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

Together, we are strong enough to stop MS.

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

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

My advice is: don’t feel bad if you have bad days. You’re human, not super human! 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. It’s easier said than done, but important.

Walk the dog, meet a friend for coffee, go to the gym, have a long bath…

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 lots of 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.

Walk the dog, meet a friend for coffee, go to the gym, have a long bath…”
Five things to know

1. You’re not Superman or Superwoman. Don’t feel you have to fix everything yourself.

2. Carers often get stressed or depressed because they don’t look for help – or accept it. Decide what your limits are and what you need help with. Then ask for it.

3. Over time things will get more of a challenge. You might not be able to count on friends and family for help. So finding other sources of support is really important.

4. 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.

5. Get help to have breaks before you ‘burn out’. This booklet has ideas on how to look after your own needs. Then you’ll be in a better position to look after the person you care for and your family.
About this handbook

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

They are ‘severely affected’ by their MS. This 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

‘Advanced MS’ isn’t a separate type of MS. It can happen when someone’s had progressive MS a long time or if their MS is very active.

When the advanced stage of MS is reached, as a carer you’ll need much more support than before.

If you’ve been caring for someone in this position for a few years already, you can dip into this guide and get valuable tips.

If you’re new to this stage of MS, hopefully it can help you prepare for what the future might bring.

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

We’ve talked to carers about how they manage. This handbook brings into one place what they’ve learned.

If the person with MS in your life isn’t this badly affected, we have another booklet called ‘Supporting someone with MS’. Page 178 has details of how to get a copy.

One last thing. Where you see a word in bold in this booklet, turn to the back to find it explained.

There you’ll also find where you can get more help, such as from the MS Helpline on 0808 800 8000.
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 and not lose sight of them.

Carers have told us they need*:

- information and advice about advanced MS
- practical support, including help with money and care
- emotional support, from friends, family or someone like a counsellor
- ways of sharing experiences with people in the same boat
- ways of solving problems, coping better or seeing things differently (such as help to accept the situation they’re in)
- help to look after themselves (such as breaks and things that ease the pressure and isolation)
- help when relationships become difficult
- to be listened to, for example, by doctors
- to have other people value the support they give

Inside this handbook you should find a ‘Carers assessment checklist’. That’ll help you work out in more detail what help you need. But the key is to build a network of people to help you.

“I’d like help coming to terms with my wife’s condition, First Aid and how to pick her up safely after a fall, which is quite regular.”

Jerry

* From a 2016 MS Society survey and a 2017 study by Queen Margaret University (‘Scoping the Needs of Families and Carers of People with Multiple Sclerosis’). Quotes in this guide come from these two studies and carers who helped write this handbook.
I want to know more about this stage of MS

Keeping informed can help you feel you’re doing something to support yourself and the person you care for.

MS is unpredictable but having 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’.

This can help them feel life is carrying on as normal. They might feel they’re protecting themselves and the family from harsh facts.

But as MS gets more severe, doing this becomes less of an option.

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

As MS becomes more advanced or ‘progresses’, it becomes less about taking treatments like a disease modifying therapy (DMT) that can slow it down.

Instead MS becomes more about:

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

Hands-on help from other people is probably most useful. But you’ll probably also need more detailed
information about symptoms and how to manage them. This guide points you in that direction.

“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

Local groups
You can get information and support from your local carers group or MS Society group.

You’ll discover and share valuable things that other carers have already found out. They’ll respect and value what you’re doing.

Some groups meet during the day which is a problem if you work. But many make sure they have events or meetings at times like weekends that people who work can go to.

“It’s just listening to how other people cope with that and building up a toolkit to help you in the future.”

