answer questions about your financial situation (such as your income and savings) and then you'll be able to see what benefits you can claim. Organisations, like Citizens Advice, can also guide you through the application process and offer support if your claim is rejected.

Don't forget to revisit your benefits if your circumstances change in the future. For instance, you may find yourself eligible for help when you didn't meet the criteria before, or you may be entitled to benefits at an enhanced rate.

Final thoughts

Adapting to the presence of MS in your family, social and work life can be a challenge that can take some getting used to. In all these areas, communication really is key to ensuring that you're supported in the right way, helping you to remain independent in every aspect of your life for as long as possible.

Find out more

Our website resources

Benefits
mstrust.org.uk/benefits

Equality Act
mstrust.org.uk/equality

Equipment
mstrust.org.uk/equipment

Family, care and money
mstrust.org.uk/family-care-and-money

Grants
mstrust.org.uk/grants

Working life
mstrust.org.uk/work

Our publications

Someone I know has MS (information sheet)
mstrust.org.uk/441

Talking with your kids about MS (book)
mstrust.org.uk/316

Telling people at work you have MS (information sheet, including disclosure checklist)
mstrust.org.uk/459

Other organisations and support

Acas (Advisory, Conciliation and Arbitration Service) – free, impartial advice on workplace rights
acas.org.uk

Access to Work
gov.uk/access-to-work

Benefits
gov.uk/browse/benefits

Citizens Advice
citizensadvice.org.uk

Disability Law Service – an independent charity providing free legal advice to people with MS on employment and welfare benefit issues
dls.org.uk

Scope – a disability equality charity providing free, impartial advice and support on issues affecting people with disabilities, including finance, work and benefits
scope.org.uk

Turn2us – a national charity offering financial support and information on welfare benefits and grants, including a benefits calculator
turn2us.org.uk

7 Ageing with MS

In the past, MS was considered a young person's condition. Diagnosis was typically between the ages of 20 and 40. But MS doesn't significantly shorten your life expectancy and many people with MS live for as long as the general population. Studies suggest that on average MS reduces your life expectancy by six to seven years, and advances in MS treatments mean this gap is closing all the time. Many people diagnosed in their 20s and 30s will live with MS for 50+ years, so well into their 70s or 80s.

The age that people are diagnosed has shifted slightly in recent years. It is now more typical to be diagnosed in your 30s and 40s. Also, at one time, it was thought that MS rarely developed in people over 50, but opinion is changing as more cases are now being identified in this age group. When diagnosis is after the age of 50, this is known as late-onset MS (LOMS), regardless of the type of MS you're diagnosed with. The number of cases of LOMS is particularly increasing in women.

The pattern of MS usually changes as you age. Relapse rates tend to decrease, with fewer acute active lesions seen on MRI scans. Where relapses do occur, recovery is not as good as before. You're also at more risk of your MS becoming progressive as you get older.

Why the disease course changes as you age

There are a variety of possible factors that could explain the changes in disease course seen in older people with MS.

The ageing immune system

Our immune system works until the end of our lives. But as we age our immune system changes. This change is known as immunosenescence. The balance of immune cells alters with a decline in many cell types. So, our immune response may not be as good as when we were younger. For example, you may find you are more prone to infections, and they are more severe in nature. Another thing that can happen is that you don't respond as well to vaccinations. They

may not be as protective as they have been in the past. This increased susceptibility to infection that comes as part of ageing can make it more challenging to manage MS.

As we grow older, we also experience low levels of constant inflammation, even in the absence of any infection. This is often referred to as inflammaging. This low-level chronic inflammation is separate to the inflammation that is part of MS.

In MS, some white blood cells release chemicals that cause acute inflammation. It's this type of inflammation that damages the myelin, nerve fibres and oligodendrocytes (myelin-making cells) which can result in relapses. The reduced function of white blood cells as we age could explain why older people with MS tend to have fewer relapses, or none at all. If the cells aren't working as well as they used to, it's likely they'll cause less acute inflammatory activity.

Chromosome changes

There are other changes to the cells in our bodies as we age. The ends of our chromosomes are protected by a region of DNA called telomeres. Over our lifetime, as cells divide, the telomeres get shorter. In people with MS, this shortening can happen more quickly than it does in normal ageing – especially if you have progressive MS. Shorter telomeres have been linked with higher levels of disability and a decrease in brain volume in MS (atrophy) – which can contribute to worsening cognitive symptoms.

