

# Secondary progressive multiple sclerosis



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We hope you find the information in this book helpful. If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

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## Contents

	<b>Introduction</b>	<b>4</b>
<b>1.</b>	<b>What is secondary progressive MS?</b>	<b>5</b>
<b>2.</b>	<b>Diagnosing secondary progressive MS</b>	<b>8</b>
<b>3.</b>	<b>The transition to secondary progressive MS</b>	<b>13</b>
<b>4.</b>	<b>Managing secondary progressive MS</b>	<b>17</b>
<b>5.</b>	<b>Managing the transition to secondary progressive MS</b>	<b>23</b>
<b>6.</b>	<b>Research into secondary progressive MS</b>	<b>27</b>
<b>7.</b>	<b>Tips for coping with secondary progressive MS</b>	<b>31</b>
<b>8.</b>	<b>Appendix 1: Living with secondary progressive MS</b>	<b>33</b>
	• Living well - health awareness, activity, diet	33
	• Work	36
	• Welfare benefits	37
	• Maintaining social relationships	38
<b>9.</b>	<b>Appendix 2: ACT exercises</b>	<b>41</b>
<b>10.</b>	<b>Appendix 3: Research trials</b>	<b>44</b>
<b>11.</b>	<b>More information</b>	<b>46</b>

## Introduction

Over time, many people originally diagnosed with relapsing remitting multiple sclerosis will find that the pattern of their MS has changed and that they now have a type known as secondary progressive MS or SPMS. This transition can be a challenging time, requiring a different approach to managing the condition and possibly contact with a different range of health and social care professionals.

This book is written as an introduction to secondary progressive MS - both for those living with the condition and for their family and friends. It aims to give an outline of what is happening in this type of MS, how it is identified and why making a diagnosis is not straightforward. The book also looks at how rehabilitation is used in the management of the condition and some of the health professionals who may be involved.

Sometimes thought of as a neglected area of MS, interest in finding ways to treat progressive MS is increasing and the book looks at some of the research areas currently being explored.

The text is illustrated with the comments and experiences of health professionals and people who live with secondary progressive MS.

# 1. What is secondary progressive MS?

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Multiple sclerosis is a very unpredictable condition and the variety and severity of symptoms will vary from individual to individual. However, there are two underlying processes at work in MS:

- inflammation around nerves, which is associated with the relapsing remitting pattern
- destruction of nerve fibres, which is associated with progression.

Current thinking is that both processes occur from early in the condition, though for most people inflammation is more prominent at first.

## Inflammation

For reasons that are not yet understood, when someone has MS, cells in their immune system attack myelin - the layer of fatty protein that surrounds nerve fibres (axons) in the brain and spinal cord (central nervous system) - and the cells (oligodendrocytes) that make and maintain the myelin.

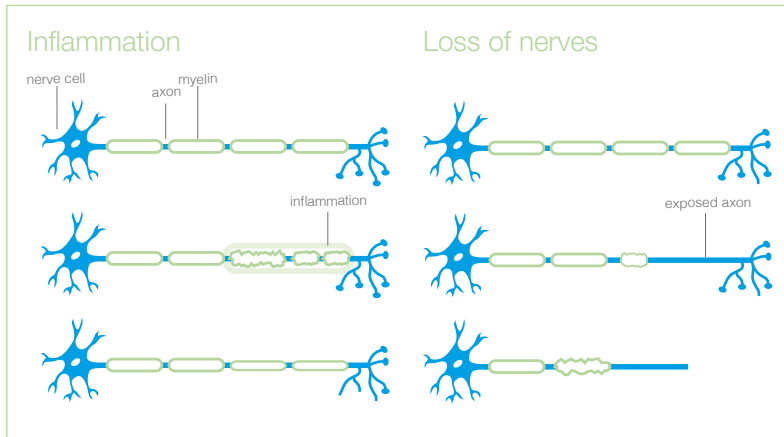
The attack on myelin causes inflammation around the nerves, which can be seen as white patches on an MRI scan. Once the inflammation is over, it is possible for damaged myelin to be replaced to some degree, a process known as remyelination.

This pattern of damage and repair is reflected in the relapsing remitting type of multiple sclerosis with which most people are diagnosed. Inflammation is associated with attacks of symptoms (relapses) that come on quickly and last for more than 24 hours, though can persist for weeks or months. As the inflammation dies down, symptoms recover to some degree (remission). Although

symptoms may not return to the same level as before the relapse and may fluctuate between better and worse days, the overall level of disability remains fairly constant between relapses.

## Loss of nerves

Over time, the ability to repair damaged myelin is lost, leaving axons exposed and vulnerable. As axons carry nerve messages to surrounding nerves, if they are destroyed, the connections



are broken. The brain can reroute nerve signals past areas of damage to some degree, which is known as plasticity or neuroplasticity. However, continuing damage to axons leads to the gradual increase of symptoms seen in progressive MS.

For most people with relapsing remitting MS, the balance between inflammation and loss of axons changes slowly over time. As loss of nerve cells becomes more prominent, relapses happen less often and eventually stop, but disability gradually increases in between relapses. As it follows an initial (primary) period of the relapsing remitting type, this is known as secondary progressive MS.

The longer someone has had relapsing remitting MS, the higher the chance of it changing to secondary progressive. Studies suggest that about 19 years after the onset of MS, 50% of people diagnosed with the relapsing remitting form will have reached the transition to secondary progressive MS.

It is possible, though less common, for someone's first diagnosis to be of secondary progressive MS. This would suggest that multiple sclerosis activity may have been taking place for several years but symptoms had been put down to other causes or not been troublesome enough to lead to a diagnosis at the time.

For about 15% of people with MS, the loss of nerve cells is the main process from the start of their condition. In this case they are diagnosed with a form of multiple sclerosis that is progressive from onset and so is known as primary progressive MS.

**Other MS Trust resources**

Primary progressive multiple sclerosis (book)

## 2. Diagnosing secondary progressive MS

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Identifying when multiple sclerosis has changed from a relapsing to a progressive course is not straightforward. The change between types is not a sudden switch but a gradual process where the relapsing and progressive patterns overlap for a while.