Simon

“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 you

- benefit from years of other carers’ experience and knowledge
- learn from talks, discussions and share information in other ways
- get help filling in forms, having assessments and applying for support and grants
- pick up tips on getting a good care package
- find out what help is available locally
- meet people in the same boat so that you feel less on your own
- learn ways to relax and de-stress
- have the chance to let your feelings out to people who understand
- hear about activities that you and the person you care for can go to

Tips:

- call the MS Helpline on 0800 800 8000 to find MS Society and carers groups near you
- find your nearest MS Society group at mssociety.org.uk/near-me
- find your local carers group on the Carers Trust website. In the search box for ‘Find local care and carer services’ put ‘carers’ followed by the name of your town or county
- or search the Carers UK site at carersuk.org/help-and-advice/get-support/local-support
- ask your GP surgery about local support for carers
- if you work, ask HR or people you work with if there’s a carers network
Updates on drugs and treatments for symptoms

New treatments for symptoms come along, such as Botox for muscle spasms and bladder problems. So it pays to keep in touch with what’s happening.

The person you care for probably no longer qualifies to take a disease modifying therapy (DMT). But research is looking into 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:

- make sure the person you care for has the once a year review with an MS specialist that NICE guidelines say they should get

- for the latest news check out this part of our website mssociety.org.uk/research

- read our magazine MS Matters (and its Research Matters insert) for treatment news and tips on symptoms

- we send it to our supporters three times a year as part of their membership. Join by calling 0300 500 8084 or email supportercare@mssociety.org.uk

- or join (and see back issues) here mssociety.org.uk/get-involved/become-a-member/ms-matters-magazine

- find back issues of Research Matters here mssociety.org.uk/ms-research/Research-Matters-magazine

- or call the MS Helpline to talk to someone about symptoms or news about drug treatments
On pages 72–78 we look at key information about three symptoms common in advanced MS. These are bladder and bowel problems and pressure ulcers (bed sores).

Find much more detailed information about these and other symptoms in our free booklets and factsheets. These are listed in our resources list.

You can find this list by putting ‘information resources list’ in the search engine on our website.

Order our free publications through the MS Helpline or online shop, or download them from our website. Just put the symptom that interests you in the search box on our home page, followed by the word ‘booklet’.
How severe might MS get? And how fast?

When you don’t know for sure what the future will bring, it can leave you feeling out of control, anxious, angry or even helpless.

Some carers feel they might be better prepared if they had an idea of what could be ahead.

Knowing what to expect can help lessen the shock as MS worsens.

The EDSS scale

How MS gets worse over time is measured by a scoring system called the Expanded Disability Status Scale (EDSS). But it’s only a rough guide.

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<tr>
<td>0.0</td>
<td>Normal examination</td>
</tr>
<tr>
<td>1.0</td>
<td>No disability but clear signs of impairment</td>
</tr>
<tr>
<td>2.0</td>
<td>Moderate disability</td>
</tr>
<tr>
<td>3.0</td>
<td>Able to walk without aid</td>
</tr>
<tr>
<td>4.0</td>
<td>Minimal disability</td>
</tr>
<tr>
<td>5.0</td>
<td>Death</td>
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For example, someone can have a high EDSS score but still be in a job.

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

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 there are general trends that 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 a further 10 years after that for people to reach EDSS 7 (restricted to a wheelchair). That’s happened on average by the age of 63.

### Status Scale (EDSS)

| EDSS 6.0 | Help needed to walk 100 metres |
| EDSS 7.0 | Essentially restricted to wheelchair |
| EDSS 8.0 |
| EDSS 9.0 | Essentially restricted to bed much of the day |
| EDSS 10.0 | Bedridden and unable to communicate effectively or eat/swallow |

Death
It made no real difference whether someone started out with relapsing 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. They may be out of bed much of the day, with their arms generally 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. 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. The graph below shows the results. But remember: DMTs weren’t around for the people in this study who’d had MS for decades.

* Fox et al, ‘Prevalence of multiple sclerosis symptoms across lifespan’
How might our lives change?

With advanced MS your focus will be more on helping the person you care for 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 both realise that there’s no option but for you to do certain things for them (while helping 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.

Emotional support from outside can help, from family, friends and professionals (you’ll find ideas on pages 165–166).

When relapsing MS becomes progressive MS

As MS gets more severe, the focus will switch 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 even feel doctors and MS nurses lose interest.
The person with MS is often taken off the DMT they were on as the drug won’t have any effect now. 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 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, no matter what kind of MS they have, should get a review with an MS specialist at least once a year.