Chronological vs biological age

We all age at different rates. Your chronological age is how old you are whilst your biological age is how old your body thinks it is based on how much ageing and damage has occurred to your cells. For some people, their biological age will be the same as their chronological age, but we all know someone who seems young for their age whilst some people appear older than they actually are.

Our biological age is influenced by many factors including our chronological age, our genes, our physical and mental health, and our lifestyle. Although you can't change your genes or some health conditions, there are positive steps you can take to reduce your biological age.

These include:

- managing your MS and any other health conditions well – taking medication as prescribed, attending check-ups, engaging with any recommended screening and/or vaccinations
- looking at your diet and making healthy food choices
- staying active and taking part in exercise where possible
- taking care of your mental health – managing stress, anxiety and/or depression
- not smoking
- having a healthy relationship with alcohol
- improving your sleep – both the amount and quality
- maintaining relationships and social contact to avoid loneliness/social isolation.

Increased risk of infections

When you have an infection, it can cause a temporary worsening of your symptoms which can often resemble a relapse – known as a pseudorelapse. Once the infection has cleared, the symptoms usually subside. It's important to recognise infections early and get them treated if appropriate. Older people with MS are particularly at increased risk of recurrent urinary tract infections (UTIs), skin infections and pneumonia.

Although vaccinations may not work quite as effectively when you're older, it is still important to keep up with recommended immunisations, such as the flu jab, as they may reduce the severity of any infection. Your GP surgery will be able to advise you on which immunisations you're eligible for.

Comorbidities

As you get older it's not unusual to live with several health conditions whether you live with MS or not. These are known as comorbidities. Common comorbidities as we age include conditions such as recurring infections, high blood pressure, type 2 diabetes, osteoporosis and depression. Living with two or more health conditions can affect your health in many ways. They can have a greater impact on your health together than they might separately.

In MS, having comorbidities is linked to higher levels of disease activity and can impact on relapse rates and physical disability. Cognition can also be affected – older people with MS often have more difficulties with memory and visual learning.

Living with MS is linked with an increased risk of cardiovascular disease, particularly heart attacks and stroke. MS patients with heart disease have higher levels of brain atrophy – the loss of neurons and the connections between them – and progress more quickly than those who have a healthy heart. People with LOMS are particularly at higher risk of heart disease.

Having one or more comorbidities can make MS management and treatment more complex. Living with additional conditions can further impact on your quality of life, your ability to work or socialise, and increase your risk of dying prematurely.

Addressing any comorbidities should be part of your MS care. Don't assume changes to your health are related to your MS. It's better to get any health concerns investigated thoroughly by your GP so they can be treated effectively, and to limit their impact on your MS. It's also important to let your MS team know if you've been diagnosed with another condition.

It is not unusual to be taking a variety of medications both for your MS and any other conditions you are living with. This is known as polypharmacy. Although it's important to take your medications as prescribed, there is the risk that some medications may interact with one another or negatively impact on your MS. For example, some drugs prescribed to help with bladder problems can cause constipation, which can worsen other symptoms like spasticity. They

can also have a negative effect on your memory and thinking. It's important to have regular reviews of your medication to monitor the benefits and any negative impacts, and determine what treatments might be reduced, stopped, or switched, to resolve any issues.

Preventative measures are key to living better with MS. Blood pressure and cholesterol checks are important to help prevent cardiovascular disease. As are vaccinations to reduce the risk of infections. Looking after your bone health can reduce your risk of osteoporosis. This might mean reviewing your diet and other lifestyle factors including exercise. Some medications, particularly steroids and antidepressants, can affect your bone health too. Consider attending bone density screening if offered.

All these actions can help reduce your risk of developing comorbidities.

Changes in sex hormone levels

The sex hormone oestrogen protects nerve cells against damage and degeneration (i.e. is neuroprotective) in both women and men. As we age there is a change in the levels of our sex hormones. For women going through the transition to menopause, there is a dramatic drop in the levels of oestrogen. Men also see a decline in sex hormones at around the same age as women experience menopause, but it is more gradual.

As well as the reduction in the neuroprotective effect of oestrogen, the drop in oestrogen levels also has other consequences. As we age, our bones naturally lose strength and become more likely to break. The decline in oestrogen can cause the bones to weaken more quickly. This puts you at greater risk of developing osteopenia (low bone density for your age) and osteoporosis. The reduction in oestrogen levels also drives additional changes to the immune system.