There is no test to show that someone's MS is now secondary progressive. Diagnosis is often done by looking back at changes across the previous year or so. The neurologist has to decide if an ongoing, sustained increase in disability has occurred and that this is due to the underlying MS and not to other factors.

### Factors that can make the change hard to spot

- **Relapses**

Recovery from a relapse is often not complete and the level of disability might be higher once the relapse is over than it was before. However, so long as the level of disability remains stable between relapses, this is not considered to be MS progressing. For multiple sclerosis to be classed as secondary progressive, disability levels need to increase independently of any relapses that occur.

While the relapsing and progressive patterns overlap, people with secondary progressive MS can still experience relapses, although these tend to become less frequent.

People may also experience 'pseudo relapses' - a temporary worsening of MS symptoms that may seem like a relapse but are actually caused by other factors.

- **Fluctuation in symptoms**

MS symptoms do not stay constant, with some days better than others. A run of bad days does not necessarily indicate that MS is progressing.



- **Other MS symptoms**

The worsening of symptoms may not be due to the underlying MS. For instance, bladder or bowel symptoms can make spasticity feel worse. Similarly, symptoms such as pain, low mood and weakness can feel more pronounced during periods of fatigue. A proper assessment of symptoms to identify and treat any triggering factors can help to manage the effects.

- **Non MS factors**

Problems that are not part of MS, such as being under stress or having an infection, can also make symptoms worse. Many people with MS find that heat can worsen symptoms. A smaller proportion find that cold weather can have a similar effect. When the trigger factor is removed or reduced, symptoms may improve.

## **Sustained progression**

Having taken account of these factors, the neurologist will be looking for indications that an increase in disability has been sustained. To be certain that disability has permanently increased and that it is not a temporary worsening of symptoms, the neurologist will look for changes that have not improved for at least six months.

### **Not progressive**



### **Progressive**



Although the level of disability might be higher after a relapse than it was before, MS is not considered to be progressive unless disability levels continue to increase independently of relapses.

Increasing difficulty with walking, or the ability to walk shorter distances than before, is often the factor that leads people to realise that their symptoms have been gradually getting worse. However, it is not the case that secondary progression only starts when someone may need to use a walking aid or a wheelchair. Disability is not only about mobility. Progression may be indicated by increases in less visible symptoms such as bladder function, numbness or altered sensations, or symptoms associated with memory or thinking.

Although none of the symptoms of MS are unique to the different types of the condition, MRI scans of people with progressive MS tend to show more signs of damage in the areas at the back and base of the brain - the cerebellum and the brainstem - and in the spinal cord. Symptoms associated with these areas - impaired coordination, mobility problems, bladder and bowel symptoms and tremor - tend to be more pronounced.

People with secondary progressive MS are also more likely to show signs of damage and tissue loss in the centre of the brain in the areas associated with cognition (memory and thinking). Cognitive symptoms occur more frequently in secondary progressive MS than in other types of multiple sclerosis.

### **Other MS Trust resources**

See the More Information section on page 46 for other resources about the symptoms of MS

## Diagnosing secondary progressive MS

*Jeremy Chataway, consultant neurologist*

Defining secondary progressive MS is certainly not an exact science from the clinical perspective. There is no test, such as an MRI scan, which can say that someone has moved from the relapsing remitting to the secondary progressive stage. In fact, we wouldn't expect that, this is a gradual process.

In addition, there is often a reluctance to talk about progression, by both the doctor and the person with MS. Perhaps it conjures up feelings of failure and disappointment, of fear, and lack of treatment. Therefore, the discussion is often postponed or left hanging in the wind.

The general test I use is to ask someone how they were two years ago, for example, how far they could walk at a holiday destination or taking the children to school. If that has changed considerably, eg from 1.5km to 300m, then progression has taken place - they have moved from relapsing remitting to secondary progressive MS. It is important that other, non-MS conditions have been thought about and excluded if necessary, eg a prolapsed disc.

Once the point has been reached of formally defining secondary progressive MS, then I feel that a full re-evaluation of the situation is required. Aspects such as spasticity, urinary function, depression and fatigue may have been ignored in the relapsing remitting phase and now it is a chance to put them right.

In secondary progressive MS the chance of relapse is lower. It might be an opportunity to stop disease modifying treatments (and any side effects) and to explore other approaches to treatment. In one way it's a new beginning and things might now be calmer as the 'forest fire' of relapsing inflammation dies down.

## Managing the transition

*Susan Hourihan, occupational therapist*

People with MS are often the first to be aware that their MS has changed but are not always sure what that means.

Despite awareness of change, it may still come as a shock to be told that their condition has been reclassified to secondary progressive multiple sclerosis. Some people have never heard of the term and others living with relapsing remitting MS had hoped or assumed that their MS would stay in that stage of the disease.

Commonly, people describe that when they are told they have secondary progressive MS, the information is given fairly casually and with little time for discussion. Yet the individual often describes this as a very significant moment, often as significant as the giving of the original diagnosis of MS. It brings up similar feelings as when first diagnosed and can sometimes be more upsetting if little is offered to help them.

However, so much can be done at this point to help people stay independent, manage symptoms and improve wellbeing. People at the transition from relapsing remitting to secondary progressive MS should speak to their MS nurse or other trusted healthcare professional. If an MS multidisciplinary clinic is available, ask to be referred for an assessment. Alternatively, a review by a neurologist, MS nurse, physiotherapist and occupational therapist should be considered.

People may benefit from a review of their medications, mobility, every day activities including work and leisure, benefits and symptoms such as pain, bladder problems, spasms and mood. Specialist equipment for mobility or for the home or workplace may be beneficial.

Most people want good, safe information on their condition and psychological support. Everyone is different but an individual assessment at this time can be really valuable to help manage the condition and optimise independence.

## 3. The transition to secondary progressive MS

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Sometimes difficulty in identifying when secondary progression has started can lead to differences of opinion. The person who is living with MS may feel their MS is progressive. The neurologist, who is observing it in a clinical setting, may take a more cautious view and prefer to monitor symptoms over a longer period.