Don’t accept being told that from now on a GP can deal with things and 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 or MS nurse 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, there might be new services since then.

To get a referral to a specialist or service, you’ll usually need to go through the doctor, MS nurse or other healthcare staff treating the person you care for.

Someone with MS might be put off going to appointments by their fatigue, problems getting around or other symptoms. If so, home
visits or **open appointments** might be possible, especially from a community-based service or MS nurses. Ask them when you visit, or phone them to discuss this.

If you can’t use public transport and don’t have your own, some areas have free non-emergency patient transport organised by your 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 get greater, you’re more likely to see yourself as their carer.

You might find some parts of caring easier than others. For example, not all people find giving emotional support easy. Instead they get on with practical stuff, such as washing, dressing and other personal things. The person with MS might prefer their carer to do this, rather than a stranger.

Your relationship was once about intimacy and friendship. Now you’ve become their legal representative, the person who looks after their finances, gives them medication and helps them with their bladder or bowel.

On days when symptoms ease off, the balance might shift back to how things used to be for a while.

You’ll become a sort of ‘care manager’, filing documents, keeping medical notes and getting treatment at home to avoid trips to hospital.

You have to plan each day so things go smoothly. You need to co-ordinate visits from care assistants, nurses, social care services and so on. All this planning and chasing people can’t help but put you under pressure and take the spontaneity out of life.

Losing the balance in your relationship can cause tensions
and put pressure on your relationship. So can the challenge of being with them for long periods. It can be difficult if you clash with them over things. It’s hard, too, when you lose the intimacy you both once had.

“MS is not going to beat us. We’re going to live a life as normal as MS allows it to be.”

Ted

“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 symptoms can affect your sex life, or mean it stops. Fatigue, muscle spasms or weakness, bladder problems or pain can all get 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. It can feel too awkward to bring sex up. Perhaps they’re no longer able to have sex.

But sex can be one of life’s pleasures. It doesn’t have to stop. The type of sex might change. Pain, bladder issues, muscle spasms or weakness, and fatigue can have an impact on the physical and emotional aspects of sex. It may need more negotiating and planning but you might still be able to be intimate.

Perhaps the person you care for isn’t able to have sex anymore. Some couples find that, instead of penetration, they get a lot of intimacy from kissing, cuddling, stroking and touching each other.

Closeness, affection, sensuality and excitement are other ways of being 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. Pages 170-171 have some suggestions.

**Tips:**

- contact the MS Helpline in confidence. It can be easier to talk with someone who understands MS and how it can affect someone sexually

Our booklet ‘Sex, intimacy and relationships’ looks at this issue in more details. Page 178 tells you how to get this. If you put ‘sex and relationships problems’ in the search box of our home page, you’ll find it there to download.
• ask for help on our online forum (see page 165) or just read what’s helped other people
• contact the Sex and Disability Helpline. It has qualified sex therapists with experience around disability (see page 171)
• mention sexual problems as part of a wider chat about bowel or bladder issues with, for example, an MS nurse
• download booklets for men and women about sex from the MS Trust at mstrust.org.uk/a-z/talking-about-sexual-problems
• the organisation Relate offers advice or counselling, face to face, by phone or through its website (see page 170)
• sexual and relationship counsellors often offer counselling using Skype (see pages 170-171). Ask your GP or an MS nurse what’s available on the NHS or privately

**Other ways MS can affect us**
Caring can bring you closer together. It can also take its toll. It can affect your money situation, your own health (mental health, too), your work and social life. You’ll find tips in this booklet. 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 moving around gets harder for them. You may both feel sadness, a kind of grief, because you can’t do some things together anymore. You can learn to deal with these feelings.

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, such as mood changes and depression. Sometimes MS causes behaviour that’s very hard to deal with.

Caring is more stressful if the person with MS can’t accept or adjust to being severely affected by it.

It’s tougher, too, if their attitude is uncooperative. For example, they might refuse to let other people take care of them. This can stop you having a break.
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.

One idea that’s helped a lot of people 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 and 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. It won’t boost your social life, self-esteem or bank account like a regular job does.

Instead, you can find yourself in a brand new role that you weren’t expecting. You might find yourself the sole breadwinner, or the manager of other people. You might have to take on all the responsibility for bringing up the kids.