Menopause

We know that both women and men see changes in their MS as they age. But many women with MS will go through the menopausal transition after their diagnosis. Research in pregnant women with MS has shown that changes in sex hormone levels can affect the course of

MS. It's therefore reasonable to assume the changes in sex hormone levels at menopause could also have an impact on MS.

Generally, women with MS are found to have more acute inflammation and relapse activity than men up to the age of menopause. After the age of 50, this difference disappears. For both men and women, getting older is associated with a switch from a relapsing pattern to one of progression and increasing disability.

There is a general lack of research published around menopause and MS, and results are often inconsistent between studies. This makes it difficult to draw any firm conclusions about how the changes in levels of sex hormones and the changes to the immune system seen at menopause might impact on your MS.

We do know that the risk of osteoporosis increases in all women post-menopause. But it is more common in women with MS than the general population, which is why it's important to try and carry out some weight bearing exercise if you're able to. Ask for a referral for bone density screening (DEXA scan) if you're concerned.

A major challenge is that many of the symptoms of menopause overlap with those of MS. It can be difficult to determine whether the symptoms being experienced are due to MS or the menopause. Women often report increased problems with sleep, memory, attention and thinking. These symptoms are frequently seen in both menopause and when ageing with MS.

This combination of menopausal and MS symptoms, and their overlapping effects, might impact on your wellbeing at a potentially stressful time in life.

If you think you could be perimenopausal or are going through the menopause, ask for an assessment to address the issues that are most important to you. Any treatment should be tailored to your needs and wishes. As it can be difficult to establish whether symptoms are due to menopause or MS, it's common to treat them as menopausal symptoms initially and then investigate further if there is no improvement.

There are numerous treatment options for menopausal symptoms. It can take a bit of trial and error to find the right one for you. Approaches can include lifestyle changes, alternative therapies, supplements, conventional medication or talking therapies. You may want to explore whether hormone replacement therapy (HRT) is suitable for you. This can be taken in a variety of ways, including tablets, patches, gels and sprays. Again, you may have to try a few options to find the one that works best for you.

Frailty

Frailty, or being frail, is a term that's often used when describing older people, but it can be misunderstood or used incorrectly. When used properly, it describes your overall resilience and how well you're able to recover after illness or an injury. If you're frail, what would usually be a relatively minor health problem for most people, such as a urinary tract infection, could have a much more severe and long-term impact on your health and wellbeing.

The following are some of the signs and symptoms of frailty.

- Unintentional weight loss.
- Reduced muscle strength – which can affect your ability to stand, your balance and grip strength.
- Fatigue – feeling exhausted or that you have no energy.
- Incontinence.
- Changes in mobility – such as not moving as much, reduced walking speed or immobility.
- Being more susceptible to falls.
- Delirium – where you're confused, disorientated, or not able to think or remember clearly.
- Being more susceptible to side effects from medication.

Frailty is different from living with a long-term condition or disability. Many people living with frailty don't have any other health conditions. But many people with a long-term condition will also be frail. Frailty can be masked by other conditions. Many of the signs and symptoms of frailty overlap with those of MS. This means that frailty isn't always picked up by health professionals as they're focusing on your MS.

When you're frail, if one symptom deteriorates, it often has a knock-on effect on other symptoms and can lead to a downward spiral. For example, if you're struggling to eat a balanced diet, this can lead to weight loss and having less energy. If you have less energy, you become less physically active. This can impact on your strength and walking speed. If you're less mobile, your balance may worsen and put you at increased risk of falls.

If you think you're living with frailty, it's important to be proactive to maximise your health and wellbeing. Being aware of how deterioration in one area can have a knock-on effect on others is vital. Focusing on your diet, staying active, and maintaining balance, muscle strength and bone health are especially important. You can find out more in chapter 5 on living well.

There are professionals who can support you and your family if you're living with frailty. For example, an occupational therapist can help with a care and support plan to meet your individual needs, based on your goals and preferences. In some areas, there are specialist frailty teams. If you're concerned that you're living with frailty, ask your GP to assess you and refer you for appropriate support if needed.

Healthy ageing

Just as with other stages of MS, it's important to recognise that as you age any worsening you experience might not be related to your MS. It could be due to one or more of the contributing factors detailed here or may simply be changes associated with the normal ageing process. Looking after your general physical and mental wellbeing as discussed in chapter 5 can contribute to ageing well.

