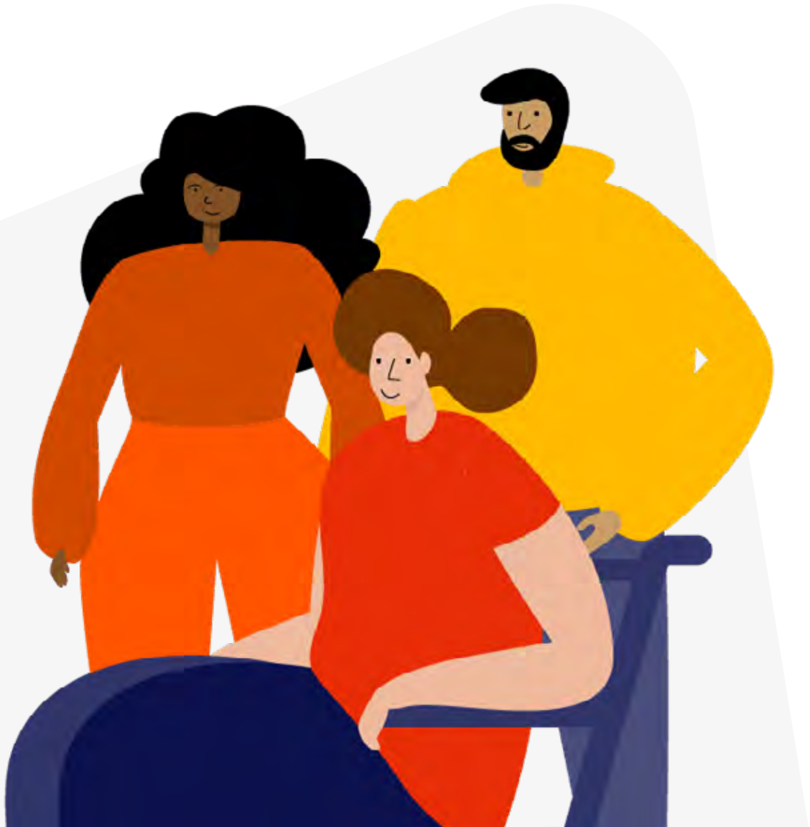
Advanced MS

A carers handbook



We're the MS Society and we're here for you. Funding world-leading research, sharing information, making voices heard and campaigning for everyone's rights.

Together we are a community. And together we will 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: **donate.mssociety.org.uk**
- Posting your donation to: MS Society, Carriage House, 8 City North Place,
  London N4 3FU.
- Please make cheques payable to the 'MS Society.'

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A word from Liz, whose husband has advanced MS

One of the biggest challenges is when to help my husband Neil keep his independence.

He wants to do everything for himself, but I have to be realistic about when to step in and take over. He doesn't always agree. It's resulted in difficult conversations to reach a compromise. But they were needed for his safety.

Another challenge is juggling everything. I'm Mum, wife, the main worker, cook, cleaner, DIY and car maintenance specialist, finance officer and homework club. Now add 'carer' and those responsibilities!

Don't feel bad if you have bad days. You're not superhuman! It gets to us all sometimes. Don't bottle it in. Realise you're just as important. And never feel guilty. Make time for yourself. Easier said than done, but important.

Walk the dog, go to the gym, have a long bath, meet a friend for coffee… You don't have to talk about MS.

It's the physical demands as well as the emotional ones. You're exhausted from lifting. But then you have to cook dinner, get kids to bed, and so on. And there's no rest when you feel ill.

Prioritise what's important. Only do so much in one day. Who cares if your house isn't tidy today? It can wait.

Nothing comes to you. You have to do things for yourself. Research into help you can get. You'll find ideas in this guide. Don't be embarrassed to get help.

Most importantly, talk to people. Join MS and carers groups, including ones on social media. We shied away for years, but it was the best thing we did. A problem shared is a problem halved.

Liz

Five things to know

1. Over time things will get more of a challenge. You might not be able to count on friends and family for help. But support is out there.
   This handbook has details of how to get it
2. Get help to have breaks from caring before you 'burn out'. You have a life too. This booklet has ideas about how to meet your own needs. You'll then be more able to look after yourself and others
3. You're not superhuman. Don't feel you have to fix everything yourself
4. Without help carers can get stressed or depressed. It can be hard to accept that you need it. Don't be afraid to decide what your limits are. Or to ask for help
5. Caring brings out strengths and abilities you never thought you had. Feel pride in what you do well. Don't feel guilty about things that go less well

About this handbook

This guide is for family, partners or friends who care for someone with advanced multiple sclerosis (MS).

‘Advanced MS’ isn’t a separate type of MS. It’s when it affects someone severely. This can happen after someone’s had progressive MS a long time. It might also happen over a shorter time when MS is very active.

When someone is ‘severely affected’ by their MS, it means:

- they’re usually very restricted in how much they can move around
- they rely a lot, or completely, on you and other people for their everyday care
- they’ve got many symptoms, at the same time. These are complicated to deal with and aren’t going to go away

As a carer, when the advanced stage of MS is reached, you’ll need much more support than before. Keep coming back to this guide for useful tips. It can point you towards where to get support.

Being there for someone with MS is an incredibly valuable thing to do. It has its own rewards. But it can have a major impact on you and your family.

A heavy burden is put on carers. With the NHS and care sector under huge strain, carers can expect extra stress.

To help, we spoke to carers about how they manage. This handbook brings into one place what they learned.

If the person you care for isn’t this badly affected by their MS, page 182 has details of our other booklets for family and carers. You’ll also find there how to contact our MS Helpline.

One last thing. Any words in **bold** are explained at the back.

What do I need?

What you need to support the person in your life with MS is individual to you. There's no 'one size fits all' answer.

MS is unpredictable. So what you need will change. You might think that what you need is the same as what the person you care for needs. But try to separate out your own needs. Don't lose sight of them.

Carers have told us they need*:

- information and advice in one place about advanced MS and being a carer
- help finding what they need, when they need it among all this information
- practical support. That includes training to do certain tasks, as well as financial help
- emotional support, from friends, family or someone like a counsellor
- ways to share experiences with people in the same situation
- ways to solve problems, cope better or see things differently (such as accepting the situation they're in)
- help with looking after themselves. This includes breaks and things that ease the pressure and isolation
- help when relationships change or become difficult
- to be listened to, for example, by doctors
- to have other people value the support they give
- support to stay in work
- for people to recognise the carer is at a new stage of MS and they need more support

Building a network of people to help you is very important.

Inside this handbook you should find a 'Carers assessment checklist'. That'll help you work out in more detail what help you need.

* MS Society research 2016-2022. Quotes in this handbook also come from there.

I want to know more about advanced MS

MS is unpredictable. But information about what's happening, or what might happen one day, can help you worry less.

During the early stages of MS carers might avoid seeking out lots of detailed information. They might avoid calling themselves a 'carer'. They might just prefer to see themselves as a husband, wife, partner, and so on.

Avoiding information and things for carers can help them feel life is carrying on more or less as normal. They might feel this protects them and their family from harsh facts.

But this becomes more difficult to do as the impact of MS gets more severe.

Information can be especially good to have when relapsing MS changes to progressive MS. Read more about this on page 22.

As MS 'progresses', or becomes more advanced, the picture changes. It's likely to be less about taking a disease modifying therapy (DMT) to slow MS down. Instead life with MS becomes more about:

- medical care
- managing long-term symptoms (and learning the skills you need for this)
- problems with mobility
- getting social care services to work together
- getting support from a network of people who can help, including other carers
- and looking after your own physical and emotional health

Hands-on help from other people is probably most useful. You'll probably also need more detailed information about symptoms and how to manage them. Check out 'Meet the medical team' on pages 58 and 59 to see who's available.

> **"My wife has primary progressive MS. I'm only learning about the disease as I go along. I'd like more information about what to expect or an information package explaining the difference it will make to both our lives."**
>
> Grant

> **"It's just listening to how other people cope with that and building up a toolkit to help you in the future."**
>
> Simon

Local groups

Local carers groups or an MS Society group offer information and support. Discover and share valuable things that other carers have already found out. These people will respect and value what you're doing.

Since Covid, groups often have a mix of in-person or online meetings. They might meet at different times of the day or week. All this makes it easier for people to take part, especially if they work.

If you can't make meetings, you can still get in touch for help. Find out which groups are nearest to you by searching the MS Society website for 'local groups'.

> **"We joined this group and I think that was the best thing we could've done. That was very helpful because you talk to people who've been going through the experience."**
>
> Lorna

What a local carers group or MS Society group can offer

- benefit from years of other carers' experience and knowledge
- learn from talks, discussions and share information in other ways
- get help from others in the group with filling in forms, going through assessments and applying for support and grants
- pick up tips on getting a good **care package**
- meet people in your situation. Fell less on your own. Enjoy social events
- find out what help is available locally
- learn ways to relax and de-stress
- have the chance to let your feelings out to people who understand
- hear about activities that you both can go to

Tips:

- our MS Helpline can tell you about MS Society and other carers groups near you. See the different ways to contact the helpline on page 182
- search our website for 'local support' to see the different kinds of help we offer
- find your local carers group on the Carers Trust website at **carers.org** Search for 'network partners'. Then add the name of your town or county
- or search the Carers UK site at **carersuk.org/help-and-advice/get-support/local-support**
- check out forums like Carers Connect at **forum.carersuk.org** or our own at **forum.mssociety.org.uk**
- ask about support for carers at your GP surgery
- if you work and there's a carers network, join it
- find out if your workplace has support like an **Employee Assistance Programme**

Specialist support groups can be very helpful. Search our website for ‘MS Support groups’ or call our MS Helpline. Examples include:

- Mutual Support. For serving and ex-serving members of the Armed Forces and their families
- Asian MS
- JEMS. The Jewish MS Support group
- the Shane Project (for Afro-Caribbean people)

Updates on drugs and treatments for symptoms

New treatments for symptoms can come along. So it pays to keep in touch with what’s happening.

When the person you care for has advanced MS, there’s a good chance they no longer qualify to take a DMT. But trials are now underway testing other drugs that might help one day. These include treatments that:

- protect nerves from more damage (neuroprotective drugs)
- repair damaged nerves (neuro-regeneration drugs)
- repair **myelin** (remyelination drugs)

> **“Advice about some real advances in treatment would help. My wife has never been offered any drugs of any description at any time. She’s had MS since she was 21. She’s now 62!”**
>
> Graham

Tips:

- call our MS Helpline to talk to someone about symptoms or get news about drug treatments. MS nurses work on our helpline
- make sure the person you care for has a review of their treatment with an MS specialist. See page 55.
- for the latest news check out this part of our website **mssociety.org.uk/research**

- read our magazine MS Matters for treatment news and tips on symptoms. Find out how to get it (and read back issues) by searching our website for ‘MS Matters magazine’. Or call **0300 500 8084** or email **supportercare@mssociety.org.uk**
- when someone needs to take lots of tablets, there’s a risk of a missed or double dose. Use ‘dosette’ boxes with ‘breakfast’, ‘lunch’, ‘dinner’ and ‘bedtime’ compartments for each day, in a 7 day pack
- many people use medication reminder and pill tracker phone apps like MyTherapy

Starting on page 75 we look at three symptoms that are common in advanced MS. These are bladder and bowel problems, and pressure ulcers (bed sores).

You can find much more detailed information about these and other symptoms by searching our website for the name of that symptom.

If you prefer printed information, page 182 tells you how to get this.

How severe might MS get? And how fast?

Not knowing for sure what the future will bring can be unsettling. It can leave you feeling out of control, anxious, angry or even helpless.

Many carers told us they might feel better prepared if they had an idea of what could lie ahead. As MS worsens, knowing what to expect can help lessen the shock.

The EDSS scale

A scoring system called the Expanded Disability Status Scale (EDSS) measures how MS gets worse over time. But it's only a rough guide.

Someone can have a high EDSS score but still be in a job, or take an active part in things like hobbies.

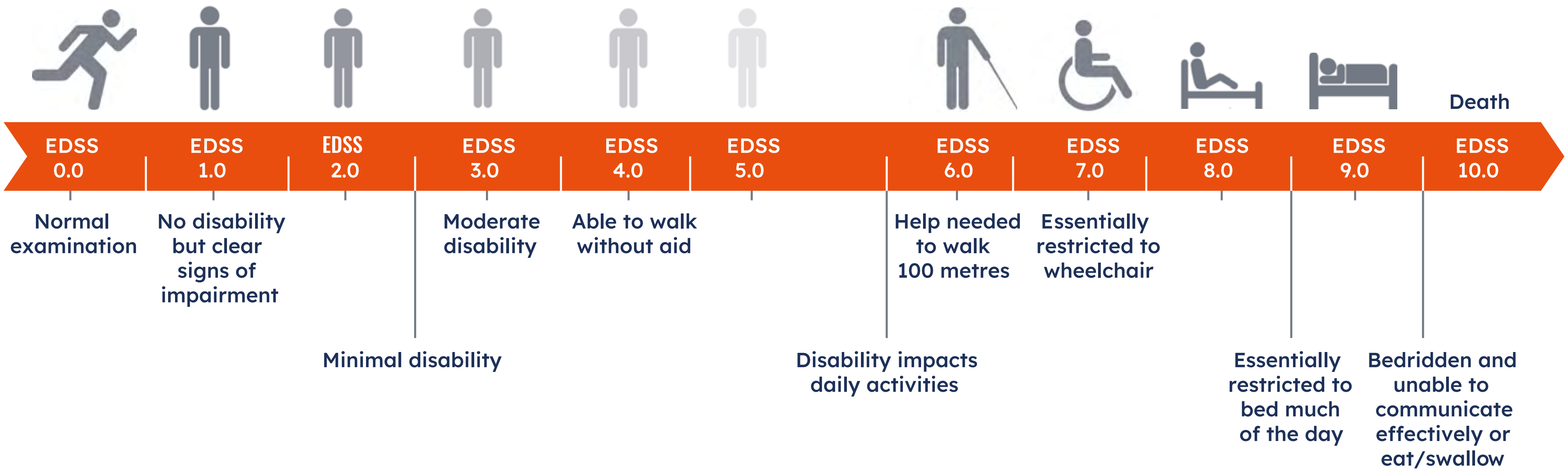
This scale focuses on how well people can use their legs (but not arms). It also doesn't take into account invisible symptoms like fatigue, pain, or memory and thinking problems.

But you'll read about EDSS scores in news about drug trials and who might qualify for certain medicines. MS specialists you deal with might talk about it, too.

Each person's experience of MS is unique to them. But general trends give some idea of what could happen as years go by.

On average, in the past it's taken people 20 years to reach EDSS 6 (a stick or crutch needed to walk 100 metres). This has happened on average by the age of 55. It's taken about 10 years after that for people to reach EDSS 7 (needing a wheelchair). It made no real difference whether someone started out with relapsing

The Expanded Disability Status Scale (EDSS)



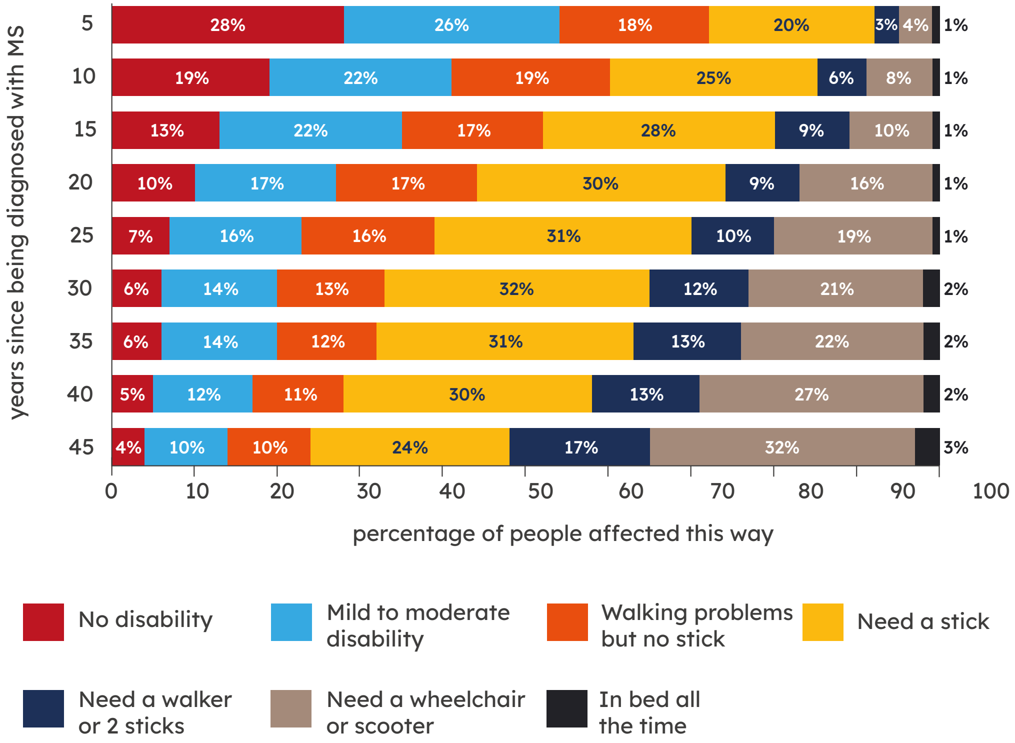
remitting MS, or whether their MS was progressive from the start.

A study of people with secondary progressive MS found on average they reached EDSS 8 around 15 years after their MS became progressive MS. EDSS 8 means restricted to bed, chair, or wheelchair. But they may be out of bed much of the day, with their arms working OK.

These studies come from the time before we had DMTs. People who've taken these drugs often see a slowing down in how fast their MS gets worse. So in the future MS isn't likely to progress this quickly in people who were treated with DMTs.

A 2015 American study* looked at how MS developed over the years in the pre-DMT era. The graph below shows the results.

* Fox, 'Prevalence of multiple sclerosis symptoms across lifespan'



How might our lives change?

When the person you care for has advanced MS, your focus is likely to change. It'll be more on helping them with basic day-to-day living and their bodily functions.

In the past, when their MS was less advanced, you might've focused on what it stopped them doing. You might've worried you were doing too much for them. Or you worried you'd make them frustrated and less independent.

Now that MS affects them more severely, you may both realise you simply have to do certain things for them. But you still help them stay as independent as possible.

You'll find yourself dealing more with symptoms. You're on a learning curve, growing in the experience, skills and confidence you need. You'll surprise yourself by managing to do things you thought you'd never be able to do.

The person you care for might struggle at times to hold on to their sense of who and what they are. This is a risk when they can't stay in work or do their hobbies.

At times, they may feel frustrated, low or even become depressed. Emotional support can help. This can come from you, but also from family, friends and professionals. Find ideas on pages 171 and 175.

When relapsing MS becomes progressive MS

As MS gets more severe, the focus often switches from slowing it down with DMTs.

Hope tends to fade that MS can get better or even stabilise. Plans and hopes for the future might seem over. The person you care for might give up work. Their ability to move about is likely to get worse.

This change to secondary progressive MS can be frightening. Many people say it's like being diagnosed all over again. You might have the upsetting feeling that doctors and their MS team lose interest

Some people with secondary progressive MS can take a DMT. But they must have the 'active' type of MS. If it's not active, the chances are they'll be taken off their DMT. That's because it's not likely to have much of an effect now.

But research is looking at that again. One trial (called ChariotsMS) is looking at whether staying on a DMT protects hand and arm function. If it does, things might change in the future.

But without a DMT, visits to the neurologist, and contact with MS nurses, can drop off or stop. It's easy to feel 'nothing more can be done'.

But lots can still be done. When someone is taken off a DMT, they'll need more medical attention, not less. For help with symptoms, there are drugs and treatments like physiotherapy to help them keep their independence. There are devices, too, like **functional electrical stimulation (FES)**.

Getting emotional support is important. Building this support won't be easy, and you'll need to drive it.

Most UK neurologists do, in fact, stay with their MS patients for the whole of their MS. But too many people severely affected by MS stop seeing a neurologist regularly.

Don't let the person you care for be lost to medical care. Guidelines from **NICE** say everyone should get a review once a year. No matter what kind of MS they have, or for how long.

This review should be with an MS specialist so they can talk about their treatment options. To make this happen, talk to their GP, MS team or nurse.

Don't accept being told that from now on a GP can deal with things. Or that it's no longer necessary to see a specialist.

Specialists include rehabilitation services such as physiotherapy, speech therapy or **continence** services.

GPs usually won't know much about managing MS symptoms. There may be new treatments for symptoms that only a neurologist, MS nurse or a specialist will know about.

MS specialists like these will also know about services that might help. If you haven't seen a specialist in a long time, new services might have begun since then. To get a referral to a specialist or service, you'll usually need to go through their GP, neurologist, or other member of the MS team.

Someone with MS might be put off going to appointments by their fatigue, problems getting around or other symptoms.

If so, home visits, appointments over the phone or by video, or open appointments (with no fixed date) might be possible. This is more likely with a community-based service or an MS nurse. Ask them when you visit, or phone them to discuss it.

If you don't have your own car and can't use public transport, some areas have free non-emergency patient transport. It's organised by the local ambulance service.

The impact on our relationship

Changes tend to happen slowly, from day to day. But look back over the months and years, and you may see how things between you changed quite quickly.

Perhaps there was a time when you resisted calling yourself a carer. You just wanted to be known as their husband, wife, friend, son or daughter.

But as their needs have got bigger, it's clear you've also become their carer. Carers carry out their caring responsibilities as an act of love. That's something carers tell us they want other people to recognise. You might find some parts of caring easier than others. For example, not everyone finds giving emotional support easy. Instead they get on with practical things like washing and dressing. The person with MS might prefer their carer to do this, rather than a stranger.

Your relationship was once all about intimacy and friendship.

But now you've also become their legal representative, manager of their finances, the person who gives them medication, and who helps them with their bladder or bowel.

On days when symptoms ease off, there may be times where it feels like how things used to be.

You can feel more of a care manager than a partner. With all the time you spend filing documents, keeping medical notes and organising treatment at home. All this on top of your job of running the home.

You plan each day so things go smoothly. You co-ordinate visits from care assistants, nurses, social care services and so on. All this planning and chasing people can put you under pressure. It takes the spontaneity out of life.

Losing the balance in your relationship can cause tensions. It can put pressure on your relationship. So can the challenge of being with them over long periods.

It's not easy if you clash with them over things. And it's hard if you lose the intimacy you both once shared.