**“I had already suspected that my MS was now secondary progressive”**

**“I told my MS nurse that I thought it had changed, she referred me to the neurologist who agreed with me”**

### The effect of words

It is not unusual for people to think that progressive MS will be worse than the relapsing type. The medical terminology is probably unhelpful in this regard. Relapsing remitting and secondary progressive simply describe the clinical nature of MS, not the experience of a person living with the condition. Individuals with either form will have better or worse experiences depending on the nature of their symptoms and the impact these have on their lives. The fact that one form follows the other does not necessarily mean that MS has become worse.

**“Progressive sounds worse, even though it's only a word for what has been happening for a while”**

**“People get hung up about the label of secondary progressive MS. No matter how you label your MS it is not going to make any difference to how you feel at this exact point in time”**

Some neurologists may prefer to refer to 'active' or 'less active' MS as this better reflects the experiences of the individual regardless of their type of MS.

## **What the future holds**

It's not possible to predict how an individual's MS will develop. Although progression does mean that disability will continue to increase over time, it does not mean that someone will inevitably experience a rapid decline in their health.

For many, the rate at which disability increases can be very gradual and is only apparent when symptoms are compared with previous years. The increase can also flatten out and people might find that their symptoms remain unchanged for a while and, in some cases, occasionally experience temporary periods of improvement.

## **Stopping disease modifying drugs**

There are a number of drugs that have an effect on the underlying course of MS, rather than acting as treatments for symptoms. The fact that these disease modifying drugs only work in relapsing MS can sometimes be a problem at this stage.

Some doctors may be reluctant to make a diagnosis of secondary progressive MS due to the lack of disease modifying treatments for this form.

Similarly, some people may be reluctant for their MS to be described as secondary progressive as this may lead to them stopping disease modifying treatments. Even if the drugs seem to be having little or no effect, the thought of stopping taking them can seem like another milestone that has been passed in the course of the condition and can be taken as a sign of failure or loss of hope.

This is not the case. The term ‘disease modifying treatments’ may be misleading and might be taken to promise more than it actually offers. The role of the currently available drugs is to reduce the inflammation that causes relapses. None of them have been shown to have an effect on the increase in disability that occurs independently of relapses.

Given that the drugs are only effective for a particular type of MS, discussion about the fact that treatment may need to stop at some point should take place when treatment is originally started. This may not happen in all cases. Even if it does, the implications of stopping treatment may be overlooked or forgotten, particularly if there is a long period of time when the drugs are still being effective.

Stopping treatment merely means that the limited actions of the disease modifying drugs are no longer relevant to what is happening with an individual’s MS. Treatment in progressive MS will focus more on managing the individual symptoms and on rehabilitation approaches.

**“Stopping disease modifying drugs is not a cul de sac, just a bend in the road”**

## The role of the MS nurse

*Wendy Hartland, MS nurse*

It can be a very difficult time for people when they are told that their MS has entered the secondary progressive phase. The realisation that MS isn't going to go away is perhaps the time when some people need to emotionally readjust to living with a chronic illness, if necessary with the help and support from their MS team.

Anecdotally, a common experience described by some people to the MS team is that of feeling alone and abandoned. This may be partly due to people in the relapsing remitting phase of the disease being prescribed disease modifying therapies and being seen in the MS clinics on a frequent basis for monitoring purposes.

It is important to remember that the MS nurse can help to prevent these feelings. They can encourage people to say whether they would still like to be seen for a six monthly review between their annual appointments with their neurologist, and to reassess any issues or concerns they may have. The MS nurse may also suggest a referral to the local neurorehabilitation team, if there is one. Similarly the MS nurse is ideally positioned to know what facilities are available locally and can therefore signpost people to enable them to get the most from local health and social services.

It is vitally important to remember when someone is told they have secondary progressive MS not to give up hope and that they don't have to deal with it on their own. Maintaining regular contact with the MS team can ensure people are kept informed of any promising treatment options available to them in the future and they can be reassured that they are not starting the next part of their MS journey on their own.



## 4. Managing secondary progressive MS

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The services and support needed when MS becomes secondary progressive may change and can involve a wider range of health and social care services than someone saw when they had relapsing remitting MS. Sometimes the links between these services may seem less coordinated than previously. With less regular contact with an MS team, people may feel less able to raise concerns or ask about approaches to problems.

### Self-management

Adopting a self-management approach can be helpful. This recognises the expertise that someone with MS has in how their condition affects them and how this can be used in partnership with health and care professionals. Rather than being a passive recipient of care waiting to be told what will happen, self-management is a proactive approach - raising concerns about symptoms, making informed decisions about treatment or other issues that need addressing and asking what services are available.

**“Pick up on your symptoms early and ask early for help”**

**“Don’t be scared to ask your doctor questions you may have, they’re only human”**

### MS nurses

In many situations, the first point of contact might be an MS nurse, though it could be a supportive GP, a physiotherapist, occupational therapist or other health professional who is willing to help find the services that are needed. In some areas, people with a diagnosis of MS can contact the MS nurse directly without need for a referral. In others it may be necessary to ask a GP for

a referral to the local service. Initial contact will probably involve leaving a message on an answerphone. The nurse will reply, but it may not be on the same day.

**“It is reassuring to have specialist people within my area available to call on when needed. I find it very difficult to ask for any assistance/help but knowing I can use them when needed reduces the stresses and anxieties of living with MS”**

People with progressive MS can sometimes feel that they have dropped off the radar of MS services. There are a variety of reasons why people may not have the same level of contact with their neurologist or nurse:

- the symptoms of progressive MS tend to increase gradually rather than appear or increase suddenly as happens with a relapse. People may feel more reluctant to make contact about an ongoing symptom than one that has suddenly flared up
- follow up meetings about disease modifying treatments may be stopped and alternative appointments not put in place
- as there are no equivalent disease modifying drugs for progressive MS, people may wrongly feel that nothing can be done for this form of the condition and so don't think to contact a neurologist or nurse about treatment for individual symptoms.

**“I could self-refer but was apprehensive about doing so at first so needed to be approached by professionals”**

#### **Other MS Trust resources**

Map of MS nurses and other services -  
[www.mstrust.org.uk/map](http://www.mstrust.org.uk/map)

## Support from specialist health services

*Alison Smith, rehabilitation nurse*

With symptoms changing gradually over time many people continually adapt without realising it. These adaptations are generally helpful but sometimes they aren't the best way to cope and may cause problems in the future (such as hip hitching causing back pain). At this time it is useful to have regular check-ups, a bit like a yearly MOT. This can be done by a neurologist or an MS nurse but some people find a rehabilitation medicine consultant or rehabilitation nurse suits the job better.