Find out more

Our website resources

Anxiety
mstrust.org.uk/anxiety

Comorbidity
mstrust.org.uk/a-z/co-morbidity

Depression
mstrust.org.uk/depression

Diet and MS
mstrust.org.uk/diet

Exercise and MS
mstrust.org.uk/exercise

Hormones
mstrust.org.uk/a-z/hormones

Menopause and MS
mstrust.org.uk/a-z/menopause

Osteoporosis and MS
mstrust.org.uk/a-z/osteoporosis

Sleep
mstrust.org.uk/sleep

Smoking
mstrust.org.uk/smoking

Stress
mstrust.org.uk/stress

Vaccination and immunisation
mstrust.org.uk/vaccination

Our publications

Living with fatigue (book)
mstrust.org.uk/204

Managing your bladder (book)
mstrust.org.uk/429

Managing your bowels (book)
mstrust.org.uk/430

Managing spasticity and spasms (book)
mstrust.org.uk/400

8 Care and support in the future

Whether disability progression happens gradually or more rapidly, you may eventually reach a point in your journey with MS where you need more support to help you with daily life at home. This may be because you have multiple ongoing symptoms, symptoms that are difficult to treat, or substantial physical difficulties. All of which can mean you become more dependent on other people for some or all of your care needs.

There is a range of symptoms that might indicate you need more support.

- Severe bladder and/or bowel problems such as needing to use a permanent catheter or having serious issues with constipation.
- Walking difficulties caused by mobility or balance problems which mean you need to use walking aids or a wheelchair most of the time.
- Weakness that makes it difficult to bear your own weight when standing, or that affects your grip making it hard to eat or drink unaided.
- Breathing problems which mean your breathing is shallower, takes a lot of effort and is more tiring.
- Severe muscle stiffness (spasticity) and spasms which can affect upper and/or lower limbs. This could cause issues with daily tasks like eating and dressing, or difficulties with walking. They may also cause extreme pain. Spasticity can also result in a permanent tightening of the muscles, tendons, skin and nearby tissues, which causes the joints to shorten and become very stiff (known as contracture). All these effects can make it harder to look after yourself.
- Severe pain that is difficult to manage.

- Speech and/or swallowing difficulties which affect your ability to communicate or increase your risk of choking.
- Problems with coordination (ataxia) and/or tremor which affect your walking or interfere with your ability to do everyday tasks like shopping, cooking, eating, dressing, washing and cleaning.

If you're experiencing several symptoms to this extent, you might be considered to have advanced MS. Many MS teams have members with experience of supporting people with more complex issues and some areas have an advanced MS practitioner. If you're living with advanced MS, there is still support available for your physical and mental health.

Increasing care needs

It may be that a partner, friend or other family member can help with some, or all, of your care needs to enable you to remain at home. In some situations, it may simply not be possible for someone close to take on a caring role. For example, it may be that they provide the main income for the household and need to keep working.

Equally, this might not be something that you or they want. Caring often involves carrying out intimate tasks. It can be easy to lose your identity as partners if one partner is providing hands-on care for the other. You may prefer not to blur the roles in your relationship in this way. Nobody should have to take on a caring role if they don't want to. Caring can be demanding and emotionally draining. It can lead to a complex range of emotions and feelings such as resentment, stress, guilt and burnout, even in those who take on the role willingly.

In either of these circumstances, it may be better for everyone if you think about getting some professional support in place. Social services at your local council can carry out a care needs assessment to see if you're eligible for any help with care. If you are, they'll do a financial assessment to check if you can get any help to cover the cost, but most people do have to contribute towards the cost of care. Alternatively, you can arrange your own home care through an agency or employ your own carer.

Respite care

If you're being cared for at home, you might want to consider using respite care. This is short-term, temporary care which can give you, and the people who care for you, a break and some time to yourselves. It can be given at home or, if you're able to travel, you could consider a local day care centre or other facility if you'd prefer a change of environment. If a loved one is providing a significant amount of care, a few hours of respite can give them some space to look after their own wellbeing.

Respite care can be organised through local social services or carers organisations.

Palliative care

If you're experiencing symptoms that are proving particularly difficult to treat, your GP or MS team may refer you to palliative care services. Palliative care is not just for people with cancer or with a terminal illness at the end of life. It's also available for people with other severe or complex health needs any time after their diagnosis.

Palliative care focuses on your needs rather than the underlying condition. The goal is to give you the best possible quality of life by controlling your symptoms, offering pain relief if needed, and providing you with emotional and spiritual support.