> **"You become ever more enmeshed in the medical side of the person's treatment. And you become a 'lay' medical professional yourself."**
>
> Nigel

Intimacy and sex

When the person you care for is your partner, MS can affect your sex life. Sex might stop altogether. Pain, fatigue, muscle spasms or weakness, and bladder problems can all come between you.

Maybe you or they lose interest in sex. Perhaps it's still there, but you worry they're too tired or affected by their symptoms. Bringing sex up can feel too awkward. Perhaps they're no longer able even to have sex.

But sex and intimacy might not have to stop. The type of sex just may need to change, with more negotiating and planning. You'll need honest communication about what you both need, want and are able to do.

Perhaps they can't have sex anymore, or don't want to. Instead of penetration, some couples find intimacy in kissing, cuddling, stroking and touching.

Closeness, affection, sensuality and excitement are ways to be intimate. They can help keep the physical side of your relationship alive. There are places that can help you talk to each other about sex. Page 175 has some suggestions. There is no shame in reaching out for help with sex. MS doesn't have to mean your partner doesn't want, or can't enjoy sex.

Find useful information by searching our website for 'sex and relationships problems'.

Tips:

- contact the MS Helpline in confidence. It can be easier to talk to someone who understands MS and how it can affect someone sexually
- ask for help on our online forum (see page 171). Or just read what helped others
- mention sexual problems as part of a wider chat about bowel or bladder issues with an MS nurse or continence advisor
- the MS Trust has booklets for men and women. Download them at **mstrust.org.uk/a-z/talking-about-sexual-problems**
- don't think you must manage without without outside help
- the organisation Relate offers advice or counselling, face to face, by phone or through its website (see page 175)
- many sexual and relationship counsellors now offer counselling in your own home. They use video call services like Zoom, FaceTime or Skype (see page 175). Ask your GP or an MS nurse what's available on the NHS or privately.

Others ways MS can affect us

Caring can bring you closer together. But it can also take its toll. It can impact on your money situation, your health (mental health, too), your work and social life. You'll find tips in this handbook. Caring can affect your feelings towards the person with MS, too.

Your own quality of life might suffer as their MS symptoms get worse and it gets harder for them to move around.

You can't do some things together anymore. That can cause sadness for you both, a kind of grief. It's normal to feel like this. But, over time and with the right support, it gets easier.

If the person with MS is your partner, you may feel you're no longer equals. It can be especially tough to cope with if MS affects someone's mind.

Poor memory, depression, and changes in mood can be hard to deal with. Just discussing things with them can become difficult. And in some cases MS causes changes in behaviour that's very hard to deal with.

Caring is even more stressful if the person with MS can't accept or adjust to how badly it's now affecting them.

If their attitude is uncooperative, then it's even tougher. They might refuse to let other people take care of them.

They may have good reasons. Perhaps they feel help from others means they'll lose face and won't keep their dignity. Or they don't want to be reminded how much their life has changed.

All the same, this resistance can make it harder for you to take a break. So look out for your own needs too.

Keep communicating

Communication breakdowns are another challenge. How your roles are changing can trigger these. Difficulties communicating can stem from how MS affects someone's memory and thinking, or how it can cause depression or a change in their personality. Mental health struggles might also cause strain in a relationship. But help is out there. See which professionals can help on pages 61 and 62.

One idea that's helped a lot of people communicate better is to schedule a regular weekly time for this conversation. During this 'family time' everyone's encouraged to ask questions. That way they understand better what's going on.

It might feel strange at first. You might worry people's feelings will get hurt. But over time confidence often grows until you can talk about even very sensitive things.

Why do we carry on?

Whether you're caring for a partner, parent or friend, you'll have your own reasons why you do it. Being an unpaid carer doesn't have the status other jobs have. Instead, you can find yourself in a brand new role that you weren't expecting. You might find yourself the sole bread-winner, or the manager of other people. And if you have children, you might have to take on all the responsibility for bringing them up, too.

It's normal to struggle with being a carer. You might feel others don't take seriously or respect what you do. Every carer feels this way from time to time.

Caring can have a big impact on your social life. It can take its toll on your state of mind. You can end up stressed, feeling low, or even depressed.

As your role as a carer takes over more of your life, you might feel this threatens your own identity.

This can be especially true if you have to give up your job or work fewer hours. You lose the social aspect of work, and have less money. If you still work some hours, you can feel guilty that you're away from the person you care for.

You might be happy to take on this caring role. Or you might feel it's being forced on you, and this isn't who you want to be.

You may be caring for someone to show your love and commitment. You may feel you're honouring your marriage vows.

Perhaps you feel they would've done the same for you if you had got ill instead. Or maybe you do it out of a sense of duty.

Perhaps you feel: 'If I don't do this, who will?' Or you're determined they don't have to go into a care home.

You might be doing it for your family's sake. You want to keep a sense of normality in their lives, especially if you have children.

If you're caring for your mother or father, you may feel it's expected of you. This can be especially true if you're their only child. Or you're the child who's unmarried or without children.

Becoming a carer can be easier to accept if you don't feel everyone expects you to do it.

But if it's your partner or parent that you care for, then others are likely to expect you to do this. And they don't always realise just how much this demands from carers. It can be a shock for them to find out.

All this pressure can be hard to live with. It can be even harder if you decide that being their carer is something you don't want to do.

However you're feeling, you should feel no guilt or shame. Finding someone you can talk freely with about how you're feeling can be a relief. Read more about this in 'Feelings I might struggle with' on page 40.

The rewards

Here are some of the positives that carers say help keep them going:

- pride in doing a job that needs doing
- a feeling of achievement and satisfaction in overcoming difficulties
- growing as a person and becoming stronger
- learning new skills
- feeling more confident in what you can do
- a bigger appreciation of life when you see how someone with MS lives
- inspiration you get from being involved with the MS community
- and if the person you care for can keep a positive attitude, you can both still have quality time, fun together and support each other

"Even the most mild-mannered, cheery person will get ground down by the relentlessness of the condition eventually. Good news is: life just goes on. So you go through these patches … and you move to another day!" Mark

The juggling act

At the same time as you're caring for someone, you'll have lots of other responsibilities.

Holding down a job and running a home add to the strain. There'll be hospital appointments and problems to fix. You might also have your own health issues, especially as you get older.

Caring for someone takes up much of your time and energy. If you have children, looking after them and making sure they don't get neglected can be a worry.

Juggling all this can be hard. At times it can leave you exhausted, stressed and maybe even feeling a failure.

Tips:

- find carers groups near you (see pages 171-172)
- take advantage of how, since COVID, it's easier to get things done from home like eye tests, seeing a doctor, deliveries of medicines or shopping, and online social and exercise meet ups
- use social media (like your local town Facebook page) to ask for support. Get help with odd jobs, gardening, finding mobility aids, or shopping if you can't get out
- don't think you must manage without outside help
- asking for help is a sign of strength, not weakness

> **"Don't try and do everything yourself. Find new ways to split responsibilities and jobs. You want to help, but not by making them helpless."**
>
> Claire

Caring when you're in work

Holding down a paid job and being a carer is a tricky balancing act. Some people worry they're not doing either job as well as they should. But many carers value how having a job gives them a break from their life as a carer.

In England, Scotland and Wales the law (Equality Act 2010*) protects you from an employer harassing you or discriminating against you because you're a carer.

Flexible working

There might be a time when you need to change your normal work pattern. And since Covid a lot more companies will allow working from home, all or some of the time.

Thanks to the Flexible Working Act, from mid 2024 people in England, Scotland and Wales have the right to ask their employer for flexible working.

This covers things like flexible hours, working from home, going part time or job sharing. You can ask for this from day one of your employment. But you can ask no more than twice in a year.

With 'annualised hours', for example, you work a certain number of hours over the year. But you get flexibility about when you work them. You work a period of regular hours, and the remaining time left is used on an 'as needed' basis.

Carer's leave

From mid 2024, under the Carers Leave Act, carers in Great Britain have the right to take leave.

They can take up to five days unpaid leave each year from their employer. This leave is to help them with caring. It covers taking a break. For more details search our website for 'carer's leave law'.

You also have the right to take off a reasonable amount of time to deal with an emergency. Or when something unexpected happens. This will be without pay

* In Northern Ireland carers are protected under the Human Rights Act, Section 75 of the Northern Ireland Act and under disability and sex discrimination legislation.

unless your employer agrees to pay you.

This time off could cover medical emergencies and accidents. It could also cover you if your normal care arrangements fall through. Or if you need time to set up a new arrangement.

Look at your work's HR policies, and check your contract. You might enjoy more rights than the basic ones guaranteed by law.

An example would be compassionate leave to cover an emergency. But it couldn't be used for something you knew was going to happen (like a pre-planned hospital appointment).

Should I tell work I'm a carer?

That's up to you. If you don't want to say anything right now, at least find out what extra support your workplace might have for carers. You might need this one day.

Your workplace might have a carers support group or someone to contact about carers issues

Letting people at work know you have extra responsibilities at home should mean you get more support and understanding.

Support while you're out at work

Could you do with more help while you're working and away from the person you look after?

A carer's assessment could identify how you might get extra support from the council of the person you care for (or Trust in Northern Ireland). See page 129 for more about these assessments.

If you had an assessment before, but have since started a job, that means you're entitled to a new assessment. The new one will looks at your change of circumstances.

An assessment for the person you support looks at their care and support needs. This could lead to them getting help to live more independently (see page 123 for what kind of support). That would make it easier for you to hold down your job.

Being in work might mean you earn too much to qualify for free help. This is different from place to place, and will depend on how much you get paid.

Private care

If you have the money, you could arrange privately for care and support while you're at work.

Your local council (or Trust in Northern Ireland) has details of local providers of care that they've approved. Under 'useful organisations' (pages 173 and 174) you'll find places that list registered care services.

Should I cut my hours? Leave my job?

If you work fewer hours or give up your job, you might be able to claim Carer's Allowance and other benefits or tax credits. This will depend on your circumstances.

Before doing anything, find out how it would impact on your money situation. For example, how much State Pension you get later in life depends on how much you've paid in National Insurance contributions.

If you stop work and don't pay these, it'll affect this pension. Stopping work will affect any private pension you have, too.

Think long and hard before giving up work. Not only does work bring in money (and, later, a bigger pension) that makes you more independent, it brings you other benefits.

Work is good for your self-esteem. A job can be a big part of your identity. It gives you a break from caring. It means you're less isolated socially. MS Society research from 2019 found that carers who worked had better life satisfaction than those who didn't work.

There might be alternatives to handing in your notice.

Could you instead have a career break? Taking early retirement or voluntary redundancy may be a better move money-wise than just giving up a job.

If you get Carer's Allowance, you'll get National Insurance credits towards your State Pension.

If you can't claim Carer's Allowance, ask about claiming Carer's Credit. This won't pay you any money but can fill the National Insurance gaps in your pension record.

This lets you take on looking after someone and still protect your rights to a State Pension.

Tips:

- Carers UK also have info on their website. Search **carersuk.org** for 'work and career'
- read more about Carer's Credit at **gov.uk/carers-credit**
- our MS benefits adviser can explain about Carer's Credits and other work-related benefits questions. Email **msbenefitsadvice@dls.org.uk** or call our MS Helpline (see page 182)
- for useful pension advice put 'help with your pension' in the search engine on the home page of the Carers UK website at **carersuk.org**
- they also have information on flexible working. Search their site for 'requesting flexible working'
- encourage your workplace to put a carer's policy in place
- get help in Great Britain with discrimination at work from our MS legal advice service. Search our website for 'legal advice'

"My manager and team help keep me stress-free in work when my partner's MS is raging. I can work from home and can request special leave too. Friends have been a great help. I just have to remember to ask and accept help."

Jo

"Stay in work if you can. For me this is the only financially safe option. Reducing hours or stopping work all together could involve enormous stress and hardship. Stop work and you're at the mercy of the benefits system."

Mark

Looking after myself

You deserve to feel good and be healthy. Try not to let MS totally take over your life. It's not selfish to look after your own needs too.

Be proud that, in difficult circumstances, you're doing all you can for the person you care for. So, it's OK to do things for yourself as well if you can.

You need to take care of yourself, eat, sleep and exercise as well as you can. But you also need to do the things that you love. You'll need help from other people so that you can have rests from caring. And don't neglect your own medical appointments and check-ups.

That said, lots of carers find it hard to get enough practical support. If you have to pay for help, that's a major problem, too.

Some people might even tell you to put your own needs second. But that's not helpful for you or, in the long run, for the person you care for.

The impact on you can build slowly so that you don't really see it. Or it can hit you without any warning, for example, if their MS suddenly gets worse.

Your quality of life can really suffer if you don't look after your own needs and health. You risk getting ill. Then you can't be the good carer you want to be.

You also risk losing your sense of who you are. You can become isolated. You become a carer and nothing else. Try to keep a balance if that's possible.

"I don't really look after myself in the way I should. I'm aware of that, because I'm at the end of the priority list, in my head, anyway."

Andrew

Feelings I might struggle with

You're not alone if you feel:

- guilt. For example, that you're not doing enough, or not doing it right
- physically and mentally exhausted (burn-out)
- fear and anxiety (especially over money)
- loneliness
- depression
- feeling trapped, angry, frustrated or resentful

It's common to feel helpless or a sort of grief. This is often triggered by reminders of the days before MS came into your lives. Or when you see people living 'normal' lives.

Do you put your own needs and plans on hold? Perhaps neglect your own health? It can be stressful being with the other person all the time. Reach out to others so that you regularly get some time to yourself.

When things get really tough, it's not uncommon for carers to think about leaving. This can be especially true if MS is badly affecting their thinking and memory, or causing changes to their personality.

Knowing that others sometimes feel that way might help you feel less guilty.

Feeling trapped often happens if:

- you don't have time for yourself
- you don't enjoy a good relationship with the person you care for
- you don't have enough contact with other people

Ease the tension by not bottling up your feelings. Talk to someone from outside the family if you can't share how you're feeling with the person you care for or another family member.

Can you speak to your GP, an MS nurse, a friend or another carer? Is there someone totally unconnected to your home life who you could open up to?

A counsellor would be good. Or someone at our MS Helpline. They're qualified in giving emotional support.

If the person you care for has problems with their moods, memory or thinking ('cognition'), or if their behaviour is difficult, this can be very stressful.

Ask to see a neuropsychiatrist so that the person with MS gets a neuropsychiatric assessment and the treatment they need. Pages 61-62 have more on these professionals.

Is it time for help?

Do you turn down support when it's offered or available? Are you trying to be superhuman, needing no outside help?

Don't wait until you reach a crisis point before you accept help. Family and friends won't magically know you need support.

Don't be afraid to ask them for help. If you turned down their help in the past, don't feel you can't ask again.

Recognise signs you're under physical or mental stress. These include:

- being irritable
- getting angry
- sleeping too little or too much
- muscle stiffness
- stomach problems
- feeling anxious, down or overwhelmed
- a racing heartbeat
- thinking the worst will always happen

> **"You soon realise… if I'm no good, I'm no good for her."**
>
> Iain

> **"I use my friends for mental support. I phone them. I would've gone mad without my friends."**
>
> Marion

Am I depressed?

It's normal to sometimes feel sad, frustrated, angry, tearful, maybe even hopeless. Speak to other carers, a counsellor or helpline so that these feelings don't overwhelm you.

Symptoms of stress are similar to those of depression – sleeping poorly (or too much), feeling down, irritable ...

But if you're feeling this way for weeks or months, this is a symptom of depression. This is serious and needs to be diagnosed and treated by your GP before it gets worse.

Read more about signs of depression at **nhs.uk/Conditions/Depression/Pages/Symptoms.aspx** Search the web for 'Depression - NHS Self Assessment' for a test to see if you might have depression.

Tips:

- set limits of what you can do and are willing to do. Know when it's time to call in help
- learn to delegate. Share the care. Don't try to do everything on your own
- make plans for what you and the person you care for both need (now and in the future). Not having a plan often causes more stress and anxiety
- listen to what your body tells you about your stress levels
- create some time in the day or week for things that make you feel good – a hobby, a walk, reading or music
- don't bottle up fears and worries. It makes stress worse
- people try to cope with stress through alcohol, smoking, prescription drugs or comfort eating. But these do you no good in the long run. Reach out for help if you're starting to depend on any of them
- many people take comfort from their faith. Places of worship can also offer practical support
- learn relaxation techniques. Try meditation, muscle relaxation, **mindfulness**, yoga, visualisation/guided imagery or exercise
- many councils have Carers Support Teams or Carers Support Services. Check your local council's website to see what's available

"My son suggested a meditation group. I went along, feeling sceptical. But I left feeling a bit better. A year and a half later, I'm still going fairly regularly. Because I almost always leave feeling better than when I arrived."

Roger

"I go for counselling myself once a fortnight because I find it really helpful to go and just let it all go."

Debbie

"It's somebody I can talk to and offload, somebody who understands my viewpoint. That's very helpful to me."

Ralf

"I think it is important to find things that you can immerse yourself in – hobbies and interests. Even if only for brief amounts of time. 'Me time' is important and must be regular. It can be flexible but must still happen at some point."

Nigel

Looking out for each other

People might take out feelings of anger, frustration or resentment on the person they care for.

Maybe they become rough when they do something for them. Or use words to attack them.

If you recognise yourself in this, find an outlet before it escalates.

Get help if the person you care for becomes emotionally or physically abusive towards you.

Or maybe you feel something's not right about how paid carers or medical staff treat them.

Call in help from a counsellor. Confide in someone on our MS Helpline or email them.

You could also contact the adult services department of your local council (or Trust in Northern Ireland).

> **"Don't waste time or effort on stuff you can't change. Decide what it is you can do, do it and then knock it off your list and stop worrying. You've done what you can. No-one can ask more. I can't have an impact on the progression of my wife's illness. But I can do something about her quality of life. That's where my effort goes."**
>
> Nigel

> **"Make 'time for me' – you need to make it happen, even if it doesn't win approval from your other half! And make it regular, not a one-off."**
>
> Paul

Me and my GP

Tell your GP you're caring for someone. You can get free flu jabs, quicker appointments and be seen at more convenient times.

They'll tell you about events for carers and point you towards other services. Letters from your GP to hospitals will tell the staff there that you're the carer.

When seeing your GP, don't hide how you're really feeling. Make a list of what you want to bring up. Put the important stuff first.

Tips:

- make a list or keep a diary about how you and the person you care for have been
- keep a medical file of all the doctors letters, together with details of medical events as the MS has got worse

Protecting my back

Knowing how best to lift or move the person you care for is very important. You need to know this before their MS gets so advanced that you need to be regularly moving them.

A bad back (or even a **hernia**) will stop you being able to look after them for a long time. You could also hurt them or yourself if there's an accident.

Ask a GP, MS nurse or district nurse or **occupational therapist** for tips. For health and safety reasons their advice might be restrictive. They might be reluctant in case you injure yourself following their advice.

Your local social care services might know of training you can have.

Be sure to mention you need help with moving and lifting if you have a carer's assessment (or if an earlier assessment is reviewed). There might be training they could give you, or equipment like hoists, slings or stair lifts.

Think about arranging with social services for paid carers to come to your home. They could lift the person out of bed in the morning and back into bed in the evening.

You can tell them what times to come. But there might be some restrictions over the exact time of day they do this.

Tips:

- before helping someone to move, ask them if they feel up to it
- think about where you're going to place your hands
- try not to pull the arms. Shoulders can be very sensitive to injury
- if it's a bad day or time, think about doing something different, or avoid moving them altogether
- use things like a handling belt or hoist when you need to
- use your biceps, not your back

> **"I've had one problem actually from caring … I had a hernia operation and I would say that was from lifting her."**
>
> Ben

More tips:

- prepare the area so there's enough space around you
- wear shoes with a good grip and clothes that aren't too tight
- move according to what you can manage on the day
- make sure you both know the planned movement so you work as a team. Count in the start of the movement: 'ready, steady, go'
- keep your back straight, bend at the knees and avoid twisting
- use your body weight to provide power to avoid strain on your back
- keep your head up when carrying out a manoeuvre. This promotes good posture
- try not to give more help than the person needs, and move at a speed that lets them join in
- position your hands carefully to avoid damage or discomfort to the skin

Read about equipment to help move someone on page 100.

The organisation Backcare has a booklet for carers. Your council may give you a copy. Or you can buy it from:

backcare.org.uk/new-backcare-carers-guide/

We have information on lifting. Put 'posture and movement' in the search box on our website.

The NHS also has information at **nhs.uk** Search the site for 'how to move, lift and handle'.

Disclaimer: this information on lifting is not meant to take the place of professional training or guidance. All moving and handling carries risk, to you and the person you care for.

> **"I did the pilot course on handling, moving and lifting and I would recommend that for everyone. Because if people have got that, they can deal with things a lot better."**
>
> Mike

I need a break

Breaks will help you hold things together, mentally and physically. Try to take them as often as you can.

A break can be with or without the person you care for. It doesn't have to be a holiday. It could just be time out from your usual routine, or the chance to learn something new.

The phrase 'short break' usually means a holiday for you or the person with MS. It might be for the two of you together or separate holidays.

'Respite care', on the other hand, gives you and the person with MS a break from the demands of your usual routine.

Respite lets you recharge your batteries, relax and think about other things than caring. The person with MS can go for a while to a care home, nursing home or a specialist centre.

When you get respite, a paid care worker provides the help to the person with MS. They're arranged by the council (or Health and Social Care Trust in Northern Ireland) or another care organisation.

Respite can happen at home or in a special centre. In some centres, carers can stay too. It can last a week or two, or just be a day or half a day each week.

Some carers find it hard to get respite or residential care that will take the person they care for. Maybe that's because they need a lot of medical care. Or they have a disability the respite centre won't handle. Or perhaps the respite centre expects the carer to still go in and do certain things for them.

Sometimes it's hard to get the replacement carers trained up enough to give care that's as good as what you give.

Our MS Helpline, or a local MS group or carers group will know of respite centres. That includes ones that can take someone with a disability or who needs specific types of care.

> **“A break from the world of MS has been really important for me. To be able to do things where I can switch off and forget about MS and the effect it has.”**
>
> Sunita

Feeling guilty

It’s not unusual to feel bad about taking a break. Perhaps you feel you can’t enjoy one because you worry about the standard of care the person would get while you’re away. Maybe you tried respite care before and found it wasn’t as good as the care you give.