## Rehabilitation

Rehabilitation is an approach to treatment that doesn't attempt to cure symptoms, but instead works in partnership with an individual to maintain and make the best of functions, to promote independence and to achieve their own particular goals. The approach taken will depend on the needs of the individual and the nature of their symptoms.

To be most effective, rehabilitation should work alongside medical treatment, rather than be something that is only used after drug based approaches have been tried. Rehabilitation should also be an ongoing process, with periods of intense therapy and regular reviews of goals.

Rehabilitation is provided at different levels across the NHS, from a consultant in rehabilitation medicine and their team, to services accessed through a GP, neurologist or MS specialist nurse. Treatment may require a stay in hospital or may be provided in a community setting.

Depending on the individual's needs, a number of different professionals may be involved in providing rehabilitation. Therapies provided might include:

### Physiotherapy

Physiotherapy uses physical approaches such as exercise, stretching and posture to promote health and maintain function. In MS, physiotherapy is particularly useful for managing stiffness, balance, dizziness, spasticity and spasms, fatigue, weakness and tremor.

**“I think physiotherapists are essential for people with secondary progressive MS. It is good to be assessed on a regular basis and have a clear programme of exercises which can be rearranged to suit fluctuating needs”**

### Occupational therapy

Occupational therapy aims to make day to day living more manageable by helping people operate better within their

environment. This can involve finding ways to save energy and minimise fatigue, suggesting equipment to help with daily activities in the home or at work, strategies to help people to stay in their jobs, and assessing for mobility equipment and wheelchairs if required.

### Clinical psychology

A clinical psychologist approaches the psychological and emotional problems associated with MS. This may include help with cognitive symptoms, low mood or depression. A psychologist may use approaches such as cognitive behavioural therapy (CBT) or acceptance and commitment therapy (ACT) to help people approach life with MS more positively.

### Speech and language therapy

A speech and language therapist can help find ways to manage difficulties with speaking and swallowing. This might involve exercises to strengthen and improve the muscles involved in speech and breathing, advice on aids for communication and ways to minimise or avoid swallowing problems.

It can sometimes be difficult to access rehabilitation therapies on the NHS, particularly on an ongoing basis. For instance, a course of physiotherapy is typically for a fixed number of weeks and the number of courses available in a year is limited. However, many aspects of rehabilitation involve teaching approaches that can be maintained by someone when not in contact with the rehab team. There may be an element of self-management in between treatment episodes, such as maintaining the motivation to carry on doing the suggested exercises or finding other resources that may be available, for example a local exercise class.

#### **Other MS Trust resources**

Map of MS physiotherapists, OTs and rehabilitation services - [www.mstrust.org.uk/map](http://www.mstrust.org.uk/map)

## Rehabilitation in secondary progressive MS

*Alison Smith, rehabilitation nurse*

A long time ago I met a lady with secondary progressive MS in a Young Disabled unit. She wasn't engaging in the rehab process as it was then being practised. New to the territory, I asked her why she didn't want to participate in 'washing and dressing' practice. She told me she had fatigue and if she did her own personal care she was good for little else for many hours. She said that anyone could dress her but only she could read a book, go to the theatre or spend time with friends and family. So she ensured that all of her energy was spent doing things that were important to her and her loved ones.

I have never forgotten that conversation. Long before it was integrated into routine practice, she encompassed the goal directed principles of rehabilitation that we use now.

Rehabilitation is not just therapy, although therapy is part of rehabilitation.

In relapsing remitting MS, medication and therapy are the drivers of treatment. In secondary progressive MS, if a rehabilitation approach is taken, the individual can become the driver of the treatment. Fully informed in symptom management (medication, therapy and adaptive techniques/equipment) and supported by a rehabilitation practitioner, a goal based, lifestyle centred approach can be taken.

People new to rehabilitation often ask me what they can do to manage their MS if they aren't receiving a disease modifying drug and they just appear to be getting worse. I suggest the above approach because biological, psychological and sociological wellbeing is a successful route to managing the impact MS has on a person's life and life choices.

# 5. Managing the transition to secondary progressive MS

*Dr Sarah Gillanders, clinical neuropsychologist*

The transition from relapsing remitting to secondary progressive MS is a stage of MS that many people find challenging. I have often met people who felt able to cope with the relapsing stage of the disease, but found the transition to secondary progressive MS much harder. The challenges vary, but often people feel scared, uninformed, powerless, vulnerable and of being generally overwhelmed.

It is worth remembering that there are others who manage this stage of the condition without such distress.

So what is it that helps some people adjust more easily than others and what can help the many people who find it difficult?

Acceptance and commitment therapy (ACT, said as one word), is a type of psychological therapy, similar to cognitive behavioural therapy (CBT). ACT encourages people to become more aware of their thoughts, feelings and beliefs and the helpful and unhelpful ways they respond. It tries to support people to become more aware of and in touch with what matters to them (being a loving husband, a caring mum, a fun grandad, a committed friend, a challenging quiz master) and to help them find ways to do those things, even with MS.

**“I don’t like MS, I don’t want to have MS but this is how it is. I can’t take my granddaughter to nursery like I used to but I am great at reading stories with her, and she loves talking to me about Disney princesses. I used to think that I wasn’t a good grandma because I couldn’t do the physical stuff. Now I know that I can do plenty of things that my granddaughter loves and we are very close”**

Another useful tip is to notice when you are responding in an unhelpful way, pause and decide whether you want to continue like that or do something that is helpful to you.

## “I inevitably have ‘why me?’ days, but I try to stay positive and get on with living life”

There are examples of ACT exercises in Appendix 2.

There are a number of other ways of gaining psychological support when coping with secondary progressive MS.

