

MS Society

Balance and MS



We're the MS Society. Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

We rely on the generosity of people like you to fund our vital work. If you would like to make a donation, you can do so by:

- Calling us on: **0300 500 8084**.
Lines are open Monday to Friday, 9am – 5pm
- Visiting us at: **mssociety.org.uk/donate**
- Posting your donation to: MS Society, National Centre, 372 Edgware Road, London NW2 6ND. Please make cheques payable to the 'MS Society.'

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A word from Bruce, who has MS

When I was diagnosed with MS, it was actually a bit of a relief. I know it sounds strange to say, but I'd been experiencing symptoms, and I didn't know what was happening. So actually to have some certainty made me feel better.

I made a plan that I wouldn't let it take over my life. When I experience relapses I just take it one day at a time.

I started having balance problems a couple of years ago. These days I have to walk with a stick. I just have to take my time. At first I was quite self conscious with the walking stick. I thought people would be staring at me and wondering why someone who is still fairly young has a walking aid.

My friends and family have reassured me that I don't look silly, and these days I don't even notice I'm using it.

Booklets like this, from the MS Society, are really helpful. The advice you'll find in here will be reassuring, no matter how bad your balance problems are.

A handwritten signature in black ink that reads "Bruce". The signature is written in a cursive, slightly slanted style. Below the name is a single, thick, horizontal black line that tapers at both ends, serving as a decorative underline.

Five things to know

- 1** MS can affect your balance, including difficulties with coordination, tremor and muscle weakness, stiffness or spasms
- 2** But there are also other causes of balance problems, other than MS. Speak to your GP to find out what might be causing them
- 3** A balance assessment can help you to find out what's causing your balance problems, and to find solutions
- 4** A physiotherapist or rehabilitation specialist can help you improve your balance
- 5** You may also find aids like a walking stick, or home adaptations, can help you cope with your balance problems better



About this booklet

Balance problems are a common symptom of MS. For some people, they can just be a small issue that affects them from time to time; for other people, problems with balance can have a major impact on their ability to get about safely.

This booklet looks at how the body's balance system works, and how MS can affect it. It also offers some helpful ways to manage MS-related balance problems.

If MS has affected your balance, it's important to remember that there is often something that can be done to help. Many people do

find effective ways to improve their balance and feel more confident about getting around.

What do we mean by balance problems?

MS can affect balance in different ways. Some people have vertigo – a feeling of dizziness where the world appears to be spinning. This can be a passing sensation or last much longer.

Some people are unsteady on their feet from time to time, or find they need to move with more care than before to avoid losing their balance. This might be the result of a number of different MS symptoms, such as lack of coordination, muscle weakness or stiffness, or tremor.

There's more information about how to manage these symptoms on our website. We also have information booklets and factsheets on all common MS symptoms. You can find details of how to order these are on page 30.

We look more at the causes of balance problems later in this booklet.

“I feel as if I’m on a rocking boat, sometimes on choppy waters, sometimes on more gentle water. Occasionally I have vertigo as well... like a tornado in your head, extreme, lasts a few seconds or minutes.”

Bob

The effects of balance problems

Whether your balance difficulties are due to vertigo, or the result of other MS symptoms, they can have a significant impact on your day-to-day life.

You may find that your ability to get around on foot or by car, or to move from one position to another, is affected. Even activities which involve staying still, such as reading, or watching a film or TV, can be disrupted.

Lack of confidence in going out and about

Balance usually happens without you having to think about it, and if it changes – even temporarily – it can take some getting used to. It's normal to feel slightly nervous or apprehensive moving about if you're having difficulties with balance, particularly if it's a new or changing symptom or

you're in a place you don't know. However, this can lead to anxiety, which in turn may mean you lose confidence in your ability to get out and about. Some people stop going out at all.

“My balance problems occurred when the balance centres in my brain were affected during a relapse. I stayed at home quite a lot during the worst period, only going out when I had to and usually tried to make sure someone was with me.”

Lucy

Anxiety about balance problems can actually make them worse, so it's important not to ignore this emotional aspect. If you're

experiencing anxiety – whatever the cause – there are things you can do to help manage it. Speak to your MS nurse, GP or other health care professional if you notice changes in your mood, or you're often anxious or depressed. There's more on managing the emotional side of MS in our booklets 'Living with the effects of MS' and 'Mood, depression and emotions'.

Later in this booklet we include some practical tips for getting around safely, which can help you to feel more confident in getting out and about.