> **“I felt bad. If he’d been at home, he wouldn’t have got that bed sore. No respite will make me feel right again. So I’d rather not have it, even though I need it.”**
>
> Karen

But try to let go of guilt you might feel. If you don’t have some kind of break, you could end up so exhausted or ill that you can no longer give the care you want to.

It’s important to have breaks from time to time, even just short ones. Don’t wait until you’re ‘burnt out’ or at a crisis point before you agree to a break. By that stage a rest on its own may not be enough to let you recover.

Be realistic about what one person can be expected to do. You’re not being ‘selfish’ if you have a break. You deserve to feel good and be healthy. Not everything you do has to be for the person you care for. It’s OK to sometimes do things for you.

‘Me time’

If you can’t get away, try to create moments at home where you can grab ‘me time’ away from caring. If tiredness lets you, make times when you can do things that relax you.

These mental breaks can involve reading, listening to music, yoga, meditation, walking the dog, gardening and other hobbies. Some GPs can even prescribe exercise, yoga or dance classes.

Our website has information about complementary and alternative medicine to help you de-stress. This includes **mindfulness**, yoga, massage and other relaxation techniques. Search our site for ‘alternative therapies for MS’.

> **“The key is to enjoy those five minutes here and there. Rest, catch your breath and refresh. Again, a mental exercise you can train yourself to get good at.”**
>
> Mark

Paying for a break or respite

As the carer, you might qualify for financial support towards the cost of a short break, holiday or respite care.

Do you or the person you care for qualify for social care services from your local council (or Trust in Northern Ireland)?

If you do, you may be able to use your care package to help pay for short breaks and respite care.

Tell the council (or Trust) when you have your carer’s assessment that you need respite care on a regular basis - or whenever you need it. Page 129 has more on these assessments.

If you need respite but you’ve already had your assessment, get back in touch with them and say you need respite care.

If, after you’ve had a carer’s assessment, your **support plan** says you need a break, you might get money to spend on a break for yourself.

Does the person you care for get a **personal budget** as part of their social care? If they do, they could use this to pay for a break for themselves - if that’s in their care plan.

If they pay to have a personal assistant (PA), they could use their funding package to pay for them to go on a break with their PA. That would give you a rest.

Charities or charitable trusts might help with the cost of:

- a specialist break that includes respite care at a respite centre or nursing or care home
- paid care workers, specialised accommodation and equipment that add to the expense of a holiday

Your local MS Society group or carers group will know about organisations that help with the cost of breaks. Find your nearest carers group by searching for 'network partners' at **carers.org**

Check out our web pages on holidays. Start by searching our website for 'breaks and holidays'. It lists places that offer respite. Other pages cover how to pay the costs of breaks, and find places accessible for disabled people.

Finally, there are '**sitting services**'. Someone comes to spend time with a person who normally has a family carer. They can't give medical or personal care, but can let a carer have a few hours' break.

These services are run by local councils (Trusts in Northern Ireland), health authorities or private companies.

Many carers struggle to get respite. It can be hard to get. But help is out there to find a way to avoid burn-out and get the break you need.

More tips:

- the Respite Association offers help paying for care so that you can have a break. Check out **respiteassociation.org**
- to help you enjoy a day out with the person you support, the Carers Trust have some practical tips on things like parking, transport, toilets, free entry for carers, and so on. Go to the 'help and info' part of the **carers.org** site, then click on the 'out and about' section
- 'Tourism for all' is a charity dedicated to making tourism welcoming to all its members **tourismforall.co.uk**

"The local MS therapy centre lets my mum go and exercise and socialise with people with MS. Centres like this really improve mental and physical health, and give me a half day off, too."

Caroline

"I've not had much support as a carer. But I now have six hours a week sitting service. This has been a godsend."

Terry

"My most important thing is to get a break. Because without that, I would not be able to cope. If I don't get respite, I don't think I'd survive long. You can feel the weight coming off you."

Mike

Meet the medical team

A wide range of medical staff can help someone with advanced MS. So who's who? And what do they do?

Official guidelines from **NICE** say the person you care for should get medical care from a '**multi-disciplinary team**' **(MDT)**. That's a collection of staff who are each experts in different types of medicine or care.

This team should involve an MS specialist. One person in the team should coordinate the care. But you might find it's more likely you who takes on that coordination role.

Guidelines also say the person with MS should get support to stay active if they have problems with fatigue or getting around. They say the person should get a review of their MS at least once a year by an MS specialist.

It's not a 'must' that someone severely affected by MS sees a neurologist. But most do. If they don't, they should at least see an MS specialist nurse or someone with experience of MS looking after their care.

The MS multi-disciplinary team is based at a hospital or in your community. Pages 58 and 59 show who's usually in this team.

It also shows other medical staff who care for people severely affected by MS. This gives a clearer picture of what sort of services are available.

You shouldn't buy into the idea that 'nothing more can be done' when someone's MS becomes progressive or advanced. Or when they no longer take a DMT.

There's no reason to lose touch with MS services. Having advanced MS means more needs to be done. The care team should be bigger, not smaller.

You shouldn't try to manage MS symptoms on your own or rely only on a GP.

It can be easy to give up on services because the person you care for is no longer very mobile.

If so, ask if it's possible to be visited at home, or be seen in a community outreach clinic.

An MS specialist might offer open appointments. This is when you aren't given a date but have a specific period (say, six months) to book an appointment in, without needing to be referred by a GP.

There's a shortage of neurologists, MS nurses and other services across the UK. So what's available might be patchy depending on where you live. If they do exist locally, they may be dealing with a lot of people.

Who's who?

On the next few pages you'll find a rundown of medical staff people with MS might see and what they do. Often it'll be left to you to co-ordinate them all.

They're often not as good at working together as you might expect. If you make a note in pencil of names and contact details on pages 69-73, you can update this when staff change.

neurologist

A hospital-based doctor who specialises in nerve-related conditions. Some are specialists in MS. For others MS is just one of a range of nerve illnesses they treat. They prescribe drugs, order tests and refer to other specialist services.

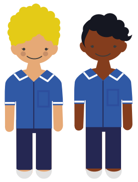
You don't have to wait for your next scheduled appointment if there's a sudden change in someone's MS. To make an appointment ask your GP, MS nurse (if you have one) or contact the neurologist's secretary.

MS nurses

They give advice about symptoms and treatment and can be the link between hospital and specialist services, including social care.

They can answer questions by email or phone. Some might do home visits in some situations.

We have ex-NHS MS nurses working on our MS Helpline.



GP ('general practitioner')

Your family doctor who looks after people's general health. A GP may have just one or two patients with MS. So they don't usually know much about it. They can't prescribe DMTs but can give some meds for MS symptoms (preferably after talking to an MS nurse or neurologist). They'll refer on to specialist MS services.

district/community nurse

They tend to work away from hospitals, often linked to GPs. They visit clinics, care homes or where patients live.

They can provide quite complicated care to do with things like **catheters**, wounds, bowel and bladder issues. They give advice on symptoms, equipment and taking drugs. But they don't usually prescribe drugs.

occupational therapist (OT)

They offer practical suggestions on how a person does everyday things. This ranges from eating, dressing or washing, to hobbies and work-related tasks.

They advise on equipment and alterations to the home or workplace that make life easier. They can also help with fatigue, balance and tremor. If you apply to have your home adapted, they'll carry out the assessment. Ask a GP, nurse or other heath professional for a referral.

physiotherapist

They use exercises and movements of the body so that someone can move around better. This can give them better balance and less fatigue, pain and muscle spasms. Those trained in conditions affecting the nerves (like MS) have 'neuro' before 'physiotherapist'. Home visits may be possible. Referral comes via a GP or MS nurse.

pharmacist

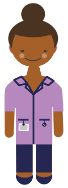
They give drugs (and sometimes equipment) prescribed by your doctor or specialist. They also offer expert advice. They can discuss issues people have with their meds. NHS community pharmacists are based in hospitals, health centres or pharmacies. But they may visit patients at home or in residential homes. Some work in high street chemists and supermarkets.

spasticity specialist

This is often a consultant in rehabilitation medicine. They work in a clinic inside a hospital and treat severe muscle stiffness. Spasticity clinics prescribe treatments, including drugs (such as Botox or Sativex). Clinics where they work may carry out assessments by an **OT** and sessions with a physiotherapist. It may be possible for a patient to refer themselves to a spasticity specialist. Or an MS nurse, neurologist or GP can do this.

continence advisor

This is a bladder and bowel specialist nurse based in a hospital or clinic. They might do home visits. They can prescribe exercises, medicines, equipment and incontinence products. You can contact these services directly or be referred by an MS nurse or GP.

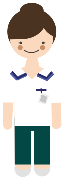


urologist

A hospital-based specialist whose work includes MS-related bladder problems. They work with continence advisors and can give Botox for the bladder and other treatments. They give advice on different types of **catheters**, and how to manage them. Referral is through a GP.

speech and language therapist (SLT)

Someone who treats communication and swallowing difficulties. They can help when someone struggles to find the right word or follow a conversation. An SLT might see a patient in a hospital, community centre or clinic or at home. Referral is usually by a GP, MS nurse or neurologist, but it's possible to self-refer.



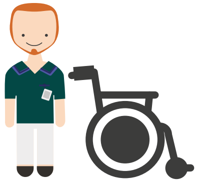
neurorehabilitation team

They help people get back their independence after a nerve-related injury like an MS relapse. They might do visits to homes or day centres. They're usually based in a hospital or clinic. They offer physiotherapy, occupational therapy or speech and language therapy. The team might include a dietitian, psychologist or social worker. A GP or MS specialist makes referrals to them.

wheelchair services

Often part of a hospital, they give manual and electric wheelchairs free of charge on a long-term loan (and do repairs). Each centre has its own rules on who qualifies for wheelchairs.

Assessments by an **OT** or physiotherapist can take place at a clinic, your home, day centre or care home. Referral is via a GP, neurologist, district or MS nurse, physiotherapist or OT.

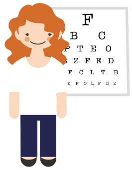


dietitian

Someone who helps with eating healthily, losing or gaining weight and preparing food when a person has problems swallowing. A GP makes the referral.

orthoptist

They help test for and treat sight problems and eye movement issues, like MS-related double vision. They work in the eye department of a hospital or community clinic, or in a **MDT.**



neuro-(clinical) psychologist

Someone who treats problems with behaviour, emotions, memory and thinking (‘cognition’). This can include depression or anxiety. They don’t prescribe drugs but teach counselling techniques (such as **CBT**), including ways of coping mentally as MS gets worse.

If trained in conditions that affect the nerves (like MS), they’ll have ‘neuro’ before ‘psychologist’. Referral is through your GP or MS specialist.

neuro-psychiatrist

A medical doctor who treats more serious mental health problems. They use a more medical approach than a psychologist. This usually involves prescribing drugs, but sometimes counselling techniques. If trained in conditions affecting the nerves (like MS), they have ‘neuro’ before ‘psychiatrist’. Referral is through your GP or MS specialist.

mental health nurse

They support people with mental health problems. These include anxiety, depression and stress-related illness.

They work with psychiatrists and psychologists. They work in a hospital, community clinic, in patients’ homes, in residential homes or as part of a GP surgery.

orthotist

They work in a hospital and help with some MS-related walking problems. They provide equipment to support part of someone’s body, such as splints for foot drop and devices that support the foot or go inside shoes. They might offer **Functional Electronic Stimulation (FES)** for foot drop.

Referral to an ‘orthotics’ service is via a physiotherapist or MS specialist, or by an MS nurse or GP.

palliative care team

They help with hard to control symptoms, especially pain. They can plan end of life care. But palliative care with MS is often about helping people and carers have a better quality of life, not getting ready for death.

A typical team has a palliative medicine consultant, palliative care nurse specialist, **OT**, social worker and physiotherapist.

This care happens in a care home, hospice, hospital or at home. The team works alongside the standard care the person with MS is getting.

social worker

They help people live independently and find solutions to problems. They organise support and make referrals to other services. They work in the community, often employed by the local council. Some work in a hospital, healthcare centre, care home, and many do home visits.

counsellor

Someone who helps people talk about their feelings and gets them through a difficult time. They deal with emotional problems, including family relationships, depression and anxiety. They can be based in a hospital, community centre or GP surgery.

community matron

This is a senior nurse with a lot of experience who works with people at home with long-term and complicated health care needs. They carry out regular nursing tasks. But they also manage someone’s care and refer them to other services, including home care and respite.

Being listened to

Carers often say they feel doctors and other medical staff don't listen to them. As their carer, you know more about the person with MS than the professionals do.

Health care staff should recognise your knowledge and experience. If they don't, politely remind them!

You might get the feeling medical staff are interested only in the person with MS. It's not unusual to feel that you, and what you do, get overlooked, especially when decisions are being made.

Contact details

On pages 69 to 73 you can make a note of the details of the medical staff who look after the person you care for.

Either photocopy and use it as a blank form you can fill in. Or fill it in with pencil so you can alter it if details change later.

At appointments

Meeting doctors and other medical staff can be intimidating, especially if time with them is short. Here are some tips on getting the most from appointments:

- make a short list of questions (put the most important first)
- take something to make notes with. You can record the appointment. But out of courtesy it's best to let the doctor know
- take copies or printouts of things you've seen and want to bring up
- say if you don't understand something they say
- be clear what you will and won't do in terms of medical procedures and caring tasks
- in the weeks or months before the visit keep a diary recording the symptoms of the person you care for

If doctors or other medical experts don't have time, or aren't good at communicating, take your questions or worries to their support staff (for example, the MS nurse). Call the MS Helpline if there are still things you don't understand.

> **"It's important not to be overawed by health care providers... even up to consultant level. Don't lose your rag, be polite but firm. Say if they use terms you don't understand, or if you disagree with their proposed actions."**
>
> Paul

Access to medical records

We all have separate medical records depending on what part of the NHS we use - the GP, hospital, and so on.

There are several ways someone can see their medical notes. The person you care for can give permission for you to see theirs. This could be formal written consent to act on their behalf. Or they can grant you 'power of attorney' (see page 159). This lets you make health or care decisions in their best interests.

For more details on accessing health records, go to **nhs.uk** and search 'how to get your medical records'.

To give someone else permission to do this, search for 'access someone else's medical records'. If you have their permission, you can do things like make appointments, order repeat prescriptions, look at their GP notes, and so on.

The NHS App

You can download the NHS app onto your mobile phone or tablet. It lets you do things like:

- book appointments at your GP surgery
- order repeat prescriptions
- check your symptoms
- see what medicines you had in the past
- manage referrals
- access other NHS services
- look at your health records

Download the NHS App, or log in to the NHS website, at **online.nhs.uk/nhs-app**. You'll get access to a range of NHS services.

Find more information about this app from **nhs.uk** by searching for 'NHS app help and support'.

If you live in Wales, you can download the NHS Wales app at

https://apphelp.nhs.wales

There's no NHS app for Northern Ireland or Scotland that allows you to do the same things as the apps above. But in Scotland the NHS 24 Online app allows you to find your nearest services and to check symptoms and find out what you should do next.

Download it at **nhsinform.scot/care-support-and-rights/tools-and-apps/nhs-24-online**

Ask your surgery if they have their own online service you can use.

The Patient Access app lets you book GP appointments, order repeat prescriptions and access local health services through your mobile phone, tablet or PC. Read about Patient Access at **patientaccess.com**

'Continuing Healthcare'

Continuing healthcare (CHC) is a package of free NHS care in England, Wales or Northern Ireland. It's possible to get this care at home, or in a care home or hospice.

To qualify for CHC, the person you care for must have very major and complicated health needs that aren't going to go away. It can also give support with things like bathing, dressing and laundry. It can also pay towards a care home.

This isn't part of social care. So it's not dealt with by the council (or, in Northern Ireland, by the Health and Social Care Trust). It's paid for by the NHS.

There won't be charges for any health care you get from the NHS. And it doesn't matter how much money or '**assets**' you or the person you care for have.

To get CHC the person you care for must first have their needs assessed. They'll score points on a checklist that looks at 12 needs. If the person is being sent home after a stay in hospital, then the assessment will be done in hospital before they leave. Pages 84 and 85 have more about leaving hospital.

Next an assessor (usually a nurse) organises a meeting with other professionals. These will either know the person with MS, or they'll be MS experts. This can include the person's GP or MS nurse.

The patient (or their carer or **advocate**) should be at this meeting, along with any medical professional that the patient feels should be there. They go over the needs on the checklist. The patient has their say, too. If it's decided that the person qualifies for CHC, a care plan is drawn up.

This plan is looked at again after three months, then again once each year. If someone's MS gets any better, they may find after their review that their funding for this care gets reduced.

Continuing healthcare isn't easy to get. A lot of people who try get turned down. If the decision is a 'no', the patient will be told how to appeal. For those who do get it, it makes more resources available than you can get from your local council (or Trust in Northern Ireland).

Do you feel social care services no longer cover what the person you care for needs? Then ask their social worker, GP or MS nurse about being assessed for continuing healthcare.

Tips:

- more information is at **nhs.uk**. Search for 'money, work, benefits and social care', then choose 'NHS continuing healthcare'
- before the assessment search **gov.uk** for 'NHS continuing healthcare checklist'. Download the assessment forms and fill them in, using the scoring you'd give
- if you can, share this with your social worker or person who referred you. Refer to this in the meeting where it's worked out how many points the person you care for will score. This way, you'll feel under less pressure during the assessment

- in England the Beacon organisation can give you 90 minutes free advice on continuing healthcare. They have free booklets. For a fee they can take up a case or help with an appeal. More information is at **beaconchc.co.uk** or call **0345 548 0300**
- find out more about CHC from Care to be Different at **caretobedifferent.co.uk/** or call **0161 979 0430** or at **ukcareguide.co.uk/chc-funding**
- if you're turned down for CHC find advice on appealing at **caretobedifferent.co.uk/nhs-continuing-healthcare-appeals/**
- if you're getting CHC in England, you can ask for a personal health budget. That gives more choice in what this money is spent on.

Find out more by searching **england.nhs.uk** for 'Personal health budgets in NHS Continuing Healthcare (CHC)'

Scotland

Instead of CHC Scotland has Hospital Based Complex Clinical Care. Assessment for this is based around one question: can a person's care needs be properly met somewhere that's not a hospital?

If yes, they'll be discharged from NHS care to a suitable community setting. This will be their home (with support), a care home or supported accommodation.

They'll be assessed to see what services they need. A financial assessment will be carried out to check whether they need to pay any of the costs.

Any health care they need will still be free on the NHS. Find more information by searching for 'complex clinical care' at **gov.scot** or **careinfoscotland.scot**

Contact details for medical staff

Contact detail for medical staff

GP (family doctor)

Name:

Based at:

Phone number: Email:

Neurologist

Name:

Based at:

Phone number: Email:

MS nurse

Name:

Based at:

Phone number: Email:

District (or community) nurse

Name:

Based at:

Phone number: Email:

Social worker

Name:

Based at:

Phone number: Email:

Neuro-rehabilitation team

Names:

Based at:

Phone number: Email:

Occupational therapist (OT)

Name:

Based at:

Phone number: Email:

Community matron

Name:

Based at:

Phone number: Email:

Dietician

Name:

Based at:

Phone number: Email:

Physiotherapist

Name:

Based at:

Phone number: Email:

Speech and language therapist (SLT)

Name:
Based at:
Phone number: Email:

Counsellor

Name:
Based at:
Phone number: Email:

Continence adviser

Name:
Based at:
Phone number: Email:

Urologist (bladder)

Name:
Based at:
Phone number: Email:

Spasticity specialist

Name:
Based at:
Phone number: Email:

Wheelchair services

Names:
Based at:
Phone number: Email:

Orthoptist (eye specialist)

Name:
Based at:
Phone number: Email:

Pharmacist

Name:
Based at:
Phone number: Email:

Orthotics service

Name:
Based at:
Phone number: Email:

Psychologist

Name:
Based at:
Phone number: Email:

Psychiatrist

Name:

Based at:

Phone number: Email:

Mental health nurse

Name:

Based at:

Phone number: Email:

Palliative care worker/team

Name:

Based at:

Phone number: Email:

Other

Name:

Based at:

Phone number: Email:

Other

Name:

Based at:

Phone number: Email:

Other

Names:

Based at:

Phone number: Email:

Other

Name:

Based at:

Phone number: Email:

Notes

Managing three common symptoms

Here we look at three symptoms that can be common with advanced MS. These are bladder and bowel problems, and pressure ulcers.

Bladder

MS can stop someone being able to control when they wee (pass urine). This is ‘incontinence’.

MS can also stop their bladder emptying properly.

A urologist will do tests to check how their bladder’s working.

Wee that gets left in someone’s bladder can lead to a bladder or urinary tract infection (UTI).

UTIs are very common in people with advanced MS. They can badly affect a person in a number of ways.

Signs to look out for are:

- the person has a burning feeling when they wee
- they feel the need to go more often than usual
- they can’t go when they feel they need to
- just a dribble comes out
- there’s a bad, ’fishy’ smell
- their wee is cloudy, has blood in it or is dark (pale wee is less likely to trigger an infection)
- the person has a fever, chills or feels pain or tired

What you can do

Act fast. If you empty a **catheter** bag and there’s a fishy smell, take a sample to your GP surgery within an hour. Or call out the district nurse to do a test on it.

That way, within a couple of hours the person you care for could be on the antibiotics that they need.

The sooner a UTI gets treated, the less chance that they'll need to go into hospital.

Left untreated, the infection can be very dangerous. It can spread to the kidneys and infect the blood, causing **sepsis** - which can kill.

Search our website for 'bladder'. You'll find lots of information about avoiding and treating infections. It covers different types of **catheters**, exercises for bladder issues, and Botox as a treatment for an overactive bladder.

> **"Getting a catheter fitted and using it is just the start. Blockages and the whole management of catheters is a job in itself. District nurses are crucial. You'll get to know urine well: its colour, odour and opacity as you develop a nose, literally, for spotting UTIs."**
>
> Mark

Tips:

- lower their risk of an infection by getting them to drink more (1.5 to 2 litres each day)
- plain water is good, but that's not all they can drink. But sweeteners, fizzy drinks and caffeine in coffee and tea can irritate the bladder. So think about switching to decaf
- drinking more helps stop a catheter getting blocked
- be sure to keep the catheter clean
- replace the leg bag each week, the night bag each day
- keep your stocks of bags up so that you don't run out

Bowel

Advanced MS often causes constipation. This can mean:

- not being able to poo (have a bowel movement)
- having to strain a lot
- bloating
- if someone can go, their poo (stools) are hard

They can also lose control over their bowels (incontinence).