Accessing palliative care doesn't mean that your other treatments will stop – it can take place alongside other therapies and treatments. Often, you'll only need palliative care for a brief period until your symptoms are better controlled. It'll only last as long as you need it – whether that is days, weeks, months or years.

There's no age limit for accessing palliative care, and it need not involve a move to residential care or a hospice. A lot of palliative care can take place in your own home or elsewhere in the community.

More specialised care

If you live with very advanced MS, you may have a level of disability that requires more specialised care than a relative is able to provide or that can be carried out in your own home. Moving out of the family home is never an easy choice to make for anybody.

Planning ahead is always better than having to make decisions in a crisis. Finding out about the options, resources and services that are available can make it a less stressful experience should it ever be a decision you find yourself having to make. Time spent in advance on research will help you decide what service is right for you and your loved ones if the time comes.

Advance care planning

Advance care planning (ACP) is the process of thinking, and having conversations, about the care you would like in the future. In Scotland ACP is known as anticipatory care planning but the principles are the same.

You might be living well with your MS. But if it were to worsen, or if you became unwell for another reason, do you know what your treatment options might be? Who would you want to make decisions about your care if you weren't able to decide yourself?

Having an advance care plan in place – and sharing your wishes with loved ones and professionals involved with your care – means you are all more prepared if a particular situation should arise. It also means you're more likely to receive the care you want in the setting you choose.

It's up to you if, and when, you might want to think about advance care planning. You may want to put plans in place as soon as you're diagnosed or, equally, you may never feel ready. Sometimes there may be a trigger, such as seeing the experience of someone you know, or a news piece, which might prompt you to think about what you might like to happen if you were in a similar situation.

Common triggers are:

- significant changes to your MS
- receiving another diagnosis alongside your MS (comorbidity)
- retirement or needing to stop work
- the death of someone close.

Advance care plans can include anything that's important to you. What would you want people to know if you weren't able to tell them yourself? It can be as basic or detailed as you'd like. See some suggestions below.

- Your likes and dislikes – for example, any dietary requirements; sleep preferences such as wanting to sleep with a light on; your favourite radio or TV programmes; whether you prefer having a shower or bath; any lifestyle, cultural or religious matters that are important to you.
- Practical matters – such as who would look after children or pets if you can't.
- Decisions about any treatments that you don't want, and your wishes around blood transfusions, organ donation and resuscitation.
- Where you would prefer to be cared for – home, care home, hospital or a hospice.
- Where you'd like to die – this may be different from where you want to be cared for.

Some things may be easier to discuss than others. Some may be more relevant depending on what stage you're at in life. Advance care planning is not just one conversation. Your thoughts and wishes may change, and you can change your plan at any time to reflect this.

Although it's a challenging thing to do, many people find that thinking ahead brings with it peace of mind. Advance care planning is not about dying. It's about helping you to live as well as possible right to the end of your life.

Find out more

Our website resources

Advanced MS
mstrust.org.uk/a-z/advanced-ms

Palliative care
mstrust.org.uk/a-z/palliative-care

Respite care
mstrust.org.uk/a-z/respite

Our publications

Thinking ahead: setting out your wishes for your future care and treatment (book)
mstrust.org.uk/516

Thinking ahead: advance statement template (a template to document your wishes)
mstrust.org.uk/521

9 Research on progression in MS

In the past, research has primarily focused on developing therapies for relapsing MS. This effort has led to the development of several disease modifying drugs (DMDs), which modify the immune system to reduce acute inflammation and the number of relapses. However, despite the success of these treatments in relapsing MS, many people continue to experience a progressive increase in disability.

This has led to an increasing interest in research initiatives aiming to find new treatments that might slow or stop MS progression. In 2012, the International Progressive MS Alliance was formed. This initiative encourages the collaboration of researchers around the world to combine their efforts to better understand the causes of progression, which will hopefully lead to new effective treatments.

Keeping up to date with research isn't always easy. There can be lots of excitement at initial results, but often drug candidates or approaches fail to live up to their early promise and so fall by the wayside – it's a constantly evolving field. For this reason, in this chapter we have chosen to look at the current general approaches to research in progressive MS, rather than at specific individual treatments that are being investigated. For the most up-to-date information on specific drug candidates for progressive MS, see the drugs in development page on our website (link in Find out more at the end of this chapter).