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 might be happy to take all this on. 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, or to honour your marriage vows.

It could be because you feel they would’ve done the same for you if you had got ill instead. Maybe you do it out of a sense of duty.

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

You might be doing it for your family’s sake, 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 – especially if you’re their only child or 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 you care for a partner or parent, other people tend to expect this of you.

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.

Whatever your reasons, and 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 big relief. Read more about this in ‘Feelings I might struggle with’ (page 38).

“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 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
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, from time to time, a crisis or two. 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.

It can help to talk to people in online forums or carers support groups who’ve been through this and found solutions.

If you need to let off steam or vent your feelings, the MS Helpline is run by people trained in giving emotional support.

Tips:

- find carers groups near to you on the Carers UK and Carers Trust’s websites (see back of this guide)
- the council (or, in Northern Ireland, your trust) might give a small monthly grant to help with tasks like cleaning
- you might decide to pay for a cleaner yourself
- 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

Being there for someone when you’re holding down a paid job is a tricky balancing act. But going to work gives you a break from caring.

There’s help you can call on. In England, Scotland and Wales the law (Equality Act 2010) can protect you from an employer harassing you or discriminating against you because you’re a carer.*

There might be a time when you need to change your work patterns. By law you have the right to ask your employer for flexible working. But only if you’ve been in that job for six months and haven’t already formally asked for this in the previous year.

Flexible working could cover things like flexible hours, working from home, going part time or job sharing. Could you negotiate your hours so that you fit your usual hours into a shorter week?

Annualised hours, for example, means 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.

You also have a right to take off a reasonable amount of time to deal with an emergency or when something unexpected happens. This will be without pay unless your employer agrees to pay you.

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

You may have extra rights written into your contract, such as compassionate leave. Check this and your work’s HR policies to see if you can get more than the basics guaranteed by law.

Some workplaces have carer’s leave but this is rare at the moment until the day a government makes this the law.

* 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.
“My workplace have been excellent in supporting me. Most importantly with flexibility, to be able to deal with whatever MS throws at us next”

Mark

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.

Some employers have a carer’s policy that offers (paid or unpaid) carers leave or time off to go to appointments with someone.

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 will hopefully mean you get more support and understanding. But often it’s down to your manager to give you the flexibility you need to balance work and caring.

Support at work

Could you do with more help while you’re out at work?

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 p127.

An assessment for the person you support would look at their care and support needs. This could lead to them getting help to live more independently (see p121 for what kind of support). That way it’s 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’ (page 168) you’ll find places that list registered care services.
Should I cut my hours? Or 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 and brings you into contact with other people.

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.

Our booklet ‘Benefits and MS’ has more on Carer’s Allowance and Carer’s Credits.

Tips:

• read more about Carer’s Credit at gov.uk/carers-credit
• for useful advice put ‘Help with your pension’ in the search engine on the home page of the Carers UK website
• Carers UK also have info on their web page carersuk.org/help-and-advice/work-and-career/
and a booklet about asking for flexible working carersuk.org/help-and-advice/work-and-career/other-rights-at-work/your-right-to-flexible-working
get help with discrimination at work from the MS legal advice service at the Disability Law Service (England and Wales only: details on page 172)
encourage your workplace to put a carers policy in place
ask your manager to look at the ‘Employers for Carers’ network run by Carers UK

“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. 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. You’ll need help from other people so you can have rests from caring. Make sure you don’t miss 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 the 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 get 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
to think about leaving the person you care for. This can be especially true if MS is badly affecting their thinking and memory or causing changes to their personality.

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 neuro-psychiatrist so that the person with MS gets a neuro-psychiatric assessment and the treatment they need. Page 59 has more on these.

Feeling trapped often happens when:

- 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. If you can’t share how you’re feeling with the person

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.

Are you putting your own needs and plans on hold? Maybe even neglecting your own health? Being with the other person all the time can be really stressful. Reach out to others for help with this.