- Speak to your MS nurse or GP about a referral to a counsellor or psychologist.
- Get answers to your questions. If there are things you are unsure about then speak to an MS nurse or the MS Trust for more information. Once you are informed then you are in a better position to make decisions.
- 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 is easy to think that you will overwhelm someone if you tell them how you feel. More often than not, the people close to you will know when you are upset and feel relieved if you can open up about how you're doing and what they can do to help.
- You may prefer to talk through your concerns with people outside your family or circle of friends. There is a range of support groups available, offering the opportunity to share ideas and let off steam 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.
- Advance care planning: some people find it helpful to explore options, resources and services that are available in case more support is needed in the future. Not only does this mean your family and professionals know your thoughts, it can also make it less stressful should a crisis ever arise.



## Positive thoughts on secondary progressive MS

For some people, the change to secondary progressive can have positive aspects. For many, progression is very gradual and only perceptible when looking back over a long period of time. The reduction or absence of relapses that might come on unexpectedly can make planning life a little easier.

**“I am relatively calm about my future as at least I don’t have to worry about relapses”**

**“Not having relapses means my MS has less of an unpredictable impact on my working life”**

**“As my symptoms are very gradual, it’s only through seeing people I haven’t seen for a while that I realise my MS has progressed. I just get on with the symptoms but generally can’t tell what’s changed”**

Depending on the nature of symptoms, stopping disease modifying drugs and the regular need to inject oneself can also be seen positively.

**“The positive thing is that I don’t have to have that regular injection together with its unpleasant side effects”**

For some, the diagnosis of secondary progressive allows them to reflect on their lives. MS may alter the opportunities that may be open to someone, but it can also help them focus on what is important and valuable. Depending on circumstances this might mean a change in career, taking up a new activity or encouraging someone to live for the moment.

**“I try to keep fit and concentrate on my body more by strengthening muscles with Pilates and doing swimming. Both giving me more confidence”**

**“My life is based very much on what I can do, rather than what I cannot”**

**“There is a line from a Western which is corny but sums it up well - ‘Play the cards life deals you.’ Nothing I can do about it so I just get on with life”**

## 6. Research into secondary progressive MS

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The change from relapsing remitting to secondary progressive MS reflects a change in the underlying disease activity in the central nervous system.

Relapses in multiple sclerosis are associated with patches of inflammation around nerves in the brain and spine. Several ways have been found to reduce or prevent some of this inflammation, which has led to the development of the disease modifying drugs.

When MS becomes progressive, inflammation becomes less prominent and the main disease activity is the destruction of the myelin layer that surrounds nerves and of nerve fibres themselves. What causes this process and how it can be altered is less well understood. Drugs that reduce inflammation are no longer helpful and new approaches are needed.

As well as trying to better understand why progression happens, research is looking for ways to reduce the rate of progression by protecting the nerves (neuroprotection) or by finding ways to repair damage that has occurred (stem cells may have a role in this).

### Neuroprotection

Damage caused by MS can lead to increases in levels of nitric oxide, calcium and sodium around nerves. Contact with high levels of these chemicals can damage or destroy nerve cells, leading to the persistent symptoms of progressive multiple sclerosis.

Similarly, glutamate is one of the chemicals involved in transmitting messages from nerve cell to nerve cell. However, excessive glutamate can also damage nerves.

The loss of nerve cells can be measured through changes in brain volume, which is known as atrophy. As cells are lost, the brain will become smaller.

The theory of neuroprotection is that, if the nerve cells can be protected from these chemicals, destruction - and thus further permanent problems - can be lessened or perhaps prevented.

Several studies have looked at possible neuroprotective drugs, though there have only been small studies in humans. Drugs that have shown potential will need to be studied in larger trials before treatments can be made available for people with MS.

Neuroprotective treatments will not be able to reverse progression or restore function that has already been lost. However, if suitable drugs can be developed, it is hoped that this will mean that further progression of MS can be significantly slowed down.

For more information on some of these trials, see Appendix 3

## Repairing and replacing myelin

Whilst drugs that alter the action of the immune system or that protect nerves may help to limit the build-up of damage, neither will reverse the progressive effects of multiple sclerosis. Finding ways to repair or replace areas of damage and thus allow people to recover ability that has been lost is another important area of MS research.

### Stem cells

Stem cells are cells that can develop, or differentiate, into any of the cells of the body. Stem cells are the first cells to develop in the embryo and allow it to develop the specialised functions and mechanisms that occur in the human body. Stem cells also occur in adults and are used by the body to replace areas of damage.

Stem cells may potentially be used to treat MS in different ways by:

- developing into **nerve cells** to repair damage in the brain or spine
- developing into **oligodendrocytes**, the cells that create and repair the myelin around nerves
- boosting the **immune system** to prevent further damage occurring.

Work is also looking at how best to deliver stem cells so that they go to the appropriate places to carry out repair and also at ways to ensure that transplanted stem cells do not harm the recipient or grow into unwanted tissue.

If processes can be developed, it opens the possibility that cells destroyed by MS might be replaced and disabilities caused by the loss of nerve pathways reversed.

Stem cell treatment has been demonstrated for experimental forms of MS. Pilot studies in humans - so far looking principally at safety - have started in the UK.

### Accelerating the growth of myelin

It is known that in the earlier stages of MS the body can to some degree replace lost myelin. If the affected area is no longer being attacked by the immune system, new myelin can be formed around nerve cells.

Research has looked at the body's own ability to replace damaged myelin and has identified proteins that may enhance this. Work to develop treatments that might encourage and enhance this process is still in very early stages and an approach that can be studied in humans is still some years away.

## Collaboration in research

Although progress will seem slow to someone living with the condition, and any actual drugs or treatments are still some years away, increasing numbers of researchers are focusing on better understanding progressive MS and how it might be treated. This led to the launch of the Progressive MS Alliance in 2012. The aim of this group of key researchers and research organisations from around the world is to identify priority areas for research in progressive forms of MS and to bring people working in this field together to share ideas and advances in both disease modifying and symptomatic treatments.