Targeting MS progression

Many of the DMDs that have been successfully used in relapsing MS are designed to reduce acute inflammation. It's known that this acute inflammatory reaction is what causes damage to myelin – the protective coating around the nerve cell axons – resulting in lesions. However, this type of inflammation is less prominent in progressive forms of MS. Different processes such as neurodegeneration, axonal loss and chronic (or smouldering) inflammation are thought to contribute to disease activity to a much greater extent. Whilst treatments that have been successful in reducing relapses may have a

role in delaying progression, they are generally much less effective in individuals with progressive MS.

Until recently, there were limited disease modifying drug options for progressive MS. In the UK, there are now two approved treatments for use in those with evidence of active disease – relapses and/or new lesions on MRI. Mayzent (siponimod) is licensed for active secondary progressive MS and Ocrevus (ocrelizumab) for active primary progressive MS (see chapter 4 for more information). However, this still leaves a large proportion of people experiencing progression who are currently ineligible for DMDs. Symptomatic treatments are available to everyone with progressive MS. Whilst these treatments don't modify the immune system, they are invaluable in managing symptoms such as bladder problems, pain and spasticity (see chapter 4 for more information on treating and managing symptoms).

The complex biological and pathological processes underlying MS progression are not well understood. So, developing new strategies and treatments to target ongoing progression is challenging. Along with trying to better understand why progression happens, current research initiatives are focused on finding new ways to prevent or reduce further progression by protecting the neurons directly (neuroprotection) or by blocking the chronic inflammation that causes nerve cell damage. Other researchers are trying to find new ways to replace myelin and repair damage that has already happened (remyelination and regeneration).

Neuroprotection and targeting chronic inflammation

It is thought that the acute focal inflammation and demyelination that happens early in MS can lead to a gradual degeneration of nerve cells over many years. This is thought to occur for several reasons.

- Loss of myelin seems to make nerve cells more likely to degenerate – perhaps because they are no longer physically protected.
- The myelin-producing cells (oligodendrocytes) die away and stop supporting them.

- Nerve cells without myelin are less efficient and require more energy. If nerves are low on energy, that can release chemicals that build up in the brain and spinal cord and cause more damage.

In research studies, we can't measure exactly how many nerve cells have degenerated, but the loss of cells makes the brain and spinal cord shrink slightly – this is known as atrophy. Atrophy can be measured using MRI.

Neuroprotection is an umbrella term for any treatment that can protect nerve cells from being destroyed and ultimately stop atrophy. There are several potential ways of achieving neuroprotection, one of which might be stopping nerve cells from using so much energy.

Neuroprotective treatments won't be able to reverse progression or restore function that you have already lost. But if suitable strategies can be developed, it's hoped that any further progression will be significantly slowed. There are several neuroprotective treatments that have shown promise in phase II trials and the next step will be to test them in phase III trials.

Targeting chronic inflammation in MS may also have the potential to promote neuroprotection. Not only could it be effective in reducing ongoing damage to nerve cells, but it might also potentially create an environment where nerve cell regeneration is more likely to occur – by reducing inhibitory factors and promoting the growth of new myelin (remyelination) and neuronal connections. There are several new classes of drugs being developed with this aim, including the Bruton tyrosine-kinase (BTK) inhibitors which are coming to the end of their clinical trials. We should have a clearer idea soon as to how effective this approach might be at treating progression.

Remyelination and regeneration

Finding ways to repair or replace damaged myelin is another important area of research as it might help protect nerves from later damage. This approach may also have an advantage over neuroprotection strategies, as it's possible it may also help recover abilities that have been lost.

Oligodendrocytes are the cells that create and repair myelin. We know that in MS lesions, oligodendrocytes usually die away, so they're no longer available to repair myelin. However, the cells that can turn into oligodendrocytes (oligodendrocyte precursor cells or OPCs) are still present in lesions, so it may be possible to develop treatments that can switch myelin production back on.

As we age, this remyelination process becomes less efficient and our ability to replace lost myelin decreases. In many people with MS, the remyelination process seems to fail as it is too slow to produce sufficient levels of myelin to protect nerve cell axons from becoming exposed and dying off. This likely contributes to progression.

A treatment that promotes remyelination might be able to enhance the repair process and therefore protect cells from future damage. But for remyelination to occur, there needs to be an intact nerve cell for the oligodendrocyte to recognise and produce myelin around. In the progressive stages of MS, many nerve cell axons may already have degenerated, so it's still unknown how effective remyelination strategies might be.