Incontinence can be very upsetting for the person with MS and a challenge for you, the person who cleans up afterwards.

With constipation, if treatments like laxatives, stool softeners and changing diet don't work, certain actions can help someone poo. These include stomach (abdominal) massage or inserting a finger inside their bottom.

Inserting a finger is usually something only a qualified nurse (such as the district nurse) is allowed to do. But carers might be taught this by someone qualified.

What you can do

Try to establish a regular and comfortable routine for toilet breaks, such as after a hot meal, or half an hour after breakfast.

When monitoring toilet trips, they'll find it harder to 'go' if you don't give them privacy. Make the toilet easy to get to - and to get on and off.

Think about fitting a raised seat. Is the angle they're sitting at right? It can help having knees higher than hips, with feet apart, with something to rest feet on.

Keep a diary of their poos, what they look like, if there's blood in them, and so on.

Download from the internet the 'Bristol stool chart'. This helps you describe what you see in a way medical staff will understand.

That will be useful when talking to a GP, MS nurse or if there's an assessment by a continence service.

A GP can refer someone to their local service or they can often refer themselves.

Food and drink

If MS is causing bladder problems, it’s tempting to cut back on drinks. But this can cause constipation or make poo too hard. A few glasses of water a day can prevent this.

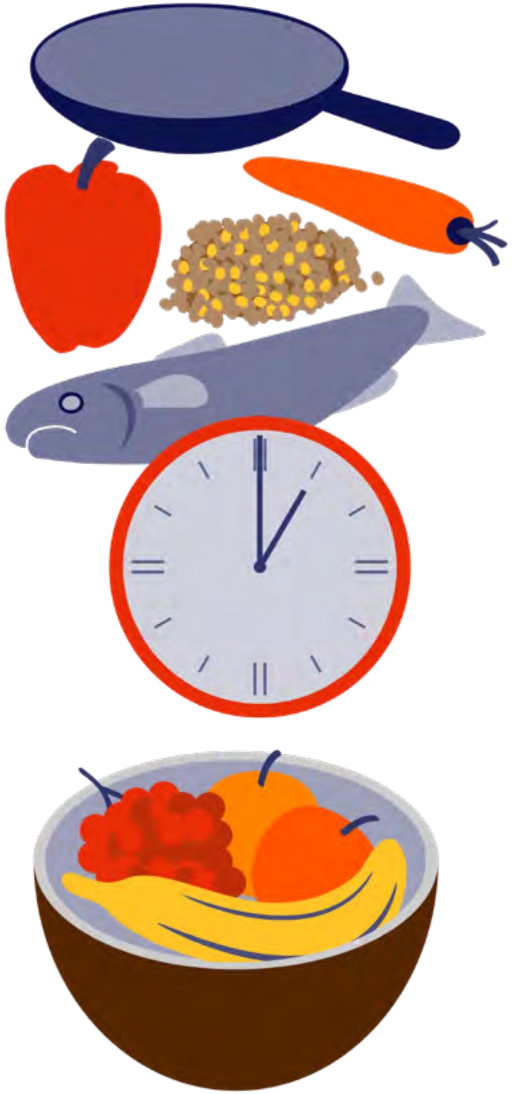
Some medication can cause constipation. Examples are some anti-depressants or pain killers. Meds for the bladder, heartburn, seizures or muscle spasms can do this too.

Antibiotics can also cause constipation (but they might also cause diarrhoea instead).

Fibre helps keep people regular. So they should eat enough wholegrains (in some breads and cereals), fruit (dried fruit is good) and vegetables, with maybe a fibre supplement, too. Enemas, suppositories, stool softeners, laxatives or bulking agents (like bran) can be used.

Search our website for ‘bowel’. You’ll find information on constipation and incontinence.

Being as active as possible stops the bowel getting sluggish. We have videos with exercises for people in wheelchairs. Search our website for ‘simple exercises for MS’.



Tips:

- caffeine, spicy food, chocolate, alcohol, milk products and high fibre can make poo too loose
- check out your local continence service. You can get your GP or MS nurse to make a referral or the person you care for can refer themselves
- a physiotherapist or continence clinic can teach strengthening exercises to increase bowel control
- call **111** if you need medical advice from the NHS out of hours
- call or email our MS Helpline for our ‘I need some help’ card. The person you care for carries it. It explains they have a medical condition and urgently need to use the toilet

Pressure ulcers

Pressure ulcers are also called pressure sores or bed sores. They happen after someone stays in one position too long.

The person you care for is at risk if they spend a lot of time in a wheelchair or in bed.

Pressure on one part of the body, especially a bony part, stops enough blood getting to the skin tissue, so it dies. Friction from moving or being moved can cause pressure sores, too.

Start thinking about these sores before they start. The risk begins once the person with MS starts to find it hard to move about. If they lose weight (maybe because of problems eating), that can put them more at risk.

If they wet themselves, don’t let their skin stay damp. If this happens regularly, wearing absorbent pads will keep them dry.

It's important they (or you) change their position regularly. If they can move themselves (in their wheelchair, for example) get them to change position every 15-20 minutes.

If they're confined to bed, change their position every two hours or use an air-filled mattress. Put pillows, cushions or leg lifters under their legs to lessen the weight on them and to keep their heels off the bed.

Tips:

- check their skin each day when you're washing them
- moisturiser stops skin drying out
- make sure they bathe when they need to
- if moving them, lift, don't drag
- cushion them with foam or air cushions
- tilt-in-space wheelchairs can help prevent sores by taking pressure off the buttocks
- don't blame yourself if they get a sore. They happen even with the best care
- read more at **nhs.uk** and search for 'pressure ulcers'

We have a factsheet about pressure ulcers that you can download from our website. Search for 'pressure ulcers factsheet'. Or ask our MS Helpline to send you a copy.

Other symptoms

We have webpages, booklets and factsheets about lots of symptoms of MS.

These are some things they cover:

- pain
- speech and swallowing
- fatigue
- muscle spasms
- tremor
- memory and thinking ('cognition')
- balance
- eye probelms

Search our website for the symptom you're interested in for online and printed information. How to order free booklets is explained on page 182.

Hospitals

Stays in hospital are likely to be a fact of life with advanced MS. But some can be avoided.

If they can't be avoided, how do you prepare for when the person you care for goes into hospital (is 'admitted') or comes home (is 'discharged')?

Sudden, unexpected trips to hospital can be upsetting. And getting an infection while in hospital is also a risk. These infections can cause lasting disability.

A stay in hospital is less likely if you do things that prevent pressure ulcers, bladder or chest infections and bowel problems (like constipation).

If you spot a problem, fast treatment can keep someone out of hospital. Tips on avoiding bowel issues and bladder and urinary tract infections (UTIs) are on pages 75 to 80.

Many GP surgeries now have a Care Coordinator to make hospital admissions less likely. For example, they could send the district nurse each week to check up on the person you care for.

MS nurses are trained to spot people at risk of getting infections or pressure ulcers, and to get the right help to them.

If your MS nurse can't pay a home visit for a week or two, phone them for advice. Get medical advice for any unexplained symptoms you notice.

Take advantage of any health screening programmes offered to the person with MS, such as free annual flu jabs. As their carer you also qualify for this. Flu can lead to pneumonia and bronchitis - and a hospital stay.

Encourage the person you care for to keep as fit and active as their MS allows. That could make them less prone to infections.

We have exercise videos for people in wheelchairs on our website – search for ‘simple exercises for MS’.

Avoid smoking, including passive smoking (breathing in other people’s smoke). Avoiding this makes both of you less likely to get chest infections.

Keeping at a healthy weight, taking meds as prescribed, and not drinking too much alcohol will help the person with MS avoid complications that need hospital care.

Benefits and hospital stays

If the person you care for goes into hospital (or a care home), it can affect benefits like Carer’s Allowance or Cold Weather payments.

Your Carer’s Allowance will stop after four weeks. You must tell the benefits authorities when they go into hospital (or a care home), and when they come out. Read more on page 145.

Getting ready for hospital

No-one knows the person you care for like you do. It’s a pain to keep repeating what you know to each new member of the hospital staff you deal with. And you might forget some things.

Here’s a solution that other carers find saves time and effort.

Have information about the person’s care in writing. It’s then ready to give people at the hospital (or at home when new people come to care for them).

Photocopy the form on pages 88 to 91. Fill it in using pencil so that you can change details. Or create your own version on a computer.

“I spend the first three hours in hospital answering the same questions over and over. I now have a sheet with all my wife’s information on it. Staff say how useful they find this.”

Nigel

Use pages 92 to 94 to let paid carers know what they should be aware of when they come to care for the person with MS in their home.

Tips:

- back up the form on pages 88-91 with a well-ordered medical file. Put in it all the information on their medical history and previous stays in hospital
- at the front put contact details for the health and care teams
- at the hospital let them know you're the carer. Wear a carer's lanyard or whatever the hospital uses
- make sure your knowledge and skills are used as part of the hospital care team
- ask to help with things like feeding if you'd like to
- if you're the main carer, you shouldn't be restricted to normal visiting hours
- build a good relationship with the Ward Nurse in charge and be proactive
- make sure the person you care for isn't left in bed too much. If there for a long time, make sure that they get physiotherapy so that they don't lose muscle strength
- the Cinnamon Trust provides help to people 65 and older with looking after their pets during a hospital stay. Find out more at

  cinnamon.org.uk

Coming home

It can be a worrying time when the person you care for is sent home from hospital. How will you cope? Have you got all you need? What help can you expect?

First of all, make sure the hospital knows you're the carer. Some hospitals are better than others at recognising this. All the same, you should be consulted. You know the patient better than most and what care they need.

If they have complicated health care needs, you should see a 'discharge co-ordinator'. Their job is to make sure the patient can carry on getting better after they leave hospital.

The discharge coordinator should make sure the person leaving hospital has a 'discharge plan' for their health and social care.

This plan should cover the services, equipment, drugs and information you need (a 'care package'). It'll cover things like medication, dealing with symptoms, dressing wounds and coordinating the different care services.

You should be involved in drawing up this plan and be given a copy.

It should have in it the name of the person responsible for making sure this plan is followed.

It should cover how to get the person home. Some areas have free non-emergency patient transport organised by the local ambulance service.

The plan should mention what training you need to care for them or to give them medication when they're back at home.

Say if you're worried about parts of the plan, or you think you might have problems with it. This includes how the cost of any social care services in the plan will be paid for.

Speak to the consultant or the hospital general manager if you feel no-one's listening to your worries. You don't have to accept a discharge plan if you feel you can't manage.

The discharge coordinator can make sure the hospital contacts your GP. If one's needed, the hospital can contact the district nurse, and other specialists such as a physiotherapist or **occupational therapist.**

If the person you care for will need significant and complicated care at home, read about Continuing Healthcare on page 66.

Discharging them will be slow. It can take hours for the doctor to sign them off and for nurses to make the necessary arrangements, including perhaps an ambulance home.

Hospitals aren't fully staffed at weekends. If you're looking to get a discharge on a Friday, make sure delays don't mean you end up staying until Monday.

Reablement

A 'reablement team' might be available from the local council (or Health and Social Care Trust in Northern Ireland). The local NHS sometimes provides it.

Their job is to help people learn to become safer, more independent and more confident when they leave hospital.

This can include things like cooking or bathing and getting basic equipment like **commodes** or alarms. This help will last for up to six weeks.

Contact your social care services department for more details or talk to the staff at the hospital.

To get this help the council (or Trust) will do an assessment of the needs of the person you care for. If they qualify to get it, this service is free for up to six weeks.

Tips:

- read more about leaving hospital by searching 'care after a hospital stay' at **nhs.uk**
- check reablement is working. If not, make sure social care services are there to pick up as soon as reablement ends

Information for hospital staff

Patient's name: **Date of birth:**

Special considerations when communicating with this patient:

Is their memory or thinking affected? ☐ No ☐ Yes

Details:

Pressure sores: ☐ No ☐ Yes

Details:

Routine for physio or movement:

Allergies:

First diagnosed with MS in:

Other health problems?

MS specialists treating this patient:

Name:

Based at:

Phone number: Email:

Name:

Based at:

Phone number: Email:

Daily drug prescriptions and doses:

Normal body temperature _____

blood pressure _____ pulse _____

Feeding instructions, such as PEG feeding tubes: ☐ No ☐ Yes

Details of system:

Special feeding instructions or prescriptions:

Feeding specialist:

Name:
Based at:
Phone number: Email:

Daily fluid requirements:

Catheter advice:

Other medical needs/procedures:

Carer:

Name:
Address:
Phone number: Email:

If carer can't be contacted, details of other family or friends:

Name:
Address:
Phone number: Email:

Name:
Address:
Phone number: Email:

GP:

Name:
Based at:
Phone number: Email:

Care agency details:

Name:
Based at:
Phone number: Email:

Care package details (including how funded):

Prescription Exemption Certificate number:

Patient's religion:

Information for paid carers in the patient's home

Daily routine:

Morning:

Afternoon:

Evening:

Weekly routine:

Monday	Tuesday	Wednesday
Thursday	**Friday**	**Saturday**
Sunday		

Things the patient likes to eat:	**Ideal room temperature:**
Things they like to do:	**Normal body temperature/ blood pressure/pulse:**
What upsets the patient:	**Transfer method:**
What calms them:	**Pet care information:**
Details of personal items (such as false teeth, glasses, hearing aids):	

Equipment and technology

There's a huge range of equipment that can make life easier for you and the person you care for. There's a growing choice of technology, too.

You're likely to need more equipment as time goes on. The equipment you need is likely to change as the MS gets worse.

Before you buy or choose equipment, get professional (and independent) advice, especially if it'll cost a lot. And don't pay VAT on it (see pages 98 and 99).

If you or the person with MS have a social care assessment, be sure to mention what you need help with. Ask if there's equipment that could make things easier.

Getting equipment and paying for it

Before you buy equipment, check to see if you can get it from the NHS or the local council (or, in Northern Ireland, the Health and Social Care Trust).

Some basic items can be prescribed by an **occupational therapist**, MS nurse, physiotherapist or GP, and be loaned out.

Some things the NHS must provide. That includes wheelchairs, environmental control units, and prosthetics and orthotics services. It also includes some computer-based devices (such as tablets with apps) that help people with major problems communicating.

Referrals are usually via a GP or other health professional. There'll be a local equipment store near you run by the NHS and local authority.

When the person you care for has a social care assessment, this might decide they should get free equipment and technology from their council (or Trust). See page 123 for more on social care assessments.

If the person you care for gets **direct payments** or a **personal budget** (see page 127) from their council (or Trust), they can use this money to pay for equipment if their **care plan** says they need it.

If you have a carer's assessment, you may qualify for help with equipment or technology if it makes your caring easier. Page 129 has more on carer's assessments.

It might take a long time to get an assessment or to receive equipment you need. You can challenge delays that are longer than what's seen as 'reasonable' (12 weeks according to the Local Government Ombudsman).

If someone's condition has got worse since their assessment, ask for them to be assessed again.

The person you care for may get some welfare benefits that can help cover extra costs of living with a disability. These include Attendance Allowance, Disability Living Allowance or Personal Independence Payment.

The person with MS (or you on their behalf) could also apply for a grant to cover the cost.

Charities and benevolent societies might help you get or pay for equipment. Page 147 has ideas of who to apply to. Ask an **occupational therapist** if they can help you apply for help from charities.

If the equipment helps the person with MS start a job or stay in work, they might get a grant from the Access to Work programme (see page 177).

The Equality Act of 2010 says employers must pay for 'reasonable adjustments' so that disabled people aren't at a disadvantage in the work place. This covers equipment and technology.

Local Rotary Clubs, Round Tables, Lions and Inner Wheels may also give grants. If you're a member of a local place of worship, they could help get you what you need, too.

Failing all else, and if you can afford to, you can buy equipment yourself.

Tips:

- sites that help people buy and sell new and used equipment include **disabilityequipmentservice.co.uk** and **themobilitymarket.co.uk**
- **independentliving.co.uk** is a website featuring things that support daily living, mobility and independence. Go to the part of the site called Independent Living Buyers Guide
- across the UK there are Equipment Demonstration Centres where people try disability equipment and get professional advice before they buy. Find a list of such centres at **goingforindependence.org/independent-living-centres**
- other organisations helping disabled people with technology are Abilitynet, Everyone Can and Disabled Living. Details are at the back of this handbook

- the Disabled Living Foundation (DLF) has factsheets to help you choose equipment. Find them at **livingmadeeasy.org.uk/dlf-factsheets**
- the DLF's specialist website Living Made Easy covers equipment and technology in depth. This includes things to help with the home, communicating, walking and mobility, and **personal care**, as well as alarm systems. Check it out at **livingmadeeasy.org.uk**
- the Research Institute for Disabled People have reviews of lots of equipment on their website **ridc.org.uk**
- the **assistive technology** department of your local hospital might help with equipment. If there isn't one, try their Speech and Language or Occupational Therapy Departments, or your GP

Pay no VAT

Disabled people don't have to pay Value Added Tax (VAT) on equipment designed or adapted to help them with their day to day lives.

This means a price cut of 20%. They shouldn't pay VAT on bills to have this equipment serviced or maintained either.

Ask whether you can be exempt from VAT **before ordering or paying for equipment.**

The seller must be registered for VAT. The disabled person just has to sign a form saying they have a chronic illness or disability.

These are just some of the things you can save VAT on:

- building work, such as having grab rails, a toilet, stair lift or alarms fitted, or widening doors
- medical and surgical appliances (including incontinence products)
- wheelchairs or mobility scooters
- specialist beds
- hoists
- **commodes**
- computer equipment only for disabled people, such as things to help you see or hear better. This won't include laptops and tablets.

You must get the VAT taken off the bill before you pay it. Any VAT you've already paid can't be claimed back directly from the VAT authorities. But you can ask who charged you the VAT to pay it back to you.

Read more on this at **gov.uk** by searching for 'VAT relief disabled'. There you'll find a full list of equipment exempt from VAT. Check out the help sheets. There's more on this at **gov.uk/financial-help-disabled/vat-relief**

AskSARA

The Disabled Living Foundation has a free self-help guide website called AskSARA.

Just choose what the person you care for needs help with (the home, their daily activities or health). Answer a set of questions and it'll give an instant customised report with suggestions for equipment. Find it at **shawtrust.livingmadeeasy.org.uk**

Equipment for moving someone

There's equipment to help lift or move the person you care for. An **occupational therapist**, MS nurse or district nurse will show you how to get and use it.

Transfer boards – wooden or plastic boards of different shapes. A person with MS (or their carer) can use them to slide from one place to another, such as from bed to chair or wheelchair to car seat.

Bed hand (or **handling) blocks** – blocks with handles that the person with MS uses to help move themselves into bed.

Bed pole hoist – the frame fits under the base of the bed. It lets someone sit up in bed, change position or get in and out of bed. Not to be used to lift the whole weight of someone from the bed.

Sliding sheet – made from a low friction material that feels slippery. Essential for moving or turning someone over in bed without lifting them. Avoids damaging their skin or causing pain or pressure sores.

Hoist – sometimes mobile and placed on the floor but often fitted to a wall or on tracks in the ceiling. Several rooms can be fitted with their own hoist.

They're mechanised and help get someone dressed or to move them from the bed to a **commode** or wheelchair. They can be used to let someone do exercises standing up.

A gantry hoist is a free standing frame with hoist rail between two legs. Gantry and ceiling hoists are much easier for a carer to use on their own than a mobile hoist.

Sling – often used by attaching it to a hoist. A 'toileting sling' is less than a full sling and gets someone on and off the toilet. Examine it regularly for signs of wear and tear.

Transfer or **handling belt** – wide, padded canvas belt with handle grips. It helps protect your back by making it easier to help the person wearing it to stand or move short distances, such as between a bed and a wheelchair or between seats.

Leg lifter – the foot goes into a stirrup loop connected to a long strap. It lets you or the person you care for raise their leg when getting in and out of a wheelchair and putting on clothes and shoes.

Positioning aids – supports that help someone sit comfortably in beds or chairs, stopping them sliding forward.

Other ways of helping people move around the home include stair lifts and lifts that go through one floor of the house to another.

The DLF has a factsheet on lifts. Find it by searching for 'adapting your home factsheet' at **livingmadeeasy.org.uk**

Bathing

A shower seat means the person with MS can shower without needing to stand. Some **commodes** can double as a shower chair.

The shower can be adjusted so it can be held by hand or have two settings: a higher one for you and one lower down for them.

The Disabled Living Foundation has a factsheet called 'Adapting your home: the bathroom' about equipment for bathing and showering. Find it by searching for 'bathroom factsheet' at **livingmadeeasy.org.uk**

A wet room can be a great help, giving you more space for easy access and flexibility.

You might be able to get a grant to help convert a downstairs room into a wet room - see page 111 (Disabled Facilities Grant).

> **"We had two shower heads installed, one at standing height, one at sitting height. Each is controlled separately by a battery powered unit.**
>
> **My wife only needs to push a single button for her (sitting height) shower to come on, at a pre-programmed temperature ...**
>
> **I push a different button and the standing-height shower comes on, at my preferred temperature."**
>
> Peter

Using the toilet

Before choosing equipment get advice from a **continence** service, your GP, **occupational therapist** or MS nurse. They can assess you and suggest things to meet what you need.

Among things available are:

- raised toilet seats that fit onto the bowl to make it higher. This makes it easier to use for people who struggle getting up and down **commodes.** They come with or without wheels. Some can be used in a shower or fit over the toilet with the bucket removed for increased support
- toilet frames (fixed to the floor or free standing)
- support rails to fix to the wall by the toilet. Like toilet frames, these give something secure to put a lot of weight on (unlike wash basins or radiators)
- **transfer** equipment (such as boards) to help someone on and off the toilet
- specially designed hoists and slings to help someone on to and off the toilet

The DLF have a factsheet called 'Adapting your home: the bathroom' that covers toilets. Find it by searching for 'bathroom factsheet' at **livingmadeeasy.org.uk.**

Kitchen, bedroom and other equipment

Special kitchen utensils to help with preparing food and eating include:

- easy grip knives and forks
- jar and ring pull openers
- 'speaking scales'
- two-handed cups
- large handles to fit over taps, knob turners to fit over controls on cookers and other equipment
- non-slip chopping boards
- 'perching stools' so that a person can sit while they wash up, cook or iron

Find these and other ideas in the DLF factsheet called 'Adapting your home: the kitchen'. Find it by searching for 'kitchen factsheet' at **livingmadeeasy.org.uk**

The bedroom

For the bedroom there are:

- mattress elevators and bed raisers to move someone from lying flat to sitting up
- rails at the side of the bed to help someone get on and off it
- leg raisers (shaped pieces of foam that support the leg and ease pain)
- slide sheets to help you move someone across the bed and move legs over the side of it
- electronic adjustable and raising beds for the comfort of the user and the carer

Check out the factsheet ‘Choosing a bed and bed accessories’. Search ‘bed factsheet’ at **livingmadeeasy.org.uk.**

For seats and wheelchairs

You might need:

- pressure relieving cushions
- riser/recliner chair and chair raisers
- portable wheelchair ramp
- head and side supports

Check out the DLF factsheet ‘Choosing a chair and chair accessories’ by searching for that title at **livingmadeeasy.org.uk**.