What other people think

If you're unsteady on your feet sometimes, you may have found that other people make assumptions about the cause: for example, thinking that you're drunk, particularly if you have few other obvious MS symptoms.

The fear of what other people may be thinking can cause some people to feel embarrassed, and may stop them from going out. If you feel like this, you may find

our credit-card sized 'Assistance card' helpful. This lists some of the common symptoms of MS, including balance problems, and can help you to explain why you may be a bit unsteady on your feet. Details of how to order are on page 30.

“The main thing for me is that I look like I'm drunk. It's not just tripping and stumbling but the general feeling of being unsteady. My family is oblivious to it now but for people who don't know me, I think it is more of a problem for them than for me.”
Lorraine

Falls

If you have problems with balance, this can increase your risk of falling. While most falls aren't serious, some can cause painful injuries – and any fall, whether painful or not, can be

very embarrassing. Fear of falling can also lead some people to avoid going outside alone or to unfamiliar areas.

We cover some practical suggestions to help prevent falls later.

“I’ve been using my stick now for about three years. After many falls I gave in and now I don’t go outside without it. If anyone stares I just give them a great big grin and carry on.”

Janet



How does balance work?

Good balance needs many different parts of your body to work together effectively. It may be helpful to think of these different parts of balance being grouped into input, processing and output.

Input

There are three main 'input systems' working to keep your body balanced, constantly feeding information to your brain through nerve fibres.

The three systems are:

1. The visual system – your eyes. These provide information about where your body is, the direction it's pointing in, what direction it's moving in and whether your body is moving or standing still.
2. The vestibular system, made up of part of your inner ear and its connections to your brain. The inner ear is deep into your

ear, beyond your ear drum, and it has two important roles. One is to process the sound you hear. The other is to measure movement of your head, rather like a complicated version of spirit levels used in DIY.

3. The proprioceptive system, which consists of sensors in your joints, muscles and skin. All over your body there are sensors providing information on motion, position and pressure. For example, messages from the skin on the soles of your feet help your brain to balance your body when you're standing up: too much pressure on the front of your foot is a signal that you're falling forwards, and too much pressure on your heels is a sign that you're tilting backwards.

Processing

Your brain takes all of these different input messages and

processes them to work out where your body is and how it's moving. There's no single part of your brain responsible for this processing, but areas called the 'cerebellum' and the 'brainstem' play major roles in balance. These include helping to control your body's overall coordination.

Output

Once it's processed the information it receives, your brain sends out messages back along the nerve fibres, through the spinal cord and out to your muscles. These outputs adjust to the movement and position of your body in its changing surroundings, keeping your body balanced.



How can MS affect balance?

MS can affect all three parts of the balance system – input, processing, and output.

Information your brain receives and the replies it sends out can be late, incomplete or misleading. The messages being passed inside your brain can also be disrupted, which affects the way it processes balance information.

“I feel like going back to bed to sleep but if I do, I don’t tend to feel any less dizzy – it really wants to last for a whole day.”

Rachel

Input

1. Visual

Visual problems, such as blurring or double vision, are quite common in MS. These kinds of changes to your vision can give confusing information to your brain when it tries to work out where your body is moving, relative

to the world around it. Problems with vision alone are not usually enough to upset your balance, but if other input messages are also affected, they may have an impact. There’s more on how MS can affect vision in our booklet ‘Vision and MS’.

2. Inner ear

Your inner ear constantly updates your brain about the angle and position of your head. If MS has affected the nerve pathways between your inner ear and your brain, the information may be disrupted or missing – which can add to balance problems.

If you experience vertigo – a spinning sensation – then this may be a sign that messages from your inner ear are involved. However, there are also other possible causes for vertigo which aren’t MS related. For more on these other causes, see later.



3. Sensory

Sensory changes, such as numbness or tingling, are common in MS. They're usually a sign that the nerves which process information from sensors in your skin, muscles or joints have been affected. As well as causing these strange sensations, this means that your brain may not be receiving the information it needs to balance your body properly.

There's more on sensory changes in our booklet 'Pain and sensory symptoms'.

Processing

The way that your brain processes balance information is complex, so the effects that MS can have on this are also complex.

Almost every part of your brain is involved in balance in some way. Depending on how MS has affected the nerves in your brain, and where the nerve damage is, this can have different effects on your balance.