Stem cell research

An area of research that attracts a lot of interest is the use of stem cells for transplantation. In adults, the role of stem cells is to produce new cells. For example, haematopoietic stem cells from our bone marrow continually make new blood and immune cells throughout our life. There are some parts of the adult body where stem cells replace areas of damage, but these are few. In MS, the hope is that stem cells might be used to reprogramme the immune system, so it's less likely to damage the nerve cells.

The most well-studied stem cell treatment in MS is autologous haematopoietic stem cell transplantation or AHSCT. This is where haematopoietic stem cells are first mobilised from the bone marrow and released into your bloodstream. They are then collected from your blood and stored. In the next step, you are given chemotherapy drugs to deplete the cells of your immune system that are causing inflammation. Finally, your harvested cells are returned to replace them. The idea is that by returning new immune cells, the immune system is rebooted in a way that is less harmful to the nerve cells.

AHSCT has been tried in all types of MS. However, it seems to work best in early MS, especially in individuals who have very active acute inflammation, and before people have accumulated much damage or disability. This group includes many people with relapsing MS but may also include a smaller number of people who experience progression.

As not many people with progressive MS have acute inflammation, the numbers who might benefit from AHSCT is thought to be rather small. In individuals who don't have active inflammation, and where there is more damage to the brain and spinal cord, another approach to stem cell transplantation may be needed. In light of this, there are many research teams around the world developing stem cell treatments which might be more beneficial against progression.

One approach is to use another type of stem cells called mesenchymal stem cells or MSCs. These cells can usually be harvested from your hip bone marrow, they are expanded in the lab and then reintroduced into your bloodstream. The hope is that MSCs will work to protect the nerve cells from further damage and encourage repair. This approach doesn't need aggressive chemotherapy and so has fewer risks than AHSCT.

Another option is to use neural stem cells (NSCs), which are cells that can directly replace cells in the brain (such as nerve cells and oligodendrocytes) and reduce both acute and chronic inflammation. Early studies which tested the safety of NSCs showed promising results, but larger trials involving more people with MS are now needed.

Other areas of research

Another area that is actively being researched in progressive MS is the possibility of enhancing brain plasticity. This involves developing strategies to adapt to the changes in the brain that MS causes and reroute messages around areas of damage. This includes rehabilitation strategies to retrain or stimulate the brain to help maintain function.

There is also research investigating the best surrogate markers of disability in progressive MS and how best to run trials so we can get results more quickly. You can read more about this later in this chapter.

Clinical trial design in progressive MS

One of the reasons that few treatments have emerged for progressive MS is that designing clinical trials in progressive MS is challenging. Progression is often slow and subtle, with disability accumulating gradually over many years. This makes it difficult to determine if a treatment is truly having an effect within a reasonable timeframe and sensitive outcome measures are needed to detect even the smallest of changes.

Over the course of the last few years, a lot of work has been done around the design of clinical trials. Significant changes are being adopted to make them more efficient, to try and obtain results more quickly.

One approach that shows promise is a multi-arm, multi-stage (MAMS) design. Here, several drugs are tested at the same time and compared to a single control group of patients who take a placebo (or dummy treatment). Initial clinical tests and complementary tests, such as advanced imaging techniques or measuring blood biomarkers, are then used to determine whether a treatment is showing early potential for slowing down progression. For example, does MRI show it slows brain atrophy? This is an example of a surrogate marker, which we cover later.

Drugs that show promise can then move into the second stage of the study. Those that show no benefit can be dropped out and new drug candidates may be included instead.

The second stage of a MAMS trial is conducted in a more traditional way, with many more participants studied over several years. At this stage, the effects on disability and progression are analysed as the main outcome. Overall, this approach makes it possible to test potential treatments up to three times faster.

Surrogate markers

Besides trial design, an important approach for researchers is to study the effects of a treatment on a surrogate marker of disability. This is something that can be reliably measured. For example, on an MRI scan, or a biomarker that can be detected via a blood test or in

your cerebrospinal fluid (CSF). These can be used to predict if you will experience progression and increased disability in the future. If the treatment shows a beneficial effect on the surrogate marker, it potentially has a good chance of having a favourable effect on disability.

Brain atrophy measured by MRI is currently the most commonly used surrogate marker, but better markers may emerge. You can read more about some of the biomarkers that may be useful as surrogate markers in the future in chapter 1.