General moving

These could be helpful:

- mobile electric hoists with slings
- reachers and grabbers let someone, especially with a weak grip, pick up things without bending or straining. Some have magnetic ends to pick up metal things.

Check out the factsheet ‘Choosing a hoist and slings for lifting people’ by searching for ‘hoist and sling factsheet’ at **livingmadeeasy.org.uk**

Find more information on making changes to your home, room by room, by searching our website for ‘home adaptations’.

Alarms, telecare and other technology

Community alarms

A community alarm is worth thinking about if the person you care for is at risk of falling. It can make you worry less if you need to leave them for a while.

They wear the alarm (see above) or pull a cord or press a button, for example, on the phone. In an emergency it activates the home phone line. An operator speaks to them and calls you, the emergency services or someone nearby with keys.

These services are often loaned, either for free or for a charge, from your council (or, in Northern Ireland, your Trust). Contact their social care services department. The person you care for might qualify to get one of these systems as part of a wider social care assessment (see page 123).

You can also pay a private company. The Living Made Easy website lists some. Your council (or Trust) will also know of local ones. You might get one for free if it’s been agreed as part of a Continuing Healthcare package from the NHS.

Whether you pay the council or a private company, it costs around £5 a week.

These alarms are part of something called 'telecare'. This also covers systems that detect smoke, gases, a fall, an epileptic seizure, and much more.

'Telehealth', on the other hand, is using technology to monitor someone's health long distance, such as blood pressure. It can also pre-set doses of medication that need taking.

For NHS information on telecare alarms go to **nhs.uk** and search for 'personal alarms'.

Carers UK have information on things like telehealth, remote monitoring, alarm systems, and systems to control the environment (including lighting and heating).

Search **carersuk.org** for 'technologies to make life easier'.

Environmental control units (ECU)

These are useful if the person you care for loses much of their mobility or use of their hands. They control things like the TV, lights, fans, music, the heating, the phone, an emergency call system and other devices.

These units use a single switch that can be operated by hand, head or chin. This means more independence and safety. It should mean you get called on less often to do things a unit can do.

Examples of an ECU are Google Nest or 'Alexa', the voice-activated device from Amazon (using their Echo speaker).

They're controlled by an app to operate devices such as central heating, lights, the TV, and to choose music, create to-do lists, and help someone shop. It can read virtual books, and the person you care for can send messages to you through it or call for emergency help.

Some people buy or rent an ECU. You might get help getting or paying for one from the local social services department.

This might be in the shape of a Home Adaptation Grant or Disabled Facilities Grant. Or in an 'Access to Work' equipment grant if it helps someone with MS to work (see page 177).

In some places you might get one from the NHS. It can loan electronic **assistive technology** equipment to very severely disabled people so they can live more independently at home.

A referral is needed through a local health or social care professional. Someone like an **occupational therapist (OT)** will visit and do an assessment. Contact the Assistive Technology Team or Disablement Services at the local hospital.

Your local **OT** department can also advise you how to get this service.

For people severely affected by MS, smartphones and tablets with low-cost assistive technology apps can help with their daily lives. Abilitynet have a factsheet about controlling computers and smart phones by voice. Go to **abilitynet.org.uk** and put 'voice recognition' in the search box.

The Equality Act of 2010 recognises these kinds of **assistive technology** as a 'reasonable adjustment' that should be made available (for example, by employers) to stop discrimination.

Alternative and Augmentative Communication (AAC) technology

These devices help people with serious speech problems to communicate. Some use computer software to turn someone's written words into electronic speech for them. Or they can recognise their slurred speech.

If the person you care for is this badly affected, a speech and language therapist can suggest technology that would suit them.

Other devices are manual, with no electronic parts, such as boards with pictures, letters or words for the person to make sentences from.

Adaptations to the home

As someone's MS gets more severe you might need to make changes to your home. These might not be needed right now. But think what you might both need further down the line.

A move to a more suitable place to live in might be needed one day. Or the solution could be staying where you are and making alterations.

These changes, or 'adaptations', can be minor ones, such as attaching a grab rail to a wall. The equipment chapter on page 95 covers what might be used for these smaller changes.

Adaptations also include bigger alterations to the building. This could be fitting a lift, making doorways wider to fit a wheelchair, replacing a traditional bathroom with a wet room, converting a garage or building an extension.

An assessment by an **occupational therapist** can identify what might make life easier for you both. They can suggest ways you could pay for the changes.

The local council (or Health or Social Care Trust in Northern Ireland) can arrange a visit as part of a social care assessment (see page 123). Or you might get help from charities.

MS is classed as a disability under the Equality Act 2010 from the day you're diagnosed. If you rent from a private landlord, and have a disability under the Equality Act (like MS), you have the right to 'reasonable adjustments'. What this covers isn't clearly defined.

> **"I've had to have a hoist put up in the lounge … a hoist put up in the bedroom … a shower room built."**
>
> Lana

You do have a right to 'auxiliary aids', which are temporary or portable adaptations. You don't have the right to remove or change physical features of your home. You also don't have a right to change shared areas like entrances or hallways. But you can still ask your landlord if they'll let you.

Landlords can get financial help to make changes to where you live. The 'Disabled Facilities Grant' section on the next page has more on this.

If you rent from the council or a housing association, they should pay for adaptations. Among things that could be changed are:

- building ramps or making doors wider for easier wheelchair access
- making external doors accessible with flat access or automatic opening systems that use a press pad or key fob
- fitting a level-access (wheel-in) shower
- taking out the bath and turning a bathroom into a wet room
- fitting lifting equipment like a hoist to walls or ceilings
- fitting stair/chair lifts
- installing lifts that get a person from one floor to another
- moving a bathroom or toilet downstairs
- extensions or conversions to the building (such as turning a garage into a bedroom or bathroom)

> **"Mum's condition is slowly deteriorating, so we have to plan for possible future events, such as different housing, different furniture and support aids."**
>
> Lou

Paying for adaptations

Pages 95 to 99 have more on how smaller changes involving equipment can be paid for.

If you live in England, Wales or Northern Ireland, you might qualify for a **means-tested** Disabled Facilities Grant for bigger, structural alterations. You get these from the local council (or trust in Northern Ireland). You'll find more details on the next page.

Scotland

Scotland doesn't have Disabled Facilities Grants. Instead it has a separate system funded through the Scheme of Assistance.

If you live in private housing, you can get grants from your local council. For more on these grants for home owners, council tenants and private renters, go to **gov.scot** and search for 'funding adaptations'.

Wales

As well as Disabled Facilities Grants, Wales also has the Rapid Response Adaptations Programme. This helps pay for minor alterations like ramps and rails for people leaving hospital, or to keep them out of hospital or residential care.

Disabled Facilities Grants

These are available in England, Wales and Northern Ireland (Scotland has its own scheme).

Councils may give them to people with a disability so they can make changes to their home.

In Northern Ireland these grants are arranged between local Housing Executive Grants Offices and Health and Social Care Trusts.

To get this grant, you or someone else living with you must have a disability. You can be renting or home owners, but you must intend to live in the property for five years.

A landlord can apply for a Disabled Facilities Grant on behalf of a tenant.

A Disabled Facilities Grant is usually **means-tested.** The waiting lists are long but by law you should get a decision on an application within six months.

If you're successful, you should get the money within 12 months of applying.

If you don't get a decision within six months of applying, write and ask why and ask them to make a decision.

If you're struggling to get a decision, or you've been prevented from applying, you can seek legal advice.

You could also write to the Local Government and Social Care Ombudsman, who may be able to investigate.

Tips:

- your local council (or Trust in Northern Ireland) can give you advice about the scheme in your area and how to apply
- if you're in Northern Ireland, you can read more about these grants by searching **nidirect.gov.uk** for 'disabled facilities grants'
- as of November 2023 the highest a DFG grant can be is £30,000 in England, £25,000 in Northern Ireland and £36,000 in Wales. But 6 in 10 grants are for £5,000 or less
- Disability Rights UK have factsheets about grants for adaptations, and how to complain if you're turned down. Search **disabilityrightsuk.org** for 'housing grants' and 'complaining about local authority decisions'
- before you start, check out the information at livingmadeeasy.org.uk. Search for 'adapting your home planning and funding'

What if we're turned down for a DFG?

You can appeal. Each council has an appeals and complaints procedure. The next step after that is to complain to the Local Government Ombudsman. As a last resort, take it to the High Court.

If you're in Great Britain, you can call our MS Helpline to speak to our legal advisers.

If you can't get a DFG, what are your options? Could you take out a loan? Or sell your home to buy something smaller?

There's also 'equity release'. This means borrowing money against the value of your house. Or you sell it (or part of it) for a lump sum or regular income, but you don't have to leave your home. Get independent financial advice before doing this. Search for 'equity release' at **moneyhelper.org.uk**

Home improvement agencies, like Local Care and Repair or Staying Put organisations, are run by housing associations, councils or charities. They help people adapt their homes.

More tips:

- ask your council's housing department for local home improvement agencies or, for England only, find them at **findmyhia.org.uk**
- in Scotland there's **careandrepairscotland.co.uk**
- if you live in Wales check out **careandrepair.org.uk/en/**
- for Northern Irelqand search the **nihe.gov.uk** website for 'home improvement agencies'
- you shouldn't pay VAT on building work to adapt a home. Read more on page 99.
- agree with your builder that you won't be charged VAT before you accept any tenders
- don't start any work and then apply for grants. If you do, you'll be turned down. Apply first

Search our website for 'home adaptations'. You'll find more on alterations room by room, how to fund them, and practical things to think about when altering a home.

Help with moving around

There's a lot of help available if the person you care for has problems getting around the house or being mobile outside the home.

Inside the home

Contact your local social services department if the person you care for needs help to move more safely and easily around the home. Ask for a needs assessment for them.

The kind of help they might get includes grab rails and portable wheelchair ramps. Check out page 123 about social care for more on this assessment.

Download our factsheet 'Posture and movement 2' from our website. Put 'posture and movement moving well with MS' in the search box on our home page. It has advice on helping someone with walking, getting in and out of chairs or cars, and getting up after a fall. It also covers 'transferring' (moving someone from one seat to another or to a bed).

Wheelchairs

If someone qualifies for a wheelchair, they'll get one on the NHS as a free long-term loan from 'wheelchair services'. This is often part of a hospital, but is sometimes run by an outside company on behalf of the NHS.

A person must be referred to their local wheelchair service by a GP, hospital doctor or other health or social care professional like an **occupational therapist.**

An assessment will decide if they qualify for an NHS wheelchair, and what kind of wheelchair they will need.

Wheelchairs can be manual or powered. Powered wheelchairs are also known as electric wheelchairs or powerchairs.

Which wheelchair someone gets will depend on the service's criteria. The NHS will only prescribe a powered chair if someone can't use a manual one. The wheelchair must be for use indoors and outdoors. The NHS don't provide ones made only for outdoors.

Paying for a wheelchair in England

The old NHS voucher scheme for England has been replaced by the Personal Wheelchair Budget.

If someone qualifies for an NHS wheelchair, they'll get this budget. They'll be told the cost of the wheelchair they need. Their Personal Wheelchair Budget (PWB) is the amount of money they're given to spend on it.

Someone can also add money to this budget from their own pocket, or from other places like a charity or social care services. The local wheelchair service will pay for maintenance and repairs.

This budget can be spent in one of the following ways.

- **Notional PWB.** This is the standard NHS arrangement. The person accepts the wheelchair offered to them from the NHS range. Their budget covers its value, so there's no cost to them. The wheelchair will always belong to the NHS. The wheelchair service pays for maintenance and repairs.
- **Top up alternative PWB.** The person can upgrade to an alternative model of wheelchair within the NHS range. They pay the difference between what they were offered and the alternative upgrade that they want. This can come from their own pocket, somewhere like a charity or their council's social care services.
- **Top up accessories PWB.** A person can add extra features to the wheelchair. They pay the cost of the 'add on' features. The NHS owns the chair and the wheelchair service pays for maintenance and repairs (except when this involves the extra features).

- **Third party PWB.** A person uses their budget for a wheelchair that's not part of the NHS range. The wheelchair service must agree it meets their needs. The person must pay the extra cost that's not covered by their PWB. So, for example, they can't have a powered chair if the wheelchair service prescribed them a manual one. The wheelchair will be theirs, not the property of the NHS. They must pay for maintenance and repairs themselves, but their budget includes money to cover that

Eight in ten people get a wheelchair within the 18 week NHS target time. But some wait over four months.

During the wait it's possible to rent or borrow one. The Red Cross offer loans for up to 20 weeks. Shopmobility hire out wheelchairs so that people can shop or take part in leisure activities.

For people severely affected by their MS, there are electric wheelchairs that don't need a joystick control. They have a touch pad instead, or are controlled by breathing (called 'sip'n'puff') or by movement of their head, voice or tongue.

When choosing something like a wheelchair, also get input from an **occupational therapist**, the family and the carer.

Wheelchairs need to be tailored to the individual and where they'll use it. They need to take account of how their MS is likely to develop in the future.

A wheelchair must provide proper support and pressure relief. It may need controls for the carer to use. Or a 'tilt-in-space' chair may be needed. This lets the person using it change position if they can't move their body weight.

Scotland

Scotland doesn't have the wheelchair budget scheme. A GP or healthcare professional will refer someone to one of five Wheelchair and Seating Services (WSS) centres.

An assessment may be needed if someone's needs are complicated. The centres provide manual and powered wheelchairs, together with repair and maintenance.

Northern Ireland

In Northern Ireland an occupational therapist from the local Health and Social Care Trust will give someone an assessment. A wheelchair is then provided by either the local centre or the Regional Disablement Centre.

Insurance

Wheelchairs from the NHS voucher scheme are insured against damage but not if its owner chooses the Third Party PWB option. Then they must insure it.

To protect against it being stolen or damaged in a fire, the chair can be added to the household insurance. Or it can be insured separately through a range of companies. Our MS Helpline can signpost you to them.

It's recommended that a wheelchair has public liability insurance that covers accidental damage to property and to other people. The wheelchair service can advise you on insurance. If the person with MS gets a powered wheelchair or scooter from Motability, they can advise on insurance, too.

If the wheelchair is 'class 3', it has a maximum speed of 4 miles per hour off the road, and 8 miles per hour on the road. It must be registered with the Driver & Vehicle Licensing Agency (DVLA). Slower, 'class 2' wheelchairs don't need to be registered.

Read more about wheelchairs and other mobility aids by going to **nhs.uk** and putting 'walking aids, wheelchairs and mobility scooters' in the search box.

Tips:

Motability has advice about getting a wheelchair in and out of a car. Search **motability.co.uk** for 'our adaptations'

- the Disabled Living Foundation has information to help people choose which mobility aid is right for them. Go to the 'access and mobility' section of **livingmadeeasy.org.uk** then click on 'wheelchairs, scooters and buggies'
- read more about rules for scooters and wheelchairs, including tax and insurance at **gov.uk.** Search for 'mobility scooters and powered wheelchairs'
- **themobilitymarket.co.uk** is a site where people buy or sell used mobility and disability products

Other walking aids

For information on crutches, walking sticks, and wheeled walking frames (rollators), check out **livingmadeeasy.org.uk.** Go to the 'access and mobility' section, then click on 'walking aids'.

Public transport

Using public transport is getting easier, but build into your plans extra time for travel.

Check ahead for disabled access and toilets. Have an alternative back-up plan in case things fall through.

You'll find information on getting help, accessible trains and stations and other types of transport at **gov.uk/transport-disabled.**

Find helpful tips on travel by train or underground with someone using a wheelchair at **scope.org.uk**. Search for 'transport for disabled people'.

If the person you care for has a Disabled Person's Railcard, this allows someone (a carer or not) to get a third off the price of their train ticket when they travel with them. Call **0345 605 0525** or visit **disabledpersons-railcard.co.uk.**

England

Disabled people in England who qualify can get free off-peak travel on all local buses. Someone who travels with them might get a discount too. Contact your local council for details or visit **gov.uk** and search 'apply for a disabled bus pass'.

London

Find help on using the London underground system at **tfl.gov.uk/transport-accessibility/**

Londoners can enjoy free travel within the city and free bus travel nationally if they get the Disabled Person's Freedom Pass. Apply at **londoncouncils.gov.uk** (search for 'disabled person's freedom pass').

A Freedom Pass holder who can't use public transport without the help of a carer might qualify to use the Taxicard scheme. Find out more about this way of getting cheaper taxis at **londoncouncils.gov.uk/services/taxicard**

Wales

Bus pass schemes operate in Wales. For details of bus pass schemes search for ‘apply for a bus pass’ at **tfw.wales**.

Scotland

The person you care for can claim a National Entitlement Card that gives them (and you) free travel on most bus services. These are applied for and renewed at your local council. For more about who qualifies visit **mygov.scot** and search for ‘disabled bus pass’.

Northern Ireland

Get half fare bus and train travel with a Smartpass. Learn more at **nidirect.gov.uk**. Search for ‘free and concessionary bus and rail travel’

Motability

This charity-run scheme helps people with disabilities to use their mobility allowance to get a car, a Wheelchair Accessible Vehicle, scooter or electric wheelchair.

They need to be getting either:

- the higher rate mobility component of Disability Living Allowance (DLA)
- the enhanced rate mobility component of Personal Independence Payment (PIP) - or of the Adult Disability Payment if you’re in Scotland
- or War Pensioner’s Mobility Supplement or Armed Forces Independence Payment

To see if you qualify to join the Motability scheme, contact them on **0300 456 4566** or visit **motability.co.uk**

Blue Badge

A Blue Badge helps with parking if you drive someone with MS around. To find out more and apply for one search **gov.uk** for ‘who can get a blue badge’

Social care – getting help from the council

Social care covers a range of services you and the person you care for might be able to get from the council.

Social care services help people with an illness or disability to live an independent life. These services include:

- specialist equipment, technology and changes to your home to make life easier (ramps, grab rails, wider doors, and so on)
- someone who comes to your home to help the person with MS do things like getting dressed and washed
- day centres
- residential care
- support for family and carers, such as **respite** care and breaks
- information

The person with MS you care for can ask their local council to assess them to see what services they need.

To arrange an assessment, contact their local council’s social services department. Someone will come to talk to them about what they need help with.

Afterwards, if they qualify for help, they’ll get a **care and support plan**. This will say what services the council is willing to offer and how much they’ll pay towards this.

Social care often isn’t free. Most people pay something themselves towards these services, depending on their money situation.

The council will look at their finances and then decide whether they pay, and, if they do, how much.

If their ‘**capital**’ or ‘**assets**’ are worth more than a certain amount, they’ll have to pay all the costs.

This amount in November 2023 was £23,250 in England (with an increase to £100,000 planned for October 2025) and £24,000 in Wales (this may go up in 2024).

If someone has assets under these amounts, they may have to pay some, but not all, of the costs.

In Scotland personal care is free.

If someone needs to move into a care home, the rules about how this is paid for are different. See page 155 for more on this.

The person you care for might qualify to use a day centre, have a short break, or get respite. Someone might come and provide care for them in their home. Or a sitting service might send someone to spend time with them, letting you have a break. All of these can take some of the pressure off you.

Help for carers is part of social care, too. Read more on what help you might get on page 129 (‘Carer’s assessment’)

Whether you get what you need also depends on what part of the country you live in and how

Northern Ireland

If you live in Northern Ireland, your local Health and Social Care Trust arranges social care services. Where we mention the council in these pages, for you this means your local Trust.

Personal care in Scotland

Personal care is free in Scotland no matter what age someone is or how many assets they have. But first their local council will assess them and decide if they need it. Page 180 has an explanation of what personal care covers. People of any age can get free nursing care if they’ve been assessed as needing it.

your local council (Health and Social Care Trust in Northern Ireland) manage their finances.

Carers often say they need to be 'pushy' to get what they want. They often find they need to go looking for services because they're not promoted enough.

Many carers think social care will be closely linked to NHS medical care. But they find the two don't work together like they expect.

You may find yourself falling through gaps between parts of these two systems. Carers say that, with experience, you'll learn to avoid this and spot pitfalls before you hit them.

You might be surprised to find medical and health care professionals don't work together like you imagined they would.

They often do their bit, then move on to the next person. It's left to you to connect the different services, coordinate it all, and keep the show together across the health and care teams.

Our website has more on social care. Search it for 'social care services'.

Tips:

- to save time, the person you care for can have their assessment at the same time you have your carer's assessment
- but you can always have your assessments separately. You might want this if it's difficult to talk when the person you care for is there
- keep a list of all the care services you get (plus letters and emails) to share with staff in the hospital
- try and get a named social worker if you can. That'll help with long-term care. A duty social worker won't know your situation well

The social care package

It's important you get the right package of care (the mix of social care services). This is especially true if you're a carer who goes out to work.

Speaking to people in a local carers support group or MS Society group can point you towards what's worked for other people. They'll know what your local council is willing to offer.

Other carers will have suggestions on ways of organising the filing and documents that come with having a care package. They'll have tips on coordinating the care services you end up choosing.

Carers can share their ideas on how to get treatment at home so you avoid the person you care for going to hospital (see page 82 for more on this).

And if you have a complaint about a service, they'll have ideas of what you can do.

Personal budgets and direct payments

If the person you care for had a social care assessment, and was judged as qualifying for help, they'll be given a personal budget. This is how much their council is willing to spend on the services that their assessment said they need.

If you're in Northern Ireland, it's the local Health and Social Care Trust that does this.

The council can arrange and pay for these services itself. Or, if the person with MS and the council agree, they can pay for services themselves using their personal budget.