**“Focusing on primary and secondary MS, is probably the greatest need in the MS community”**

**Prof Alan Thompson**

**“It is simply a matter of time before breakthroughs in progressive MS occur. If we keep investing in research the breakthroughs will happen”**

**Prof Gavin Giovannoni**

# 7 . Tips for coping with secondary progressive MS

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Ideas and tips submitted by people living with secondary progressive MS

**“Keeping a sense of humour is very important. Don’t forget how to laugh!”**

**“A good support network of health professionals, friends, family and charity groups helps”**

**“Keep a card to hand with the name and contact details of MS nurse, neurologist, support groups, MS charities, etc”**

**“If face to face meetings are confusing, having what you want to say written down helps”**

**“Ask for copies of the letters sent to your GP, either from the surgery or the hospital, so you know what they are saying about you”**

**“If you think something might help you then ask for it - loudly!”**

**“Take part in research studies - these in themselves can be therapeutic and may give you a boost of wellbeing because you are helping others”**

**“Get to know all you can about your illness - information is power”**

**“There is a lot of information to be had. I just try to take in a little bit at a time”**

“Talking to others with MS and going to online chatrooms has helped enormously”

“Ask people for help, eg, carrying things, asking for lifts etc. Most people are pleased to do so”

“People often don’t realise your difficulty as you might look ‘normal’ even if you cannot walk very far or are afraid of falling over”

“Raise the profile of secondary progressive MS”

“Keep doing things - I never thought I could horse-ride or splash about in a hydrotherapy pool and I might even learn to swim again”

“Take up a new hobby that you can do sitting down - art classes, playing an instrument etc”

“Keep up with friends and say yes to invitations even if you think you can’t possibly manage - you usually can with a bit of help”

“Keep an open mind - be prepared to talk openly and frankly about how you are feeling”

“Be honest because you are the best person to describe your feelings. You will have down days when symptoms may make you depressed. Share your feelings and treat it as another dropped stitch in life’s rich tapestry”

“A positive mental attitude is essential to survival and coping with everyday living with MS”

“Try not to let MS take over your life completely”



## 8. Appendix 1: Living with secondary progressive MS

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- **Living well - health awareness, activity, diet**
- **Work**
- **Welfare benefits**
- **Maintaining social relationships**

### Living well - health awareness, activity, diet

The physical and psychological effects of living with MS can sometimes mean that looking after basic health is overlooked or becomes more challenging to achieve. Fatigue, reduced mobility or continence problems can make someone become less active or follow a diet based more on convenience of preparation than nutritional value.

However, trying to stay as healthy as possible can put people in the best position to deal with the challenges presented by their MS.

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#### Health awareness

It is very easy for both the person with MS and their health professionals to assume that all health issues are in some way related to multiple sclerosis. This is, of course, not the case. People with MS are at risk from the same health problems as the general population and it is important to have any relevant health, dental or optical checks and to raise concerns with your GP.

Sometimes the effects of MS can make getting to check-ups more difficult, though this should not be used as a reason why it doesn't take place. Sometimes adaptations to the equipment may be needed - for instance for a wheelchair user attending a breast screening, or someone with swallowing difficulties receiving dental work. When the check-ups are being booked, make sure that people are aware of potential barriers and requirements.

## Healthy lifestyle

General healthy lifestyle advice also applies to people with MS and may have added advantages for people with the condition.

## Staying active

Exercise has been shown to have a range of benefits for people with MS. As well as improving general fitness, exercise can help to reduce fatigue and improve strength, mobility, bowel and bladder function. It can also help improve mood and sense of wellbeing.

The idea of 'exercise' can be off putting for some, but any activity that involves physical movement with even a slight increase in effort - such as gardening, housework or shopping - can be beneficial.

**“I find it much easier to disguise it as something fun that happens to keep me active rather than just ‘doing exercise’ ”**

Symptoms such as stiffness, weakness and poor balance can benefit from exercise and a physiotherapist can help develop a suitable, tailored programme.

If fatigue or sensitivity to heat are issues, take things gently and be aware of when to rest and when to pace activities. Otherwise, there are no hard and fast rules about what exercises someone should do. Find something you enjoy doing, whether on your own or in a group, and build up gradually.

### **Other MS Trust resources**

- Exercises for people with MS - [www.mstrust.org.uk/exercises](http://www.mstrust.org.uk/exercises)
- Move it for MS - a free DVD of exercises
- StayingActive - a collection of idea and links - [www.mstrust.org.uk/stayactive](http://www.mstrust.org.uk/stayactive)
- MS and me - a guide to self-management

## Healthy eating

Although no specific approach has been proven to be beneficial for people with MS, a diet low in saturated fat with plenty of fruit and vegetables has been shown to be good for general health. A healthy, well balanced diet and plenty of fluids provides optimum energy levels, helps to control weight and reduces the risk of cardiovascular disease.

### **Other MS Trust resources**

Diet factsheet

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## Smoking

The health risks associated with smoking are well known, but research has shown that giving up can have particular benefits for people with MS. People who gave up cigarettes following their diagnosis with MS experienced slower progression of disability than people who continued to smoke.

### **Other MS Trust resources**

Smoking - A to Z of MS - [www.ms-trust.org.uk/smoking](http://www.ms-trust.org.uk/smoking)

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## Complementary medicine

Research studies suggest that up to half of people with MS regularly use at least one complementary therapy approach to help with their condition. As well as any direct therapeutic benefits, exploring different approaches can also offer a feeling of regaining some sense of control, even if particular therapies that are tried prove not to be helpful.

There is a wide range of therapies that people might consider from acupuncture and aromatherapy to mindfulness and yoga. If a particular therapy sounds interesting, where possible, consult a practitioner who has been recommended by a trustworthy source - a friend, doctor, etc. So long as there are no safety

issues and the cost is reasonable, be your own judge as to whether the approach is helping. If you feel benefit, then keep on going. If the approach does nothing for you, mark it down to experience and perhaps try something else.

### **Other MS Trust resources**

Complementary and alternative medicine -

A to Z of MS - [www.mstrust.org.uk/complementary-and-alternative-medicine](http://www.mstrust.org.uk/complementary-and-alternative-medicine)

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## **Work**

For many people, working provides more than just a regular pay packet. Being at work can give structure to the week, be a source of social interaction and be bound up with someone's feelings of wellbeing and self worth. Work can be good for health.

People with MS are covered by the Equality Act, which protects anyone with multiple sclerosis from discrimination in the workplace and requires employers to explore reasonable adjustments that could be made to help someone stay in work. Despite this, research shows that many people with MS find that their condition has an impact on their working life and leave employment early.

Before making any decision, it is worth exploring the implications - financial, social, the effect on the family - and what support might be available to help you with these choices.