Outcome measures used in trials

Traditional outcome measures, such as clinical assessments, performance tests and patient reported outcomes, are still used in clinical trial designs alongside newer measures of surrogate markers. Which outcome measures are more meaningful to use at each stage of a progressive MS trial is still under investigation. Often surrogate markers will be used in phase II trials to decide if a treatment will progress to phase III, whereas phase III trials will rely more heavily on the other assessments.

Outcome measures need to be sensitive enough to detect the slow changes that can occur. They must also be able to show whether further progression is slowed or completely prevented. Assessments are carried out at various timepoints during a trial to determine whether an individual has remained stable, worsened or improved.

Clinical assessment and performance tests

- **Expanded Disability Status Scale (EDSS)** – measures disability and progression in MS on a scale of 0.0 (no disability) to 10.0 (death due to MS). The scale has some limitations though. It has a subjective nature, since it's based on a neurological examination by a clinician and there is a risk that different clinicians may score differently. Also, the scale overemphasises walking ability and does not consider other important aspects, such as cognition, vision, fatigue and upper body function, which are vital for self-care and independence.

- **Timed 9-Hole Peg Test (9-HPT)** – measures upper limb function by assessing the time taken to place nine pegs in a board and to remove them again. It is carried out with both the dominant and non-dominant hand. The advantage of this test is that individuals who are unable to walk can be included in trials.

- **Timed 25-Foot Walk Test (T25-FWT)** – measures lower limb function by assessing the time needed to walk 25 feet.

- **Symbol Digit Modalities Test (SDMT)** – a measure of cognitive function used to assess how quickly the brain takes in, understands and responds to information it receives (information processing speed). You are given a series of symbols to decode into digits using a key in 90 seconds.

Patient-reported outcome measures (PROMs)

- **Multiple Sclerosis Impact Scale (MSIS-29)** – a questionnaire used to rate the impact of MS on your physical and mental health in the previous two weeks. A higher score indicates a more severe impact.

- **Multiple Sclerosis Walking Scale 12 (MSWS-12)** – a questionnaire used to rate the impact of MS on your lower limb function. Higher scores indicate more walking difficulties.

- **Multiple Sclerosis Quality of Life Scale (MSQoL-54)** – a questionnaire that assesses overall physical and mental health status and quality of life. Includes some MS-specific questions. Lower scores indicate a worse quality of life.

PROMs are important as they can pick up subtle changes that you recognise, but that might not be detected by the clinical assessment or performance measures. Traditionally, they've not been used as a primary measure in trials as they can be subjective in nature.

Surrogate markers

- **Whole-brain atrophy (WBA)** – MRI may be used to determine whether the volume of the brain has decreased, and the rate at which it is happening.
- **Imaging markers of disease progression** – special MRI sequences and advanced imaging techniques can be used to look for paramagnetic rim lesions and slowly expanding lesions which are associated with progression in MS (see chapter 1 for more information).
- **Other imaging techniques** – MRI and a type of scan known as positron emission tomography (or PET scan) can be used to measure myelin damage and/or remyelination levels.
- **Biofluid assessment** – biofluids that are tested in clinical trials to see if you are responding to a treatment include the blood and cerebrospinal fluid (CSF). For example, in MS, a molecule known as neurofilament light chain (NfL) is associated with axonal damage. It may be possible to measure NfL, or other potential biomarkers in the blood or CSF, to assess whether a treatment is effective. You can read about more potential biomarkers for progression in chapter 1.

The development of effective treatments to halt MS progression is considered to be the greatest unmet need in MS by many clinicians and researchers. Hopefully, advances in our understanding of MS, coupled with advanced imaging techniques and biofluid assessment, will move us closer to better treatment options for everyone living with MS progression.

Find out more

Our website resources

Drugs in development
mstrust.org.uk/DID

MS research – our information hub on research and clinical trials
mstrust.org.uk/information-support/ms-research

Research news
mstrust.org.uk/research

Other organisations and support

The International Progressive MS Alliance
progressivemsalliance.org

Acknowledgements

About the authors

MS Trust Information Team

We are a UK charity that believes nobody should have to manage multiple sclerosis alone. We are here for everyone affected by MS, from the moment of diagnosis and throughout their journey.

Thank you

We would like to thank the people with MS – Caroline, Guy, Margaret, Patricia and Sarah – who have made this book possible by reviewing the text and sharing their experiences. We would also like to thank the following health professionals and researchers for reviewing the text.

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This edition published 2025.

This publication will be reviewed in three years.

Bibliographical information

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460-Progression in MS-Dig.03.25

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