The council will then arrange for the service to be paid for using a direct payment. The person with MS can manage this themselves. Or you can manage this budget for them as their carer.

A direct payment gives more control and flexibility over the services they get.

You can only pay for something with this money if it's been agreed in the care and support plan of the person you care for. The money must go into a separate bank account. You or they must keep records of how it's spent.

If you take on responsibility for managing direct payments, your council's social care services department can put you in touch with places to help you with this. You could also use a **broker**.

One tip: keep careful records and files. That way, managing direct payments doesn't become an overwhelming job.

Tips for self-funders

Do you or the person you care for have more **assets** than the limits allow, and so need to pay for care yourselves ('self-fund')? Or perhaps the council decides that you don't need help. What then?

You have the right to appeal against a decision not to give you help. Find more about challenging a decision on page 133.

If you have no choice but to pay towards care services, here are ways of raising money:

- using income from pensions, renting out property, investments, or by carrying on working claiming Attendance Allowance (it's not **means-tested**)
- asking family or friends for financial help
- moving to a smaller home to free up cash
- renting out a room in your home
- **equity release**. This lets someone get a lump sum or regular cash against the value of their property
- **Deferred Payment Agreements** (for an explanation see page 179)
- seeing if you qualify for NHS Continuing Healthcare (see page 66) or NHS-funded nursing care

Before making any decisions, get advice from an independent financial advisor who knows about paying for care costs.

You'll find more advice for self-funders at **nhs.uk** and **moneyadviceservice.org.uk** . Search for 'self funding'.

My carer's assessment

The law says carers have the right to a 'carer's assessment'. This is when the council of the person you support looks at what help you need to care for them.

To have a carer's assessment, get in touch with the social services department of the council of the person you care for. Or get in touch with their council's contact centre.

If you qualify for help, the council will make you a **support plan.** It looks at how a range of social care services might help you (social care is explained on page 123).

Your support plan could say you need things like:

- a break from looking after the person you care for
- help with transport costs, housework or gardening
- driving lessons (to get the person you support from A to B)
- gym membership (so you can keep fit)

Or it could arrange for the person you care for to get support, which would then make your life easier.

As a result of your assessment you might get money (called **direct payments**) to spend on things agreed on in your support plan. Or the local council might provide what you need.

Whether you pay for this depends on your council. Not all of them charge for every service. If the person you care for gets services, their money situation is looked at as part of their assessment.

Northern Ireland

If you're in Northern Ireland, your local Health and Social Care Trust arranges carer's assessments. When we mention the council on these pages, for you this means your local trust.

What happens during the assessment?

Someone from the council of the person you care for will ask you questions. These will cover:

- your role as a carer and how it's affecting you
- your health, including physical, mental and emotional issues
- how you feel about caring for someone and what choices you want to make about this
- how being a carer affects your work, study, training and leisure
- the impact of caring on your social life, relationships and what you want from life
- housing issues
- planning for emergencies

People with MS can also have their needs assessed by their council.

If you and the person you support both agree, you can both be assessed at the same time, in a joint assessment.

Or you can be assessed separately if you don't want to talk about the person you care for in front of them.

You can have an assessment even if the person you support had an assessment themselves, but they didn't qualify for support.

You can have one even if the person you care for decides not to have their own assessment.

If the council decides you don't qualify for support, they must give you information and advice on other services that could help you.

You can appeal against the decision. You can ask to be assessed again if your caring role changes a lot, for example, if the MS of the person you care for gets worse.

How long does this take?

A survey in 2022 found that one in four people were waiting over 6 months for their social care assessment.

Will it make a difference?

There's no guarantee a carer's assessment will give you all you need. You'll only find out if you ask for one.

In 2019 we asked MS carers who'd had an assessment in the last year. Only 1 in 3 felt it had properly looked at what they, as a carer, were willing and able to do.

In another study, over 2,000 carers were asked about their assessments:*

- over half got some level of support for themselves or the person they care for
- 1 in 4 got financial help for a break
- 1 in 4 got practical help at home
- 1 in 4 got more support for the person they cared for
- 1 in 3 found their assessment helpful or really helpful
- 1 in 5 found it no help

These carers were looking after people with lots of conditions, not just MS or advanced MS.

The person you care for is severely affected by MS. So it's hoped you'd qualify for more support than many of these carers got.

Tips:

- before your carer's assessment make sure you're prepared. Inside this handbook you should find an insert ('Carer's assessment checklist'). This will help you be ready
- Carers UK has more information on carers assessments at **carersuk.org** (click on 'practical support' in the Help and Advice section)
- if you've had an assessment, it should be reviewed regularly. That's because what the person you care for needs, can change

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* 'Prepared to Care?' by Carers Week, 2013

> **"My hubby was my sole carer for 11 years, before we got help in. He was dead against the idea of having extra care at home. He felt it was his job and his job alone to care for me. But five years on and we're both so glad we did."**
>
> Pauline

> **"I've had a carer's assessment. I felt it was a waste of time, to be honest. It wasted a huge amount of my time. And absolutely nothing came out of it."**
>
> Andrew

I want to complain or appeal

You can complain about a medical service from the NHS or a social care service. Or you might wish to appeal against a decision you don't agree with.

Social care services

You have a right to appeal if you think your council (or Trust in Northern Ireland) made the wrong decision about the care and support you or the person you care for get.

You can also complain if you're not happy with a service once you get it.

Appeals

You can appeal if:

- your council (or Trust) decides you don't qualify for support, but you feel you should
- you feel they didn't look at all of your needs when they made their decision
- you qualify for services, but you feel not enough is being offered

Find information on appeals at your local library or on some council websites.

Tips:

- your local MS Society group, carers group or Citizens Advice could also help (our MS Helpline has details). Or use an **advocate**
- Disability Rights UK has information about appealing against decisions about social care. Search for 'complaining about local authority decisions' at **disabilityrightsuk.org**
- If you're in Great Britain you can speak to our MS legal advisers. Search our website for 'legal advice'.

Complaints

First take your complaint to whoever gives you the service. This could be your council (or Trust in Northern Ireland) or a private company. You could also speak to your social worker (if you have one) or local social services team.

If that doesn't work, and the service comes from the council (or Trust), ask to see their 'complaints procedure'. This tells you how to complain, how it's handled and how fast they should reply.

Find the procedure on their website or call them. You can also get it from your library or social worker.

Complaining doesn't mean your service will stop or be cut back. It's important services learn from complaints so that they can be made better.

More tips:

if you live in England, Healthwatch can also find someone to advise you

- about complaining about a social care service. Find out more at **healthwatch.co.uk/help-make-complaint**
- in Northern Ireland complain to your local Health and Social Care Trust. You'll find details on how to here: **patientclientcouncil.hscni.net**
- or you can contact the organisation that regulates health and social care in the part of the UK you live in (details on pages 175 and 174)
- your local councillor or Member of Parliament (or member of the devolved parliaments and assemblies) might take up your complaint, too
- we can help you write to your MP for help with social care or other issues you may be experiencing. Get in touch at **campaigns@mssociety.org.uk**

If you don't get a reply from the service your complaint is about, or you aren't satisfied with their response, report it to the local government and social care ombudsman. Find details on pages 173 and 174.

Medical care

Unhappy about care from the Health Service? The first step is to speak to someone from the service you used.

You might be able to get things sorted out without needing to make an official complaint. You can involve a social worker if you have one.

If you want to make a complaint about a hospital in England or Wales, ask to speak to someone from its Patient Advice and Liaison Service (PALS). They'll help you try and settle your complaint or take it further if you need to.

Scottish hospitals have a similar service - the Patient Advice and Support Service (PASS). Northern Ireland has the Patient and Client Council **patientclientcouncil.hscni.net**

If you're still not happy, ask for a copy of the service's complaints procedure. It tells you how to make your complaint, who to send it to, and how soon you can expect an answer. The PALS or PASS service can help you make an official complaint.

When you go to meetings about your complaint or have to deal with paperwork, you can get help from an independent **advocate.** Your local council (or Trust) can find you one.

For more on complaining about a medical or health care service from the NHS, check their own information at **nhs.uk/contact-us/how-to-complain-to-the-nhs**

Tips for England and Wales:

- how to use the PALS system is explained by searching for 'Patient Advice and Liaison Service' at nhs.uk
- if you're not happy with the response from PALS, POHWER gives free advice (details on page 173) or gives you an advocate. POHWER covers people living in most parts of England

- Healthwatch can also find someone to advise you about making a complaint about an NHS service. Find out more at **healthwatch.co.uk/help-make-complaint**

Tips for Scotland:

- find information about complaining in Scotland by searching **nhsinform.scot** for ‘feedback, complaints and your rights’
- Patient Advice and Support Service (PASS) offer advice and support to make a complaint. This service is available through your local Citizens Advice
- if the NHS has investigated your complaint and you’re still not satisfied, you can take it to the Scottish Public Services Ombudsman (SPSO) (details on page 173)

Tips for Northern Ireland

- find full details on how to make a complaint at **nidirect.gov.uk/articles/make-complaint-against-health-service**

More tips:

- normally you must complain within 12 months of when an event happened, or when you first became aware of a problem
- you can contact the organisation that regulates health and social care in the part of the UK you live in (details on pages 173 and 174)
- unhappy with how your complaint has been handled locally? Contact your ombudsman (see page 173)

I’m not happy with a GP

You can make a complaint at the surgery. Ask for their complaints procedure. Keep a written record of any conversations you have with staff there about your complaint.

You must usually make the complaint within 12 months of the thing happening that you’re unhappy about. Or you can complain to the local NHS (details on the previous page).

You’ll find useful information at **which.co.uk** by searching for ‘unhappy with your GP’.

If you’re not happy with the response, try the ombudsman. Their details are at the back of this booklet.

You can change your GP at any time, and don’t have to give a reason.

You might be able to register with another GP locally. For details how, visit **nhs.uk** and put in the search box on the home page ‘How to register with a GP surgery’.

> **“There are things there but you have to work for them... fight for them. We don’t let things drop. We will look into all possibilities and take our concerns to the highest possible authority”**
>
> Rob

I want a second opinion

If you’re not happy with answers or treatment in hospital or from a GP, the person you care for can ask for a second opinion. Doctors’ guidelines say they must respect their wish for this. They usually say yes if someone asks for a second opinion.

In late 2023 the UK government said they plan to make this a legal right in England. For this to become the law across the UK, each national government will need to change their own law.

If the person you care for is having problems getting MS drugs, search our website for ‘getting treatment for MS’. Then check out the section ‘I’ve been denied an NHS treatment’.

Money and benefits

MS hits finances hard. There are extra costs to deal with. There can be lost incomes, and the need to rely on welfare benefits.

The person with MS might have to cut down how many hours they work – or stop working altogether. And if you need to give up work to help care for them, that's two incomes lost. You can find yourself using up savings or getting into debt.

Disabilities mean additional expense. There are extra costs of getting around, the need for special equipment, changes to the home, insurance costs, extra heating, and so on.

Some carers earn too much to qualify for financial help with things like adaptations, **respite** or extra care at home.

But you can get help from the benefits system. And the more severely affected the person you care for, the more support there should be.

You both could get benefits, even if you still work. The system can be hard to find your way around but help is available.

It can pay to check now and again if there have been changes to what benefits you might qualify for. This is especially true if the MS gets worse.

These websites have 'benefits calculators' that tell you what benefits and tax credits you qualify for:

turn2us.org.uk
entitledto.co.uk

Check our website for benefits information. Search for 'brief guide to benefits'. If you search for 'financial support for carers', you'll find information on Carer's Allowance and other sources of support such as grants.

The MS Benefits Advice Service

Our MS Benefits Advice Service offers free, confidential advice to people across the UK who are affected by MS.

Get in touch with one of these advisers by calling our MS Helpline on **0808 800 8000**. Or email **msbenefitsadvice@dls.org.uk**

Tips:

- Disability Rights UK lists all the benefits carers can claim at **disabilityrightsuk.org/help-if-you-are-providing-care**
- if you need help filling in benefit claims or having assessments, people at a local Citizens Advice, carers group or some MS Society groups can help
- as well as our MS Benefits Advice Service, get help with benefits problems from your local Citizens Advice
- to make your money go further, take advantage of food banks
- check out our benefit advisers' tips on our website.
- They could save you money on things like Council Tax, mortgage payments, rent and more. Just search our site for '10 tips to help with everyday costs'

The following benefits are especially useful to know about.

Carer's Allowance

Carer's Allowance is a benefit you might get if you look after someone with a disability (like MS). Our research found that 1 in 4 carers of someone with MS who might get this benefit aren't claiming it.

Who's it for?

Who can claim Carer's Allowance is explained in detail at **gov.uk/carers-allowance/eligibility**. But the main points are that you must be:

- at least 16 (there's no upper age limit)
- spend at least 35 hours a week caring for a person with a disability who gets one of these benefits:
- the daily living component of Personal Independence Payment

- Disability Living Allowance (middle or highest rate of its care component)
- Attendance Allowance
- Constant Attendance Allowance (see the **gov.uk** link on page 139 for details)
- Armed Forces Independence Payment
- or two Scotland-only benefits: Child Disability Payment (middle or highest care rate) or Adult Disability Payment (daily living component)

The 35 hours can include time spent helping or keeping an eye on the person you care for.

It can also cover doing practical tasks for them like shopping, cooking, washing them or taking them to appointments.

You don't have to keep time sheets or a diary to prove you've cared for someone for 35 hours.

You must:

- earn no more than £139 a week after tax, National Insurance and expenses (including 50% of any money put towards a pension). If you sometimes earn above £139, you might still qualify based on your average earnings
- not be in full-time education
- you can't get the full amount of both Carer's Allowance and the State Pension at the same time. But it might be worth making a claim for Carer's Allowance. If your pension is £76.75 a week or more, you won't get it. But if the pension is less than that, you'll get a Carer's Allowance payment to make up the difference

Figures correct as of November 2023.

You don't need to be living with the person you care for, or be their relative. If you share the caring with others, special rules apply – see the link to the **gov.uk** on page 139. That page also tells you what you might get if you're don't qualify for Carer's Allowance, and about special rules if you get Pension Credit.

What can I get?

In November 2023 Carer's Allowance was worth £76.75 a week. If you're claiming Carer's Allowance, you may get this topped up with Universal Credit (see page 143) or Pension Credit (search **gov.uk** for 'pension credit').

How is it paid?

You can choose to be paid every week in advance, or every four or 13 weeks in arrears (in other words, at the end of every four or 13 weeks). Payments go straight into your bank, building society or Post Office card account.

How do I apply for it?

If you live in England, Scotland or Wales you can apply online at the **gov.uk** Carer's Allowance link. There you'll find how to claim by post or telephone if you prefer.

If you live in Northern Ireland, search for 'carer's allowance' at the **nidirect.gov.uk** site. You can apply there or download the claim form.

Tips:

- before you apply for Carer's Allowance, check with an adviser whether applying will affect benefits you or the person you care for already get
- our MS benefits advisers can answer your questions. Call our MS Helpline on **0808 800 8000** or email **msbenefitsadvice@dls.org.uk**
- information on Carer's Allowance (and other benefits) when you're of pension age is at **carersuk.org** Search for 'pension age benefits and support'
- people in Scotland who receive Carer's Allowance automatically get an extra payment twice a year called Carer's Allowance Supplement. In November 2023 this was £270.50

Universal credit

If you're under State Pension age, Universal Credit helps with living costs if you have a low income, are out of work or can't work.

Universal Credit is a **means-tested** benefit. It replaced some old benefits, like Income Support, Housing Benefit, and income-related Employment and Support Allowance (ESA).

Find out more about this benefit by searching our website for 'universal credit'. Details of who qualifies for it and how to apply are at **gov.uk/universal-credit** You can receive Universal Credit and Carer's Allowance at the same time. Your Universal Credit payment will go down by the same amount as what you get in Carer's Allowance.

Carer's Element of Universal Credit

If you care for someone for at least 35 hours a week, and they get a health or disability-related benefit, you might get an extra amount of money called the Carer's Element of Universal Credit. This was worth £185.86 a month in November 2023.

To see if you qualify for the Carer's Element, you need to give specific information to the Universal Credit team on 0800 328 9344. You don't have to claim Carer's Allowance to get this element.

Getting the Carer's Element might affect the benefits of the person you care for in the same way Carer's Allowance does.

It might mean they lose their entitlement to the Severe Disability Premium.

Carer's Premium. Carer's Addition. Carer's Element. What's the difference?

Carer Premium

If you qualify for Carer's Allowance, Carer Premium is extra money you might get. But you must be getting at least one of these benefits: Universal Credit, Housing Benefit or Council Tax Support, Pension Credit, Income-based Jobseekers Allowance, Income Support or Income-related Employment and Support Allowance.

Carer Addition

Carer Addition is the same as the Carer Premium, but it's only given to people of pension age.

Carer Element

Carer Element is the same as the Carer Premium or Addition, but it's only for people who get Universal Credit and who care for someone on a health or disability-related benefit.

To get the Carer Premium, Addition or Element you must qualify for Carer's Allowance – even if you don't apply for it. The Premium, Addition or Element is added to the benefits you get.

The Carer Premium and Carer Addition are worth £42.75 a week. The Carer Element (paid with Universal Credit) is worth £185.86 a month (November 2023 figures).

You don't need to apply for this money. It should be automatically added when you get Carer's Allowance (or judged eligible for it even if you don't apply for it). But always check it's been added by contacting the Carer's Allowance Unit on **0800 731 0297.**

Carer's Allowance's impact on other benefits

Before you claim Carer's Allowance (or the Carer's Element of Universal Credit), check if the person you care for gets a severe disability premium.

If they get this premium, they may lose it if you get Carer's Allowance.

Applying for Carer's Allowance will also affect benefits like Universal Credit, Working Tax Credit or Child Tax Credit. This is explained at the Carer's Allowance **gov.uk** link. Or contact our MS Benefits advisers on **0808 800 8000** or email **msbenefitsadvice@dls.org.uk** to talk this through.

Benefits and hospital stays

If the person you care for goes into hospital or residential care, that can affect benefits you or they claim.

The following benefits stop after a total of four weeks. This can be four weeks in one hospital stay, or over several stays, where the gaps between stays are no more than four weeks each time:

Personal independence payment (PIP), Attendance Allowance, Disability Living Allowance (DLA) and, in Scotland, Adult Disability Payment (ADP).

With the person with MS too ill, it's usually the carer who tells the benefits authorities about the hospital stay.

Hospital stays also affect benefits you claim like Carer's Allowance or Cold Weather payments. Your Carer's Allowance will stop after four weeks. This also applies to the carer's amount of Universal Credit. You must tell the benefits authorities when the person you care for goes into hospital or residential care, and when they come out.

Find more details about benefits and stays in hospital at **disabilityrightsuk.org/benefits-hospital**

Pensions

Thinking of working fewer hours or giving up your job to care for someone? This could affect your pension. Read more on page 35.

Budgeting loans

These short-term, interest-free loans are for people on a low income. The money is to spend on basic costs such as furniture, clothing or advance rent.

You must pay the loan back within two years. The money is taken from your benefits. You or the person with MS you support may be able to get this loan if you've been claiming any of these for at least 6 months:

- Income-related Employment and Support Allowance
- Income Support
- Income-based Jobseeker's Allowance
- Pension Credit. If you were moved from Universal Credit to Pension Credit, the time on Universal Credit counts towards the 6 months
- Single people can borrow from £100 to £348. For couples it's £464 (£812 if you or your partner claim Child Benefit). Figures correct as of November 2023.

What you can borrow depends on your circumstances, like whether you have a family or savings.

You can't get a Budgeting Loan if you claim Universal Credit. You should apply for a 'Budgeting Advance' instead.

Tips:

- for more detail on these loans and who can have one, search **gov.uk** for 'I want a Budgeting Loan'
- the fastest way to apply for a Budgeting Loan is online at the **gov.uk** page. You can also call the Social Fund Enquiry Line on **0800 169 0140** and ask for a form to be sent to you
- in Northern Ireland some details about Budgeting Loans are different. Find out more at **nidirect.gov.uk** by searching 'social fund budgeting loan'

Grants

The MS Society no longer has a national grants programme. Some of our local groups offer grants. Your local group can tell you if they accept grant applications and how to apply.

Welfare schemes give grants to cover emergencies. Check your local council's website to see what their scheme provides and how to apply to it.

If you have an urgent need for cash that you weren't expecting, you might be able to get 'local welfare assistance'.

In England, contact your council about what help you might get from them. In Wales search **gov.wales** for 'Discretionary Assistance'. In Northern Ireland go to **nidirect.gov.uk** and search for 'finance support'.

In Scotland the Scottish Welfare Fund gives vulnerable people on low incomes emergency and crisis grants. Apply through your local council. For more details go to **gov.scot** and search for 'Scottish Welfare Fund'.

Benevolent societies can offer financial help, too. These are often for people who were in certain jobs or industries, including the armed forces. Benevolent societies tend to get overlooked, so often have a lot of money to give out.

Carers Trust is one organisation that gives grants. Go to **carers.org**, then in the 'money and benefits' section, choose 'grants and discounts'.

In the same section are details of other places that also give grants. Find them under 'benevolent funds' and 'charities that support carers'.

Tips:

- your local MS Society group or Citizens Advice might know of trusts or benevolent societies that help people with MS or their carers
- Turn2Us have a grants checker. Search **turn2us.org.uk** for 'turn2us grants search'
- Disability Rights UK have details of benefits and grants, and other help carers might be able to claim at **disabilityrightsuk.org/help-if-you-are-providing-care**

- the website **disability-grants.org** can identify grants available for people with MS and their carers. This could be for things like equipment, holidays, housing and bills

Disabled Facilities Grants

These are available to help with the cost of making changes to the home. Read more about them on page 111.

Prescription charges

Prescriptions are free in Northern Ireland, Scotland and Wales.

If you're in England, does the person you support have to pay for more than three items in three months, or 11 items in 12 months?

If so, they may save money if they buy a prescription pre-payment certificate (PPC). Find out how to apply and what it costs by searching **nhs.uk** for 'PPC'.

They can also get free prescriptions if their disability means they can't leave home without help. For that they need a medical exemption certificate (MedEx).

To get this their GP, hospital doctor, or other health professional must fill in an FP92A form. A MedEx lasts five years before it needs renewing. It runs out at 60 when prescriptions become free.

You or the person you care for might also qualify for free prescriptions if either of you get some benefits, have a low income or have certain conditions (such as epilepsy).