### **Other MS Trust resources**

At work with MS - book

At work with MS - [www.mstrust.org.uk/at-work](http://www.mstrust.org.uk/at-work)

## Welfare benefits

For many, the change to secondary progressive MS is a point when they might start to look for information on what help is available or find that their eligibility for benefits has changed.

Benefits fall into three categories:

- Those related to low income - such as Housing Benefit, Council Tax Benefit or Income Support. Some of these benefits will be combined in the new Universal Credit that will be introduced in the next few years.
- Those related to employment - such as Jobseekers Allowance or Employment And Support Allowance (ESA). Some of these benefits will also become part of the Universal Credit.
- Those related to the extra costs of living with a long-term condition - such as Personal Independence Payments (PIP), which have replaced Disability Living Allowance (DLA) for new claimants. People currently receiving DLA who were aged under 65 on 8 April 2013 will be moved to PIP over the next few years.

Navigating the benefit system can be challenging and the chances of making successful claims are improved by talking to organisations with expertise in guiding people through the process.

**Citizens Advice** offers free advice, though this may need to be at one of the larger centres rather than community offices. Their Advice Guide website includes a section on identifying and claiming benefits - [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

**Some MS Society branches** have a welfare officer or local support officer who can help people with MS claim the benefits to which they are entitled - [www.mssociety.org.uk/near-me](http://www.mssociety.org.uk/near-me)

**MS-UK** has a Welfare Rights and Benefits Specialist who

can help with information about benefits, making a claim or appealing a decision - [www.ms-uk.org/welfare/rightsandbenefits](http://www.ms-uk.org/welfare/rightsandbenefits)

**Gov.uk**, the government information website, has links to benefits calculators to help you find out to which benefits you may be entitled - [www.gov.uk/benefits-adviser](http://www.gov.uk/benefits-adviser)

In some areas there are local groups that can help people find their way through the benefit system.

### **Other MS Trust resources**

Benefits and tax credits - A to Z of MS - [www.mstrust.org.uk/benefits](http://www.mstrust.org.uk/benefits)

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## **Maintaining social relationships**

Contact with other people is an important aspect of life. Aside from any direct support and help that people can offer, the sense of involvement and understanding and a wider perspective on one's own situation is central to wellbeing.

Sometimes the effects of MS make someone less inclined to be sociable. Meeting people can be tiring or venues present practical problems such as difficulty with access or knowing where to find toilets quickly.

**“Can’t go out much, can’t be far from a toilet or from home generally, where everything is arranged to suit”**

**“If I go out during the day it can’t be for longer than an hour or two, I just become too weary and uncomfortable”**

Sometimes people feel embarrassed by their own restrictions and will perhaps judge themselves more harshly than those around them.

**“I hate the way MS affects me and I prefer others not to see its worsening effect”**

**“I don’t like being seen in a wheelchair”**

Getting out of the habit of being sociable can also make going out become more of a chore.

**“I have to force myself into action sometimes as it is so much easier to just stay at home”**

It is important to remember that there is a poor understanding of MS amongst the general population. If people do know about MS, they may have incomplete knowledge or make false assumptions. Friends may be unaware of just how MS affects someone and not realise what an individual with MS can or can’t do.

The person with MS has a key role in letting people know what the barriers and challenges are for them and how best to overcome these. Depending on symptoms, this could involve giving plenty of notice of get-togethers, being prepared for you to decline or pull out at the last minute, planning for easy access to toilets or choosing shorter routes for walks.

**“If I go to a restaurant I usually go to one particular one which is familiar and where they now know me and my family”**

People are often willing to help in any way they can but need guidance on what is appropriate. Through not knowing what questions are appropriate, some people may avoid talking about MS entirely. Others may give full reign to their curiosity or become overpoweringly protective. It can be useful to develop strategies to deal with unwanted or intrusive questions.

**“I don’t like going into situations with new people as they ask too many questions and some are very insensitive”**

Being sociable isn't restricted to meeting people face to face. There are an increasing number of online groups on any topic imaginable and these may be an option for someone who has difficulties with mobility or who is reluctant to be seen as a person with a disability. Online, people are defined just by what they tell people.

**“I get out less now but use the internet and the telephone to keep in touch with friends”**

**Other MS Trust resources**

Online groups links - [www.mstrust.org.uk/interactive/links/](http://www.mstrust.org.uk/interactive/links/)



# 9

## Appendix 2: ACT exercises

Dr Sarah Gillanders, clinical neuropsychologist

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As discussed on page 23, acceptance and commitment therapy (ACT), is a type of psychological therapy that encourages people to become more aware of their thoughts, feelings and beliefs and the helpful and unhelpful ways they respond. It tries to support people to become more aware of and in touch with what matters to them and to help them find ways to do those things.

### Feelings

What are some of the thoughts, feelings and beliefs you have about secondary progressive MS? What is it that is playing on your mind?

- Do you have thoughts of ‘why me?’, ‘this is not fair’, ‘my body is failing’, ‘I am no longer the person I was’, ‘MS has robbed me of so much’?
- Do you feel scared, angry, lost, frustrated, alone, vulnerable, judged?
- Do you have beliefs such as ‘the future is bleak’, ‘I couldn’t cope if this got any worse’?

Exercise: write some of these concerns on paper

### How do you respond?

When the thoughts, feelings and beliefs you wrote down pop up or are playing on your mind, do you:

- Shout, nip, make rude remarks; are you short tempered, tearful; or do you withdraw from others, miss appointments?

- Do you manage to tell someone how you feel, get some fresh air, listen to music, make a cup of tea, go out with a friend, go shopping etc?

Exercise: write down all the ways you respond when you feel upset

## What are the consequences of your responses?

Looking at the list above, which ones are helpful and which are unhelpful? If you struggled to think of any helpful responses then take a moment to think about what might help you. How can you look after yourself when you are finding things difficult?

Exercise: make a list of helpful and unhelpful responses

## What next...

Now that you have a clearer idea of the helpful and unhelpful ways you try to deal with the stress of the transition to secondary progressive MS, how can you do more of the helpful responses? What are some of the barriers that make it difficult?