In some cases, your brain can compensate for a certain amount of disruption in different parts of the balance system – so, even if the input messages have been affected, you may not have obvious problems with your balance. But if MS nerve damage is more widespread, your brain is less able to compensate for it and the effects can become noticeable. Also, if you have nerve damage in the cerebellum (an area of your brain particularly associated with balance) then this can also affect your brain's ability to compensate for missing or incorrect messages.

MS nerve damage in the cerebellum or brainstem can also cause problems with vertigo, sometimes accompanied with nausea. However, there are other possible causes for vertigo which aren't MS related. For more on these other causes, see the section 'It might not be your MS' opposite.

Output

MS can cause a wide range of symptoms that can have an effect

on balance, including difficulties with coordination, tremor and muscle weakness, stiffness or spasms.

These symptoms may mean that your muscles aren't able to respond properly to the

instructions being sent to them by your brain; a weak or stiff muscle might not move to the right position, or may get there too slowly. If this combines with misleading information about where the muscle is, you may find it harder to balance yourself.

It might not be your MS

If you notice problems with your balance, they may not be caused by your MS. There are other common causes of balance problems that can affect anyone, whether or not they have MS.

These include:

- Infections of the inner ear, which can cause vertigo and nausea
- Positional vertigo, a spinning sensation caused by particular head movements
- Side effects of medication

All of these causes are treatable. However, the way that they're managed differs, so you would need to know what's causing your balance problems before they can be treated. So if you notice changes in your balance, speak to your GP – it's important to have any symptoms properly investigated.

The Brain and Spine Foundation produces a booklet called 'Dizziness and balance problems', which has more information about these more common causes of balance problems and how they are diagnosed and treated.

What can I do to improve my balance?

In many cases, there is usually something you can do to improve your balance.

The first step is to identify what may be causing your balance problems, through a balance assessment. There may be a combination of factors involved in your balance problems, so it's important to have all the possible causes investigated. Treating one in isolation may not bring about the best results. There's more on balance assessments in the next subsection.

Once the causes of your balance problems have been identified, you can then find ways to manage them. This often involves working with a range of health and social care professionals, including physiotherapists, occupational therapists, rehabilitation specialists, MS nurses and ear,

nose and throat (ENT) specialists, to find the right treatment for you.

A health or social care professional can help you to set achievable, practical goals for improving or managing your balance. You may notice improvements only very gradually – managing balance problems is a long-term project, but one which can have results.

Balance assessment

A balance assessment can help you to find what's causing your balance problems, and to find solutions.

The assessment will usually be carried out by a physiotherapist, or other health care professional. They will want to know how, where and when you have problems with your balance – for example, if you have trouble balancing if you're out

in the open, and whether you experience vertigo at the same time.

They will assess your balance by observing you in different positions – for example, standing or sitting – and seeing how your body responds.

They may check your vision, and eye and head movements to discover whether the visual or

vestibular systems are involved in your balance problems. They will also assess any other symptoms you have that may impact on your balance, such as muscle weakness or spasticity, or fatigue.

In some cases, a more thorough assessment may be needed to find out the causes of your balance problems. This may be carried out by an ENT specialist, or within a balance clinic in a hospital.



As well as an initial assessment, you should have regular, ongoing assessments. These can help to monitor your progress, and to highlight any improvements. They can also reveal any adjustments you could make

if your circumstances, or the causes of your balance difficulties, change. You, along with your family, can also monitor any changes in your balance yourself: whether it gets better or worse, and what seems to affect it.

Other things that can affect balance

If your balance problems are caused by a relapse, or they get worse during a relapse, then treating the relapse may improve the problem. Treatment with high dose steroids can usually help to speed up recovery from a relapse. There's more on treating relapses in our booklet 'Managing a relapse'.

Your balance may also be affected if your body

temperature rises. This is sometimes known as a 'pseudo relapse', because it mimics the symptoms of a relapse. These pseudo relapses can be treated by treating whatever's causing your raised temperature, such as an infection. Many people find that their balance problems get worse when they're fatigued. There's more about managing fatigue in our booklet 'Fatigue'.



Managing balance problems

There are a number of things you can do to try to improve your balance. Some of these you can do with support, perhaps from a physiotherapist or occupational therapist, while others you can try on your own.

Medication

Fampyra (fampridine) is a tablet that's been found to improve walking speed and ability by up to 25% in four out of 10 people. Free access to this drug, which is not deemed cost-effective by NICE, is limited across the UK.

If you're having problems accessing licensed treatments, find out more about our Treat me right campaign at www.treatmerightms.org.uk

Balance retraining

In order to improve balance, it needs to be challenged. This is sometimes known as balance retraining.