You get an exemption card to show the pharmacist to get your free prescriptions.

Tips:

- find out more by searching 'free prescriptions' at **nhs.uk**
- the Pharmacy2U service delivers repeat prescriptions to your door for free if your GP is based in England
- check what help there is with NHS costs like prescriptions and travel to hospital at **nhsbsa.nhs.uk** Search for 'NHS help with health costs'

Help with heating costs

The person you care for might be able to get help cutting down their heating bills.

This might be direct help with paying a bill. Or it could be help towards making your home use less energy.

There are trusts that help people pay gas, electricity and water bills. Ask your local Citizens Advice or the company who sends the bills for details.

In 2023 the government introduced new help for people to cover energy bills, such as energy price caps.

Search our website for 'other financial help' for the latest update on what's available.

Types of support with fuel bills that are available every year:

The Warm Homes Discount Scheme

This could help cut your electricity bill (or gas bill if you get both types of energy from the same company). You might get this discount if you or the person with MS gets Pension Credit or are on a low income.

You don't need to apply for it. It's usually automatically taken off your bill. You only need to apply for it if you're on a low income in Scotland. Then you need to contact your energy company.

In 2023 this discount was worth £150. Find details of exactly who qualifies and how to claim by searching **gov.uk** for 'warm home discount scheme'

Winter Fuel Payment

You might be able to claim the Winter Fuel Payment to help cover energy costs. Find out if you can and how to claim at **gov.uk** (search 'winter fuel payment'). This used to be paid automatically if you got State Pension, but most people now have to claim it separately if they're eligible.

Cold Weather Payment

This is paid to people on certain welfare benefits. £25 is paid automatically along with any benefits if the temperature drops – or is forecast to drop – below freezing (zero degrees Celsius) for seven days in a row. A stay in hospital can affect this payment.

Details of which benefits you need to be claiming, and what to do about hospital stays, are at **gov.uk** Search for 'cold weather payment'.

In Scotland the Cold Weather Payment has been replaced with a once a year £50 Winter Heating Payment. You get this automatically if you're on certain benefits. It doesn't depend on how cold the weather is. You get a letter telling you if you'll receive it. Search **gov.scot** for 'winter heating payment' for more information.

Tips:

- for help with fuel bills and using less energy search **gov.uk** for 'find ways to save energy in your home'
- find the same kind of tips at **energysavingtrust.org.uk**
- for help cutting heating bills in Scotland, call Home Energy Scotland on **0808 808 2282** or visit **homeenergyscotland.org**
- for similar help in Wales call the Warm Nest scheme on **0808 808 2244** or visit **nest.gov.wales**
- for people in Northern Ireland with a low income the Affordable Warmth Scheme offers grants to cut their fuel bills. For details visit **nihe.gov.uk**, search 'affordable warmth scheme'
- most water and heating companies also offer help with their bills. Find out more by searching for 'help with utility bills' at **citizensadvice.org.uk**

Help paying council tax

Are you or the person you care for on benefits or have a low income, and have little or no savings? If so, you may be able to apply for a reduction in your Council Tax bill.

Councils make the rules about who qualifies for help, so check with them. In Northern Ireland this is called Rate relief.

You might qualify for other discounts, reductions or exemptions. One of these is carer's discount. You might get this if you're a carer and you pay council tax for a place you live in.

If you live with the person you care for

If you're the only other person who has to pay council tax that lives with the person you care for, they may qualify for a discount on their council tax. To get this you need to meet these conditions:

- you live in the same home as the person you care for

- you can't be their husband, wife or partner (or parent if they're under 18)
- you provide at least 35 hours a week of care for them
- the person you care for receives certain disability benefits

You don't have to get Carer's Allowance to claim a discount.

If you live somewhere else

Do you usually live elsewhere but need to move in with the person you care for? Then you may not need to pay council tax on your own home.

This is as long as no one is living there who should pay council tax.

Tips:

- for more on discounts and exemptions, contact the council's Council Tax service or advice and benefits team
- Carers UK have information about council tax. Search **carersuk.org** for 'help with council tax'
- for more on discounts in Northern Ireland contact Carers Northern Ireland Advice Line on **028 9043 9843**. Or search for 'rate relief' on the **nidirect.gov.uk** website. You'll find separate information for tenants and homeowners

Thinking ahead

With advanced MS you might think the best thing to do is to 'take each day as it comes'. But not having plans in place can store up problems for the future.

There's plenty to think about, including:

- what to do in emergencies
- what if the person you care for needs a care home
- documents that put their wishes in writing
- palliative care

Planning for emergencies

Carers often worry what would happen if they suddenly got ill. Or an emergency meant they can't look after the person they care for.

In some areas free 'carers emergency card' schemes quickly put backup care in place if you're suddenly not there.

You carry a card that has a phone number on it for you or others to call in an emergency.

If the person you care for has very complex needs, these schemes won't be enough. You'll need to put your own emergency plans in place, especially if their care needs two people or involves equipment.

Tips:

contact your local council or Carer's Centre to see if there's an emergency scheme locally

Carers UK have a webpage about emergencies, including card schemes. Search for 'contingency plan' at **carersuk.org**

The tipping point

This is when a carer reaches the point where the needs of the person they care for are more than they can cope with. This can be emotionally, physically or financially.

The tipping point can come while the person with MS is still at home, in hospital, or after they've gone into a care home.

You might get support that helps you delay reaching this stage. Support might even help you avoid ever reaching this stage.

For example, Continuing Health Care might be an option (see page 66). Your GP might be able to arrange what's called a 'best interests meeting' for you to work with your **multi-disciplinary team** (**MDT**) to discuss the options.

You or the person with MS can also get help if you ask for a social care assessment from the local council (or Health and Social Care Trust in Northern Ireland). More details are on page 123. If things have got more of a challenge since your last assessment, tell them you want to be assessed again.

The chapter 'Looking after myself' on page 39 suggests ways of getting support that might boost how you're feeling and protect your health. This could delay the tipping point.

If you feel you're reaching the tipping point, you might feel fear or guilt. It can be especially tough if MS is causing mental health problems in the person you care for, or their behaviour becomes hard to deal with.

> **"Caring on my own for my wife is physically and mentally draining. I have to put on slings, take off slings, several times a day. Now that takes quite a bit of physical strength. I'm over 70 years of age and obviously that leads to a few worries about, well, how long will I be able to keep going?"**
>
> Andrew

Going into a care home

A residential care home may be a short-lived solution. But if it's permanent, then your role as a carer doing practical things for them will be largely over. It doesn't mean you have to completely give up being their carer. You might still want to help with things like feeding at meal times. Ask the staff how you might stay involved in their care.

Paying for a care home

Care homes can be expensive. Most people are expected to pay something towards the costs of their care home.

If the person I care for moves into residential care, must we sell our home to pay for it?

If their council (or Trust in Northern Ireland) is arranging for them to move into residential care, the first step is for them to work out how much this will cost.

They'll look at the financial situation of the person with MS (also known as a **means test**). That looks at what **assets** they have. This includes savings, income (from pensions or renting out property) and the value of their home if they own it.

In England they must pay all the cost of the care home if the value of what they have is over £23,250. The plan is this will rise to £100,000 in October 2025. That plan only applies to England.

In Northern Ireland this upper limit is £23,250. In Wales it's £50,000. In Scotland this upper limit is £32,750. These were the figures in November 2023.

If the value is less than these upper limits, they'll get some help from their council to pay for the care home.

Many people do sell their home to pay for a care home. But it doesn't automatically have to happen.

If someone needs to sell their home to pay care these costs, they can arrange with their council to delay paying for their care ('deferred payment').

The council pays their costs. The person going into residential care pays them back when they decide to sell their home or when it's sold after they die.

The home won't be part of this **means test** if the following people are living there:

- their partner
- a relative under 16 or over 60
- a relative who's disabled

Tips:

- get advice from an independent financial adviser before making any decisions
- search our website for 'residential care' to find more on finding a home and paying for it

Care homes and benefits

Going into a residential home will affect some benefits. How much depends on whether the stay is a short one or permanent.

If the stay is short, it will also affect your Carer's Allowance. If it's permanent, you're no longer able to claim Carer's Allowance. Either way, you need to tell the Carer's Allowance Unit on **0800 731 0297** about the care home.

If you get other benefits, tell whoever pays those benefits if you no longer get Carer's Allowance. They'll then update your claims.

You should make sure the person with MS has told the benefits authorities that they've moved into a care home. They should do this within 28 days of the move.

Get expert advice. Turn2us has a factsheet with more details. Put 'care homes and benefits' in the search box on their home page at **turn2us.org.uk**

Paying for a care home in Scotland

No matter how many assets a person has, their council can pay towards their personal care and nursing care whatever their age if:

- they're in a care home that they pay for themselves

and

- they've been assessed as having personal or nursing care needs which need to be met in a care home

They'll be expected to cover the rest of the costs of the care home, which will be the accommodation fees.

To work out whether they can afford to pay these, they'll have a financial assessment carried out by their local council.

More information can be found by searching for 'paying care home fees' at **careinfoscotland.scot**

Advance care planning

Advance care planning (ACP) is when someone has a discussion about what they want for their care in the future.

This could be health care, social care, or even what they want to happen if they die. This discussion could be with family or friends, a social worker, health care worker or hospice staff.

An Advance Care Plan is when someone's wishes are written down. It could be documents made years before they might be needed. Examples include a will, a Lasting Power of Attorney, an Advance Decision (Living Will) or Advance Statement.

An Advance Care Plan could also be a document that's added to someone's medical notes near the end of their life. It should alert medical staff to any documents that state the patient's wishes.

An Advance Care Plan can cover:

- whether someone goes into hospital or stays at home
- any special dietary needs they have
- what medical care to give
- views on blood transfusions or organ transplant and donation
- if the person wants to be resuscitated if their heart stops
- if they want to be looked after in a place that's for their religious community
- funeral plans

A time might come when it's important to have a written record of someone's wishes.

One day they may no longer be mentally able to make decisions. Or their health has become so poor that they can't communicate.

During a crisis doctors quickly need to decide what treatment to give (or not give). But there's no way they can ask the patient. That's when advance care plans come in.

An advance care plan means someone's family, and the people taking care of them, will try to follow that person's wishes as best they can. Things can get very difficult if you don't sort out things like this in advance.

Some documents used in advance planning are legally binding, others aren't.

The documents we look at in this chapter are all types of advanced care planning: a will, a Lasting Power of Attorney, an Advance Statement or an Advance Decision (to Refuse Treatment).

When to think about Advance Care Planning

Some people decide a good time to think about this is when their MS becomes progressive. Others don't get round to it until their MS is advanced, when they're facing serious health problems.

Making a plan can ease the worry about what might happen in the future. It can take the pressure off the carer and the family.

Families and doctors often want to avoid talking about this subject. You might feel it's too upsetting to talk about the future, especially death.

But in 2022 researchers spoke to people with more advanced MS. They found most wanted to talk about advance care planning.

An MS nurse is a good person in someone's MS team to talk to about this. Making a plan well in advance gives you time to make sure the rest of the family agree.

Whatever plan someone makes, it's important to remember that it can be changed at any time if someone changes their mind about any part of it.

One thing to remember when written statements or legal documents are drawn up. They're no use if, in a crisis, medical staff don't know they exist. So make sure they know about them, and what's in them.

You can find out more about advance care plans at **advancecareplan.org.uk**

Lasting Power of Attorney (LPA)

In England and Wales this is when a person chooses someone (or more than one person) to look after their health and welfare. It gives others permission to make decisions when they no longer can.

An LPA can cover what medical treatment a person does or doesn't want. It can also cover how and where they're cared for.

Without an LPA (or an Advance Decision) a doctor will make these decisions in what he or she thinks are the best interests of the patient.

One LPA is needed to cover health and care (a Health and Welfare LPA). A different one covers money matters (a Finance and Property LPA).

Mental capacity

There's a law (the Mental Capacity Act) that decides when a person is no longer able to make important decisions for themselves. Examples could be to do with money or medical treatment.

If there's any doubt a person can no longer make these decisions, they're given an assessment to judge this. Carers UK have more on this. Search 'mental capacity' at **carersuk.org**

The finance LPA used to be called an Enduring Power of Attorney. If you still have one of those, it's valid (but it won't cover health and care).

An LPA might never be needed, but it's good to have in place. There are slightly different versions for each part of the UK.

An LPA only becomes legally binding after you register it.

England and Wales

Find out more about LPAs at **gov.uk** Search for 'lasting power of attorney'. At **gov.uk/power-of-attorney/make-lasting-power** you can make and register your LPA:

Scotland

There are three different kinds of Power of Attorney:

- a Continuing Power of Attorney for money matters
- a Welfare Power of Attorney
- a Combined Power of Attorney for both

Find out more by searching **mygov.scot** for 'power of attorney'.

Northern Ireland

If you're in Northern Ireland, you can make an Enduring Power of Attorney. Find details by searching **nidirect.gov.uk** for 'enduring power of attorney'.

An Advance Decision

The full name of this is an 'advance decision to refuse treatment' (ADRT). In Scotland it's called an 'advance directive'. You sometimes hear it called a Living Will.

This allows the person you care for to say in advance that they don't want certain treatments in specific circumstances.

It's only used if someone can no longer make a decision or communicate what they want to happen.

It can cover:

- artificial feeding (through a tube)
- artificial ventilation. This is when breathing is taken over by a machine (also known as being on 'life support')
- CPR. This is when someone's heart is restarted by repeatedly pressing on their chest and giving the 'kiss of life'
- antibiotics

An Advance Decision can't ask for euthanasia or assisted suicide. These are against the law.

The Advance Decision is legally binding in England, Wales and Northern Ireland. In Scotland it's not, but medical staff should take notice of it.

Without an Advance Decision the doctor will ask what you and the family think. But at the end of the day the doctor has to, by law, do what they think is best for the patient, unless the patient made one of these documents.

Compassion in Dying have a template form for an advance decision (Living Will). If you follow it, it should have everything needed for it to be legally binding. Find it by searching 'living will' at **compassionindying.org.uk**

An Advance Decision covers situations that often happen with no warning. So the people treating you need to know you have one so that they can follow it.

You could carry a copy with you at all times. But if that's not possible, you could ask family, friends or neighbours to have a copy (for example, on their phone).

Some people wear a bracelet that tells medical staff they have an Advance Care Plan or Advance Decision (and where they keep it, for example in their purse or wallet).

If medics come to your home, you can alert them about your Plan or Decision by leaving a note or other sign that they know to look for.

The 'message in a bottle' scheme is an example. You can read about it at **lionsclubs.co/Public/messsage-in-a-bottle** or search 'lions MIAB'.

An Advance Statement

An Advance Statement is when someone puts in writing what they want to happen about things that are important to them. It's sometimes called a Statement of Wishes.

It's to be used if the person can no longer make their own decisions. Maybe they can no longer communicate. Or they no longer have mental capacity. The Advance Statement covers things not in a Lasting Power of Attorney or Advance Decision.

This could be things like:

- what food they do or don't eat (including for religious reasons)
- other religious wishes
- their routine (such as how they like to sleep, when mealtimes are, or if they prefer baths over showers)
- what should happen to a pet
- and whether they want to be treated at home, in a hospital, nursing home or hospice

People in England or Wales can make an Advance Statement. It's not legally binding, but it is a guide to their wishes.

It's a good idea to make an Advance Statement as well as an Advance Decision (Living Will) and a health Power of Attorney. That way all situations are are covered. The Advance Statement is then backed by these legally binding documents.

If someone has a Lasting Power of Attorney, people who look after them must take their Advance Statement into account when they decide what's in their best interest.

Tip:

- Compassion in Dying offer help with writing an Advance Statement. They have a template form to help with this. Search **compassionindying.org.uk** for 'advance statement'

Wills

If someone dies without leaving a will, it can cause problems (and expensive legal battles) for those left behind. It's a good idea to have a will made with advice from a solicitor.

The person writing the will can make it clear who they want to be the 'executor'. That's the person who oversees who gets what when they die. The executor also makes sure funeral wishes are followed.

If there's no will, the state decides what happens. This might not be what the dead person wanted. For example, without a will, unmarried partners don't automatically inherit. It can lead to costly legal fees to make a claim.

Tips:

- get a solicitor involved so that any document you draw up is clear and legally sound
- check if a local solicitor will write a will for free if you donate to a charity. Visit **willaid.org.uk** to find solicitors who do this. In Scotland visit **willreliefscotland.co.uk**
- from time to time look at the documents again. Make sure they still reflect what the person you care for wants to happen
- let your GP know what plans you've made for you and the person you care for. Make sure medical records include these
- make copies for any people that give you social care services. Have them available for when you go to hospital with the person with MS

Court Appointed Deputies

What if the person you care for never made a Lasting Power of Attorney, and can no longer make decisions? You can apply to the Court of Protection to be made a Deputy.

Being a Deputy lets you legally make decisions in their best interests about some parts of their care. The court decides which these are.

In November 2023 it cost £371 to apply to become a deputy, with many more costs after that.

Being a deputy comes with much stricter regulation than a Power of Attorney has. This includes the need to provide exact accounts and an annual report. Read more at **gov.uk/become-deputy**

Palliative care

Most people think palliative care is about helping someone who hasn't long to live.

But more and more it's about getting the best quality of life for people in the advanced stage of a condition (like MS). It can be used by people who aren't close to death at all.

This kind of care can be used to manage pain or symptoms that are hard to deal with. But it's also about helping them enjoy life as best as they can, and making them as comfortable as possible.

This care can involve their GP, MS nurse or district nurse. It might be given at home, in a hospital, hospice or residential care home.

Palliative care might be useful for you, too. It can offer you some **respite** from caring. You get the chance to take more care of your own needs for a while.

But, when it comes to respite, not all carers will feel palliative care, such as in a hospice, is right for the person they care for.

A GP, MS nurse or other health or social care professional can refer someone to palliative care services to have their needs looked at.

The end of life

It can be upsetting thinking about the person you care for entering the last stage of life. Maybe you worry that bringing this up will upset them.

But people with MS often want to face the fact that the end is getting nearer. They may want to talk about their death.

They may have wishes about where they want to be cared for in those final days. For example, whether they go into a hospice or get hospice care at home.

If they do want to talk about the end of their life, this should be respected by you, the family and their doctor and other health care staff - no matter how upsetting this might be.

You might feel that talking about this last stage means you've given up all hope. But it's possible to recognise the end is coming and make plans for it, and still hold on to the hope that you both can have quality time together.

It's especially important that legal documents and the person's wishes are finalised while they can still make decisions.

If they no longer can, it's vital you put in place the legal safeguards mentioned earlier in this chapter. This is especially true about the care and treatment the person gets near the end.

This can be written, recorded or told verbally to family and carers. But having it written or recorded is the best way to make sure it's taken notice of.

Donating parts of the body

The person you care for might want to help research into MS. One way they can do this is by giving their brain and spinal cord when they die to the Tissue Bank run by the MS Society and Parkinson's UK. If they're interested in doing this, call **020 7594 9734** or visit **imperial.ac.uk** and search for 'tissue bank'

After a death

When someone dies people are often surprised by how many things need doing. At this very difficult time it can help to know what you have to do.

If someone dies in hospital, their body is stored in the hospital mortuary. A member of staff will let you know they've died. It's for you to arrange to have the body collected. A funeral director can place the body in a chapel of rest until the funeral.

If someone dies at home, and their death was expected, contact their GP. They'll write out a death certificate. If they die during the night, you can call the out-of-hours GP service.

It's not unusual for a doctor to wait until the morning before coming. A district nurse might also certify the death during the night.

You'll need to register the death with the Registrar of Births, Marriages and Deaths for the district that the death happened in (in Scotland any Registrar can do this). This must be done within five days (eight in Scotland).

The registrar will give you a Certificate for Burial or Cremation (in Scotland, a Certificate of Registration of Death). The funeral director needs this before the funeral can happen.

You'll also be given a Certificate of Death (in Scotland, a form 334/S1) for social security purposes.

If the person got a State Pension or any benefits, you fill this in and get it to the address that the registrar gives you.

You might need a Death Certificate for the will or any pension claims, insurance policies, savings bank certificates and premium bonds. The registrar can give you a Death Certificate for a fee.

There's a website that lets you tell government organisations just the once that someone has died. Search **gov.uk** for 'tell us once'.

The funeral

Find out if the person you cared for left instructions in their will about their funeral.

The person who arranges the funeral will have to pay for it. Find out where the money's coming from, and if it's enough.

The average cost in 2023 was around £1,400 for a direct cremation (no mourners or service). You can have your own service or gathering later when you have the ashes.

For a cremation with a service organised by a funeral director the cost was over £4,000, with around £5,500 for a burial. Costs are higher in London.

These prices don't cover things like catering or the legal fees connected with dealing with a will.

What if there wasn't a pre-payment plan to cover funeral costs, and you don't have the money? You might qualify for help from the Social Fund if you're income is low enough.

If you live in England or Wales, find out more from **gov.uk** by searching 'get help with funeral costs'. If this Funeral Payment doesn't cover the full cost, you might be able to apply for a Budgeting Loan (see page 146).

In Scotland a Funeral Support Payment is available for people on low incomes. Find details at **mygov.scot** and search for 'funeral support payment'.

For help in Northern Ireland search for 'funeral expenses payments' at **nidirect.gov.uk**

You might be able to use the savings of the person who's died to pay funeral costs. But you'll need a Death Certificate to do this.

If they had life insurance, you usually don't get any money until after the estate has been settled.

You might be able to get a limited amount before then to help pay for funeral costs. Some pensions include a sum that pays towards a funeral.

Funeral directors' charges vary, so compare a few. Most people use a funeral director. But if you don't want to, contact the local council's Cemeteries and Crematorium Department for advice.

If there's going to be a religious ceremony, get in touch with the appropriate person. The funeral directors can help if you're not sure who to ask. They'll also advise you about the process behind a cremation or burial.

Life after caring

Your role as a carer can end in several ways. Perhaps the person you care for moves into residential care, or a hospice. Or your relationship may end. Or they may die.

No matter how caring ends, you're likely to feel the immediate loss of your caring role. All the time and effort you had put into caring for so many years suddenly ends. This will be a major change in your life.

Look to family and friends for support with dealing with this change. Hopefully they can help with things that need doing straight away, like stopping care packages.

You might then feel out on a limb, 'redundant' and no longer with a role for yourself. This role may have defined you for years.

It can be hard to cope with this sudden change on top of the loss of the person you loved and cared for.