**“I can’t talk to my husband/wife about this; they have enough on their plate”**

**“I would like to get more fresh air but I tire too quickly to go to the park”**

**“I struggle to make tea now that my arms are weak”**

Exercise: what makes it difficult to respond in a helpful way to your distress?

## What can we do about the barriers?

There are often challenges to doing what is good for us. The key is to try to stay focused on what we want to do, even when these barriers are in our way.

Taking the first barrier above, does your husband/wife have so much on their plate that they can't talk to you about your secondary progressive MS? If it's important to you to have a close and supportive relationship with your partner, and you value the support you can give one another, then perhaps it is worth trying to open up a little more, even if that is hard to do. You might start a conversation like that by saying that you're scared of overwhelming them as it feels overwhelming to you at times, but you value the support you can give each other and want to try talking a bit more. On the other hand, if you can't get that support from your spouse, are there friends or other family members who can be that source of support?

If the barriers relate to mobility problems, then is it possible to do things differently? Perhaps you used to go to the park, but if it is fresh air that you like then is it possible to sit in the garden or on the street in front of your house instead? It's not how it used to be but you still get some of the things you like.

If it is making tea that is difficult then is it possible for someone to make one in a warm travel mug so even if there is a time when you are alone, there may still be a warm cup available.

Exercise: take a look at each of your barriers and think about how you can do more of what's helpful for you

# 10. Appendix 3: Research trials

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Some of the drugs that have been studied for their effect on protecting nerves from further damage (neuroprotection)

- Lamotrigine (Lamictal) - studied in 124 people with secondary progressive MS but found to be no more effective than placebo
- Amiloride - a pilot study in 12 people with primary progressive MS suggested less damage to nerves, loss of brain volume and a slower change in EDSS (Expanded Disability Status Scale - a commonly use measure of disability) than in the year before treatment
- Safinamide - showed a neuroprotective effect in animal studies
- Flecainide (Tambocor) - showed a neuroprotective effect in animal studies
- Riluzole (Rilutek) - a small study of 16 people with primary progressive MS did not show any definite effect. There was a trend for a reduction in MRI changes but not in clinical measures of disability
- Eliprodil - produced some degree of nerve fibre protection in laboratory based models
- Cannabis - the CUPID study involved 493 people with progressive MS taking a cannabis based pill. Results found it to be no more effective than placebo
- Simvastatin - the MS-STAT trial involved 70 people with secondary progressive MS taking a high dose of a cholesterol-lowering drug and 70 taking a placebo. Those on simvastatin showed reduced

loss of brain volume, slowed change in EDSS, and improved scores on the MSIS-29, a measure of the extent to which MS affects daily life. A larger trial will be needed

- Fingolimod (Gilenya) - this is already licensed to treat relapsing MS. The INFORMS trial is looking for indications that the drug protects nerves in people with primary progressive MS. The trial, which has almost 1,000 participants, is due to complete in 2014
- Siponimod is a similar drug to fingolimod and is being explored as a treatment for secondary progressive MS in more than 1,000 people. The trial is due to complete in 2017
- Phenytoin (Epanutin) - the neuroprotective effect of this antiepileptic drug is being explored in a study involving 90 people that is due to complete in 2014
- MS-SMART is a trial looking at three drugs - ibudilast, riluzole, amiloride - that have shown some signs of promise in progressive MS. The trial will involve 440 people with secondary progressive MS and is due to complete in 2016

# 11. More information

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## MS Trust Information Service

If you have specific questions on any aspect of MS, contact our team of information officers on 0800 032 3839 or [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk)

MS Trust books and factsheets are free and can be ordered by ringing 01462 476700 or by email at [info@mstrust.org.uk](mailto:info@mstrust.org.uk). All titles can be read or ordered online at [www.mstrust.org.uk/pubs](http://www.mstrust.org.uk/pubs)

Keep up to date with news about research and the world of MS by signing up for Open Door, the MS Trust's free, quarterly newsletter, or our weekly email alerts. Ring 01462 476700, email [info@mstrust.org.uk](mailto:info@mstrust.org.uk) or signup online at [www.mstrust.org.uk/in-touch](http://www.mstrust.org.uk/in-touch)

## Symptoms

Symptoms of MS - A to Z of MS - [www.mstrust.org.uk/symptoms](http://www.mstrust.org.uk/symptoms)

### Bladder

Managing your bladder (book)

### Bowels

Managing your bowels (book)

### Cognition

Cognition factsheet

StayingSmart - [www.stayingsmart.org.uk](http://www.stayingsmart.org.uk)

### Fatigue

Living with fatigue (book)

## Pain

Pain factsheet

## Sexual issues

Sexuality and MS: a guide for women

Sex and MS: a guide for men

## Spasticity

Spasticity and spasms factsheet

## Walking

Walking difficulties - A to Z of MS -

[www.mstrust.org.uk/walking-difficulties](http://www.mstrust.org.uk/walking-difficulties)

## Weakness

Weakness - A to Z of MS - [www.mstrust.org.uk/weakness](http://www.mstrust.org.uk/weakness)

## Other resources

- At work with MS (book / [www.mstrust.org.uk/at-work](http://www.mstrust.org.uk/at-work))
- Diet factsheet
- Exercises for people with MS - [www.mstrust.org.uk/exercises](http://www.mstrust.org.uk/exercises)
- Falls: managing the ups and downs of MS (book)
- Map of MS services - [www.mstrust.org.uk/map](http://www.mstrust.org.uk/map)
- MS and me: a guide to self-management (book)
- Posture - [www.mstrust.org.uk/posture](http://www.mstrust.org.uk/posture)
- StayingActive - [www.mstrust.org.uk/stayactive](http://www.mstrust.org.uk/stayactive)
- A short guide to understanding my MS - for friends, family and colleagues
- Making the most of appointments

## Notes

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## Notes

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## Notes

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## About the author

Simon Webster, Information Officer, MS Trust

The MS Trust is a UK charity for people with MS, their family and friends. The MS Trust Information Service offers a personalised enquiry service; produces a wide range of publications including Open Door, a quarterly newsletter; and provides web based information.

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All the people with MS and the health professionals who have made this book possible through sharing their experiences of secondary progressive MS and by commenting on draft versions of the work in progress.

Please contact the MS Trust information team if you would like any further information about the reference sources used in the production of this publication.

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