Working with a physiotherapist or rehabilitation specialist, this can help you to challenge your current levels of balance and improve your body's ability to compensate. This is not a quick fix, but over time it can help.

Simple movements or postures can retrain your balance reactions. By asking the pathways of nerves to 'work', it encourages messages to be transmitted more efficiently or responsively – a bit like the 'use it or lose it' analogy. This, combined with specific training of postural muscles (the muscles that work to keep you upright) can help improve your balance.

Physiotherapy

Having assessed what the likely causes of your balance problems are, a physiotherapist may suggest specific exercises to help manage the issue.

A well-designed physiotherapy programme can help improve

balance. There are different types of exercise that may be useful. This could include exercises specifically designed to improve balance. It could also include exercises that focus on posture, and the strength and suppleness of your muscles, which could in turn improve your balance.

This approach can also improve confidence in your ability and allow you to gradually do more.

Other forms of exercise

There's evidence to suggest that a range of exercise therapies, including yoga, Pilates, t'ai chi, the Alexander Technique and the Feldenkrais Method, along with aerobics and outdoor walking, can help with balance.

Sometimes, a therapist may suggest using equipment such as a balance board or a Swiss ball (sometimes called a gym ball or yoga ball), which may help you to balance better.

“Pilates exercises are designed to build up core stability so they're ideal for us MSers, as it can help improve your balance and walking. When I get physio after a relapse the exercises I get given are always based on Pilates exercises, and I find they help my standing and walking.”

Dan

You may find that exercise games for computers like Nintendo Wii Fit can be useful for improving balance and core strength. One small study using a Nintendo Wii Fit balance exercise programme found that it may help with balance.

Some people find that using a 'whole body vibration' platform is a good way to exercise and strengthen their legs. However,

there is no clear evidence of any benefits for balance, and it would not normally be recommended by a physiotherapist.

Hippotherapy is another form of exercise that may help with balance. It uses the motion of a walking horse to provide therapeutic movement to the rider. There is some evidence that it can help improve balance in people with MS. It's not widely available in the UK.

Before trying any new exercise or equipment it's a good idea to check with a health care professional to be sure it is safe and suitable for you. If you attend group sessions, it is worth checking whether the teacher has experience of people with MS, or knowledge of the condition. You may want to discuss how MS affects you and if there are aspects of the activity that can be adjusted to suit you better. Remember, what suits one person may not work for someone else.

Remember also that trying anything new might feel difficult

at first when your balance is not at its best. But challenging your balance, safely and gradually, can be a way to develop it. Finding the right exercises, at the right level for you, can make a real difference to how you feel.

Splints and FES

If you have problems with dropped foot (meaning that you can't lift your foot up properly when you're walking) you may benefit from a splint or Functional Electrical Stimulation (FES). These devices reduce the impact of the dropped foot, and make walking easier and make it less likely that you will trip or fall.

There's more information about FES and how to access it in our booklet, 'How to campaign for access to FES'.

Getting out and about

There are things you can do if balance issues have affected your ability to get out and about safely.

“I see the stick as a weapon in my fight against this stupid condition - MS has meant that I can no longer wear my pretty heeled shoes, and I am terrified of falling, but I’m still walking with flat shoes and a stick, it’s not going to beat me that easily!”
Luisa

You may find you need to pay more attention than usual to balancing when you walk and move around. You may find it easier if you focus on walking, without doing anything else at the same time (such as talking).

Using a stick at times can also help. Some people find it particularly helpful in open spaces, or in unfamiliar places. The decision to start using a walking stick can be a difficult one. Some people feel self-conscious about using one, or

they feel that they are ‘giving in’ somehow to their MS. But often, once they start using one, they realise how useful it is and how it can help them carry on with their normal activities.

Walking sticks and other walking aids are available from the NHS. What is on offer may vary depending on where you are. Wooden walking sticks are usually issued by physiotherapists in the NHS. There’s a wider choice of stick available if you choose to buy your own. Most physiotherapists will be able to advise you on which would be best for you.

Folding sticks are widely available from high street chemists and specialist equipment suppliers. Folding it away into a small bag can be handy, especially if you use it only in certain situations.

To get the best use from your stick, it is important to make sure it is the right height for you. A physiotherapist or an occupational therapist can help you with this.

There are a variety of walking aids available, if a stick doesn't give you enough support. They come in a range of sizes, often with brakes for the wheels, a seat if you need to rest and a place to carry bags. Your occupational therapist and the Disabled Living Foundation can give you further details about equipment available.