It might not be easy knowing how to fill the time (and silence) you find yourself with.

The responsibilities that may have hung heavy on your shoulders have gone. Instead of relief, you might feel overwhelmed by it. And if you're grieving after a death, you'll need to allow time for that.

You might want advice with:

- bereavement
- coping with being on your own
- money matters, especially if benefits stop
- getting back into the world of work or retraining

Don't forget, skills you've used while being a carer can impress employers.

You've had lots of experience organising and managing budgets, schedules and dealing with care and medical staff.

Carers UK have web pages about life after caring and going back to work. They cover:

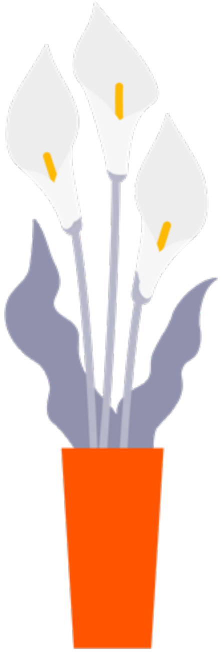
- how going back to work can affect benefits you've been getting
- how to identify your skills
- where to get help with training

Search **carersuk.org** for 'life after caring'. That same page has ideas for getting back to work.

If you search our website for 'bereavement', you'll find where to get support.

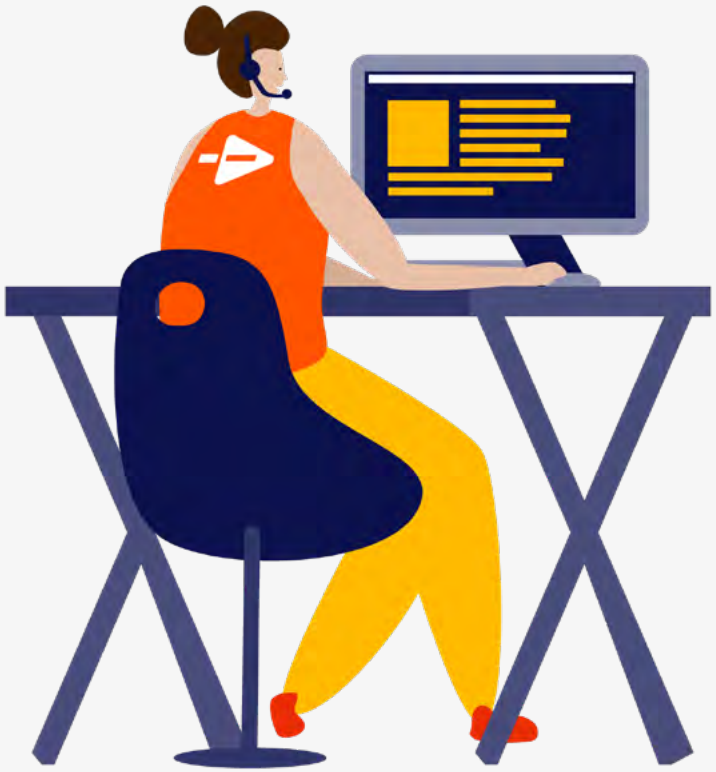
Tips:

- talk things over with someone at our MS Helpline. They're trained to give emotional support
- Cruse Bereavement Care (**cruse.org.uk**) offers face-to-face, telephone, email and website support. Call their helpline on 0808 808 1677. The back of this booklet has more on this and the service for Scotland
- your local carers group or centre will help with training and getting into work
- Work Preparation Support offers advice and training for carers and ex-carers. It's available through the Flexible Support Fund at your local Jobcentre Plus office
- in Northern Ireland the Adviser Discretion Fund might help you overcome barriers to returning to work. Speak to your Work Coach in your local Jobs and Benefits office



Useful organisations

Here are websites and discussion boards for people with MS or their families, partners, friends or carers.



Support

MS Society

Visit our website for information about help and support, money, work, looking after yourself and end of life issues. Search it for 'support for carers'.

Chat to other carers on our forum **community.mssociety.org.uk/**

Get information or emotional support from our MS Helpline. Page 182 tells you what they offer and the different ways to contact them.

Shift MS

A social network for people with MS.

shift.ms

MS Trust

Useful information about MS, including where your nearest MS nurse is. Put 'MS services near me' in the search box on their website.

mstrust.org.uk

Carers Trust

Information, advice and support through its carers' centres, website and online forum. They give grants to carers. They have local Network Partners, 150 independent services for carers across the UK. They offer information, advice, practical support and care in the home.

To find your nearest carers group search their site for 'carers', followed by the name of your town or county.

0300 772 9600
carers.org

Carers UK

The UK's national membership charity for carers. Information, advice and telephone and email support from their advice line for unpaid carers (family or friends).

Advice Line **0808 808 7777**

(Monday to Friday 9am-6pm)

Check out their online forum at **carersuk.org/forum**

To find local groups search their website for 'support where you live'.

carersuk.org

Scotland

Care Information Scotland

Information, advice and support for carers and those they care for.

0800 011 3200
careinfoscotland.com

Crossroads Caring Scotland

Provider of packages of support services for carers and their families so they can live independently at home. Local contact information is on the website.
crossroads-scotland.co.uk

Northern Ireland

Crossroads Care Northern Ireland

A not-for-profit organisation that supports carers and those with care needs.

028 9181 4455
crossroadscare.co.uk

MS Therapy Centres

These offer treatments like physiotherapy, massage, reflexology, yoga, exercise classes and chiropody. They also give people the chance to socialise and get information and advice.

Find centres near you by searching **mstrust.org.uk** and choose 'MS therapy centres' in the 'MS services near me' map.

Urgent medical advice

NHS 111

Worried about something medical? Need advice or medical treatment quickly and can't wait for an appointment to see a doctor or nurse?

If it's urgent (but not an emergency), call **111** (24 hours a day) and speak to a fully trained NHS adviser. They can decide if you need an ambulance and send one straight away if needed. They can contact an out-of-hours doctor, too.

Call **999** if it's an emergency, when someone's life is at risk.

Care services regulators and complaints

England

The Care Quality Commission

The health and social care regulator. Has an online directory of registered independent care services.

03000 616161
cqc.org.uk

Local government and social care ombudsman

For help with complaints if you're not happy with the response from the service you complained to.

0300 061 0614
lgo.org.uk/adult-social-care
lgo.org.uk/make-a-complaint

POHWER

Provides advocacy services. Helps with complaints about the NHS (England only). Find details about complaining about the NHS at:

pohwer.net/nhs-complaints-advocacy
0300 456 2370

Wales

The Care and Social Services Inspectorate Wales

Responsible for inspecting social care and social services. Has an online directory of registered care services

0300 7900 126
careinspectorate.wales

Public Services Ombudsman for Wales

Independent body with powers to look into complaints about public services (including social care) and independent care providers.

0300 790 0203
ombudsman.wales

Scotland

The Care Inspectorate

Regulates and inspects Scottish care services. It has an online directory of registered care services.

0345 600 9527
careinspectorate.com

Scottish Public Services Ombudsman (SPSO)

The final place to take complaints about councils, the NHS, the Scottish Government and its agencies and departments and most Scottish authorities. Offers help only when a complaint to an organisation that provides a service hasn't been sorted out.

0800 377 7330
spso.org.uk

Northern Ireland

The Regulation and Quality Improvement Authority (RQIA)

The independent health and social care regulator, with online directory of registered care services.

028 9536 1111
rqia.org.uk

Office of the Northern Ireland Ombudsman

The ombudsman helps when you've followed a public organisation's own complaints procedure but still aren't satisfied.

0800 34 34 24
nipso.org.uk

Equipment and technology

Abilitynet

Helps people with disabilities to use technology at home, work and in education. They run a free helpline on **0800 048 7642** and offer specialist advice and information

abilitynet.org.uk

Everyone Can

Supports disabled people with technology

Helpline 0808 800 0009
everyonecan.org.uk

Disabled Living

Information and advice about products, equipment and services for disabled adults, carers and the professionals who support them.

0161 214 4590
disabledliving.co.uk

Disabled Living Foundation

Charity providing impartial advice, information and training on equipment and mobility products for disabled people. They run website **livingmadeeasy.org.uk** It features equipment, from clothing and personal care, to mobility products and things for the home, including alarms and other technology.

Counselling (relationships and sex)

British Association for Counselling and Psychotherapy

Details of counsellors can be found on their website:

bacp.co.uk

Relate

Offers advice, relationship counselling, family counselling and support face to face, by phone or through its website.

relate.org.uk (England and Wales)

relateni.org (Northern Ireland)

The MS Society in Northern Ireland has a counselling service. Contact **028 9080 2802**

Relationships Scotland

Similar service to Relate.

0345 119 2020
relationships-scotland.org.uk

College of Sexual and Relationship Therapists

Has a list of therapists.

020 8106 9635
cosrt.org.uk

Pink Therapy

Therapy organisation that has a directory of counsellors and therapists that work with lesbian, gay, bisexual and trans people.

pinktherapy.com

Money and benefits

Carer's Allowance Unit

0800 731 0297

Disability Rights UK

Information on benefits. It can't answer general questions over the phone, but has a helpline for questions on personal budgets.

Personal Budgets helpline **0330 995 0404** (Tuesdays and Thursdays 9.30am-1pm)

Email: **personalbudgets@disabilityrightsuk.org**

This helpline can deal with questions about:

- personal budgets
- care needs assessments
- care and support plans
- hiring personal assistants
- getting funding for social care
- appealing against decisions made by your council's social services

General enquiries: 0330 995 0400
disabilityrightsuk.org

Turn2us

Helps people find out what benefits and grants they qualify for. It has useful tools and resources to help you understand what your options are.

turn2us.org.uk

Rights and legal help

Citizens Advice

Help with welfare rights, housing and disability advice. To find local offices, as well as find online advice, contact through **citizensadvice.org.uk**

Northern Ireland has the Independent Welfare Changes Helpline: Freephone **0800 915 4604**. It's provided by the local Citizens Advice, Law Centre and Advice Northern Ireland

Disability Law Service (DLS)

Free legal advice to people with disabilities and their carers in England and Wales. DLS cover discrimination and issues with care services, including social care assessments.

0207 791 9800
dls.org.uk

The MS Society has a legal advice service. We work in Wales and England with the Disability Law Service (DLS) and in Scotland with the Legal Services Agency (LSA). We offer free, confidential legal advice to people affected by MS.

For the type of problems we can help with search our website for 'legal advice'.

Call or email our MS Helpline on 0808 0800 8000

Disability Rights UK

Campaigns for improvements to the social security system. (see its entry on page 174 for more details)

Disability Information Scotland

Provides information to help guide people through the maze of disability information in Scotland.

Helpline 0300 323 9961
disabilityscot.org.uk

Research Institute for Disabled Consumers

RiDC provides information, guides and reviews about products and technology that help disabled people lead an independent life. Their information covers driving, public transport, wheelchairs and walking aids.

020 7427 2460
ridc.org.uk

Motability

A scheme that lets disabled people get mobile by exchanging their mobility allowance for a lease on a new car, scooter or powered wheelchair.

motability.co.uk

Work

Access to Work

Help for people with MS to get a job or stay in work. Applications can be made directly to the Access to Work Centre or through local job centres.

gov.uk/access-to-work/overview
0800 121 7479

Dying and Bereavement

After a bereavement our MS Helpline or these organisations can be helpful.

Cruse Bereavement Care

Face-to-face, email and telephone support for people after the death of someone close. Covers UK except Scotland. Helpline **0808 808 1677** (Monday to Friday)

cruse.org.uk

Cruse Scotland

Helpline **0845 600 2227** (Monday to Friday)

crusescotland.org.uk

Compassion in Dying

Their website has templates to make an Advance Decision (Living Will), Advance Statement, and a health Lasting Power of Attorney. You can also download their Planning Ahead guide.

Information Line 0800 999 2434
compassionindying.org.uk

Hospice UK

Guidance about hospice and end of life care, advice on caring, and support with bereavement.

hospiceuk.org

New words explained

adaptations – changes in the home that make life easier, such as structural alterations, gadgets and changes to furniture and fittings

advance care planning (ACP) – having a discussion and making decisions about what health or social care they want if they get too ill to communicate their wishes. An advance care plan is the written record of these wishes. Things like Advance Decisions or Statements, a will or Lasting Power of Attorney can all be part of ACP

advocate – independent person to help with care and support plans, assessments and making complaints

assets (or ‘**capital**’) - this includes savings, income (from pensions or renting out property) and the value of the home

assistive technology – products, equipment, and systems that help with learning, working, and daily living for people with disabilities

broker – someone who gives advice, support with care plans and tries to solve problems with services. This service is free for people getting funding from their local authority, but self-funders must pay to use a broker

care package – a mix of services that can include help with things like cleaning and shopping, equipment and **adaptations** to your home, **personal care** and cooking. The service can cover a day centre to give you or the person you care for a break and let them socialise. It could include going into a care home

care plan (or **care and support plan**) – when a person with MS has an assessment of their support needs by their local council (or Trust in Northern Ireland). It puts in writing what services they need

catheter – thin tube that takes wee from the bladder and into a bag via the urethra (the body’s ‘pipe’ that takes wee from the bladder to outside the body)

CBT – cognitive behavioural therapy is a technique you can learn from a counsellor that helps you manage your problems by changing the way you think and behave. It can reduce anxiety, negative thinking and depression

commode – a chair, often on wheels, that has built into it a chamber pot that you can use when you need to go to the toilet

continence/incontinence – when you can/can’t control your bladder or bowel and you can/can’t hold on when you need the toilet

deferred payment agreement – if someone needs to move into a residential care home, they can put off paying for it until their house is sold (after they die, for example)

direct payments – a way of using the money a council (or **HSCT** in Northern Ireland) gives someone with MS to pay for their social care. They can only be spent on social care services and things that meet the needs in their **care plan**

Employee Assistance Programme - confidential support, advice and short-term counselling offered by employers to their workers

equity release - a way people who are 55 or older can get cash out of their home without needing to move. They take out a loan secured on their home. It’s paid back when the property is sold

functional electrical stimulation (FES) – when small electrical signals from a small box attached to your leg help you walk better if you have the MS symptom called ‘foot drop’

Health and Social Care Trust (HSCT) – the local body that provides social care services in Northern Ireland (in other parts of the UK councils provide these)

MDT (multi-disciplinary team) – a collection of staff, each experts in different types of medicine or the care of people with MS

means-tested – you only get a welfare benefit that’s ‘means-tested’ if you can show that the money you have coming in from wages, savings, and so on, is below a certain level

mindfulness – a type of meditation. You focus on the present, your breathing and how you feel. You become more aware of your body, thoughts and feelings, helping you manage your emotions. Studies show it helps with stress, anxiety and depression

myelin – a fatty covering around nerves that protects them. In MS this gets damaged, causing MS symptoms and disability

NICE (**National Institute for Health and Care Excellence**) – NICE is part of the Department of Health. it draws up guidelines for England and Wales on which drugs can be available on the NHS and how to treat conditions like MS

occupational therapist (OT) – a person who helps people do everyday things by offering suggestions and equipment. They advise on disability equipment alterations to the home or workplace that make life easier and help with fatigue, balance and tremor

personal budget – the money set out in the **care and support plan** of a person with MS that their council (or **HSCT in Northern Ireland**) will spend on meeting their social care needs. This budget can be managed by their carer

personal care – help with things like getting up, washed or dressed, eating and going to the toilet

reablement – help lasting up to six weeks after coming home from hospital. It helps you get back your independence

respite care – a break for a person with MS or their family carer where specialist care is provided (from a few hours a day or week, to longer holidays)

sepsis – blood poisoning caused when an infection (such as in the bladder or urinary tract) gets into the bloodstream. Symptoms include fever or low body temperature, chills and shivering, fast heartbeat or breathing. Must be treated quickly with antibiotics, to stop organ failure and death

social care – support and care services arranged by local councils (or **HSCTs** in Northern Ireland). Includes help at home with **personal care**, care homes, day centres, and breaks for carers

support plan – when the carer of a person with MS has an assessment of their support needs by the local council (or **HSCT**). It puts in writing what services they need

to transfer – to move from one place to another, such as from bed to wheelchair

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Further information

MS Helpline

Our MS Helpline gives emotional support and information to anyone living with MS. And through the helpline you can also access our:

- MS nurses
- MS benefits advisers
- MS legal advisers
- Physical activity service
- Short breaks service

We can provide information in different languages through an interpreter service. And by text relay and British Sign Language interpreters.

Find out more at **mssociety.org.uk/helpline**

0808 800 8000
(Mon-Fri 9am to 7pm except Bank Holidays)

helpline@mssociety.org.uk

Or direct private message us on **Facebook** (Mon-Fri 9am to 7pm)

Resources

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

You can read them online or download at **mssociety.org.uk/publications**

You can order printed resources from **onlineshop.mssociety.org.uk** or call **0300 500 8084**, select option 4

Another boooklet for carers

Our booklet for carers called '**Supporting Someone with MS**' is for when the person you care for doesn't have advanced MS.

Search our website for that title to download it. Or order it free as explained above.

About this resource

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

We'd love to hear what you think about this information at **mssociety.org.uk/yourviews**

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.
Call **0300 500 8084**.

Photography

All photography Amit Lennon, except: Paul Moane (pages 17 and 152), Susannah Fields (page 37), Marton Schneider (page 54), Simon Rawles (page 158), Davie Dunne (p 143) and Rebecca Cresta (page 170).

This resource is also available in large print.

Call **0300 500 8084** or email **shop@mssociety.org.uk**

MS Society

Contact us:

MS Helpline
Freephone 0808 800 8000
(weekdays 9am-7pm)
helpline@mssociety.org.uk

MS National Centre
020 8438 0700
supportercare@mssociety.org.uk

MS Society Scotland
0131 335 4050
enquiries-scotland@mssociety.org.uk

MS Society Northern Ireland
028 9080 2802
nireception@mssociety.org.uk

MS Society Cymru
0208 438 0700
mscymru@mssociety.org.uk

Online
mssociety.org.uk
/MSSociety
@mssocietyuk
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Trusted Information Creator
Patient Information Forum

BK37

This title will be reviewed within three years of publication (October 2026).

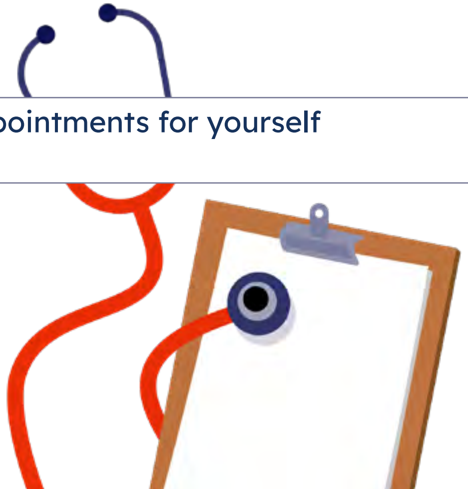
Carer's assessment checklist

Getting ready for my assessment

If you have a carer's assessment, it's important to be prepared for it. Here's a checklist of things to think about. Fill this in for a week or so before your assessment. It could help you be clearer about the help you need. Have it with you during your assessment to jog your memory.

	Yes, I do this for the person with MS I'm supporting	I do this for them every day/every week/every month (say which). Don't forget to include if you do this during the night	Each time I do this for them it takes me (say how long)
Day-to-day help			
Cleaning the house			
Shopping			
Cooking meals			
Washing clothes			
Helping them wash or have a bath			
Helping them go to the toilet			
Helping them feed themselves			
Helping them take their medicines			
Helping with other medical care			
Helping them use specialist equipment			
Arranging appointments for them			
Making sure they follow therapy routines (like physio exercises)			
Helping with paperwork (mail, money, paying bills)			
Getting them from A to B (help with walking, driving them, pushing their wheelchair)			
Giving them emotional support			
Helping them express what they want to say			
Emergency care (you're available by phone, or you have a house key)			

	Yes	**No**
Your health and mental wellbeing		
Do you have any health problems of your own? Is caring for someone making these worse?		
Do you feel anxious, stressed or depressed?		
Do you get backaches or headaches?		
Does your GP know you're a carer?		
Do you have to move or lift the person you care for?		
Would you like any aids or adaptations to help you, like a raised chair, bed, or hoist?		
Do you get enough sleep?		
Do you sometimes get a break from caring?		
Do you eat healthily?		
Do you get enough exercise?		
Can you leave the person you care for alone in the house?		
Can you look after your own day-to-day needs? Are you getting support from other people?		
Would you like to have any telecare equipment to help you like a pendant alarm, flood detector, bed occupancy sensor or door exit sensor?		



	Very difficult	**Fairly difficult**	**No problem**
How easy is it for you to get to appointments for yourself (GP/dentist/hospital/optician)?			

	Yes	No
Family responsibilities		
Do you have family commitments as well as your caring role?		
If you’re a parent, is caring making this role harder?		
Do you feel you have time for your children?		
Do you feel you have to ask your children to support you in your caring role?		
Support and leisure		
Does the person you care for have home care, or go to a day centre or lunch club?		
Does another family member or friend sometimes provide care?		
Do you get breaks where you have time for yourself, your leisure interests or time with friends? Or is caring getting in the way?		
Work, education and training		
Are you struggling to be a carer and hold down your job?		
Have you had to cut down how many hours you work?		
Would you like to go back to paid work?		
Is caring stopping you from getting any training or further education?		
Money		
Is being a carer giving you money problems?		
Would you like advice on benefits or debt?		
Risks		
Does the person you care for sometimes show challenging behaviour?		
Do you feel your housing and living conditions are suitable?		
Culture and religion		
Do you want to go to a place of worship or other regular religious and cultural activities?		
Do you have any specific religious or cultural needs?		

	Yes	No
Emergency planning		
Do you need help planning what happens if either of you suddenly becomes ill or have an emergency?		
Your views on caring		
Do you feel you don't have a choice about providing care?		
Do you have particular concerns about the future for you and the person you care for?		

For you what's the hardest thing about caring?

You may feel that you can't carry on at all, or only if you reduce the amount that you do. What would you most like to change about your situation?

Who or what helps you at the moment, and is this enough?

Information and advice

**How do you like to get information and advice?
Such as leaflets, face to face, on the phone, on the internet,
email, or in large print**

Is there specific advice or information you need now?

Any other problems or worries you'd like to bring up?

Contact us:

MS Helpline
Freephone 0808 800 8000
(weekdays 9am-7pm)
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