Adaptations

Simple adjustments, or perhaps some adaptations, may help if you find it difficult to move around your house safely. Some people find that simply arranging the furniture differently provides a series of balance points around the home, which helps them get around. Small adaptations to the home may be helpful: for example, hand rails along a garden path or at the entrance to the house, or a second banister on the stairs.

An occupational therapist can also help you find suitable adjustments or adaptations. To arrange for an assessment of your home, contact your local authority social care

services department (social work in Scotland) or ask for a referral from your health care team.

Our booklet 'Adaptations and your home' has further information about choosing and paying for adaptations.

There may also be useful changes that can be made in your workplace. Employers have a legal duty to make 'reasonable adjustments' to help you do your job. Our booklet 'Work and MS' has further details, for both employers and employees.

What about research?

A lot of research into MS-related balance problems has looked at existing therapies – such as exercise therapies – and whether they can help.

However, research is also looking into whether technology can help with balance. Small studies have looked into techniques using ‘auditory feedback’ (in which clicking sounds fed through headphones respond to the types of footsteps the person takes) and virtual reality technology.

The results of these studies suggest they may help some people with MS to improve their balance. While these techniques (and others in development) are not yet being used outside of research studies, they are adding to researchers’ understanding of how MS balance problems can be managed.

Useful organisations

Brain and Spine Foundation

Has information about brain and spine conditions, including dizziness and balance problems.

3.36 Canterbury Court
Kennington Park
1-3 Brixton Road
London SW9 6DE

Telephone **020 7793 5900**
Helpline **0808 808 1000**
www.brainandspine.org.uk

British Association of Occupational Therapists and College of Occupational Therapists

The professional body for occupational therapy staff in the United Kingdom. Provides details of private, registered OTs. It also has information about how occupational therapy can help, and useful leaflets on equipment, getting the most from life and how to access services.

Telephone **020 7357 6480**
www.cot.co.uk

Chartered Society of Physiotherapy

The professional body for physiotherapists in the UK. Provides details of registered physiotherapists who specialise in neurological conditions such as MS.

14 Bedford Row
London WC1R 4ED

Telephone **020 7306 6666**
www.csp.org.uk

Disabled Living Foundation (DLF)

Provides information and advice on equipment to enhance independence.

Ground Floor
Landmark House
Hammersmith Bridge Road
London W6 9EJ

Helpline **0300 999 0004**
(Monday to Friday, 10am–4pm)
Textphone **020 7432 8009**
www.dlf.org.uk

Multiple Sclerosis National Therapy Centres

A federation of therapy centres around the UK, offering a variety of therapies. Some centres have physiotherapy clinics.

PO Box 2199
Buckingham MK18 8AR

Telephone **0845 367 0977**
www.msntc.org.uk

MS Trust

Has a useful booklet on falls and MS, 'Falls: managing the ups and downs of MS'.

Spirella Building
Bridge Road
Letchworth Garden City
Hertfordshire SG6 4ET

Telephone **01462 476700**
Information line **0800 032 3839**
www.mstrust.org.uk

Further information

Library

For more information, research articles and DVDs about MS contact our librarian.

020 8438 0900

librarian@mssociety.org.uk

mssociety.org.uk/library

Resources

Our award winning information resources cover every aspect of living with MS.

020 8438 0999

shop@mssociety.org.uk

[mssociety.org.uk/](http://mssociety.org.uk/publications)

[publications](http://mssociety.org.uk/publications)

MS Helpline

The free MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers.

Information is available in over 150 languages through an interpreter service.

0808 800 8000

(weekdays 9am–9pm, closed on bank holidays)

helpline@mssociety.org.uk

About this resource

With thanks to all the people affected by MS and professionals who contributed to this booklet.

If you have any comments on this information, please send them to: resources@mssociety.org.uk or you can complete our short online survey at surveymonkey.com/s/MSresources

Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. Seek advice from the sources listed.

References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge).

Contact the librarian on **020 8438 0900**, or visit mssociety.org.uk/library

Photography

Credit for photography belongs to Simon Rawles (cover, p6, 11, 13 and 19), Alex Grace (p15), Graham Allison (p21) and Amit Lennon (p26).

This resource is also available in large print.

Call **020 8438 0999**
or email shop@mssociety.org.uk

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This title will be reviewed within three years of publication.

Multiple Sclerosis Society. Registered charity nos 1139257/SC041990.
Registered as a limited company in England and Wales 07451571.