You might feel less guilty knowing that, when things get really tough, it’s not uncommon

Feelings I might struggle with

You’re not alone if you sometimes feel:

- guilt (for example, that you’re not doing enough or not doing it right)
- burn-out
- fear and anxiety (especially over money)
- loneliness
- depression
- a feeling of being trapped, angry, frustrated or resentful

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You might feel less guilty knowing that, when things get really tough, it’s not uncommon
you care for or a family member, then talk to an outsider.

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, like a counsellor?

You can always talk to someone at the MS Helpline. They’re qualified in giving emotional support.

**Is it time for help?**

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

It might help to know a common pattern with carers is at first they reject and resist support. Then they eventually look for it and, finally, welcome it.

Don’t wait until you reach a crisis point before you get to that last stage.

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 part of caring 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, and so on.

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 and take a test to see if you have it at nhs.uk/conditions/clinical-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 is telling 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
- dealing with stress with alcohol, smoking, prescription drugs or comfort eating does you no good in the long run
- many people take comfort from their faith. Places of worship can also offer practical support
many councils have Carers Support Teams or Carers Support Services. Check your local council’s website to see what’s available to help you

learn relaxation techniques like meditation, muscle relaxation, yoga, mindfulness, visualisation/guided imagery or good old-fashioned exercise

Our booklet ‘Complementary and alternative medicine’ covers these relaxation techniques.

“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

If you don’t do something about feelings of anger, frustration or resentment, you might end up taking it out on the person you care for.

Maybe you become rough when doing something for them. Or you lash out with your tongue.

Find an outlet before this escalates. If this goes unchecked, you might find the situation coming to the attention of the authorities, putting you under even more stress.

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 they’re treated by paid carers or medical staff.

Confide in someone on the MS Helpline on 0808 800 8000 or email them at helpline@mssociety.org.uk. You could get help from a counsellor – 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 a carer. You can get free flu jabs, quicker appointments and be seen at more convenient times.

You’ll be told about events for carers and pointed towards other services. Letters from your GP to hospitals will tell them you’re the carer.

When seeing your GP, don’t hide how you’re really feeling. So that you don’t forget, make a list of what you want to bring up (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, plus details of medical events as the MS has got worse

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 a hernia) will stop you being able to look after them for a long time. You could also badly hurt them if there’s an accident.

You can 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). But at least you’ve tried to be informed.

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

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

You can also arrange for paid carers to come to your home to 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 as the 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 in February 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 your abilities 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/

Download our factsheet ‘Posture and movement 1’ with its advice for carers on lifting. Put ‘posture and movement’ in the search box on our web site.

The NHS also has information: nhs.uk/Conditions/social-care-and-support-guide/Pages/mobility-problems-carers.aspx

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

Having regular breaks can help you hold things together, both mentally and physically.

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.

If you see the phrase ‘short break’, this 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 they need a lot of medical care or have a disability the respite centre won’t handle. Or the 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.

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

“Having 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 had that [bed sore and urine infection] and no form of 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 - or prepare more beforehand. 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.

A one-off break won’t be enough. Breaks need to be regular. 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 and you can do things to relax you.

The key is to make time. It might just mean staying up a bit later after the person you care for is
asleep so that you can watch a DVD, for example.

These mental breaks can involve reading, listening to music, yoga, meditation, walking the dog, gardening and other hobbies. Did you know that some GPs can prescribe you exercise, yoga or dance classes?

Our booklet ‘Complementary and alternative medicine’ has information about ways of de-stressing. These include mindfulness, yoga, massage and other relaxation techniques.

“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
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, then 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 (see page 127) that you need respite care on a regular basis - or whenever you need it.

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 might be able to help with the cost. For example, the MS Society may be able to help with paying for:

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

A local MS Society group or carers group may help with funding respite care. They’ll know about other charities that help with the cost of breaks, too. Find your nearest carers group here carers.org/search/network-partners

You can apply for a grant through your local MS Society group. Call 020 8438 0700 or email grants@mssociety.org.uk or visit mssociety.org.uk/grants

Our booklet ‘Short Breaks – a guide to holidays, short breaks and respite’ has details of how we might help you pay for a holiday.

It also lists accessible travel agencies and respite companies, together with other charities that might help with holiday costs.

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 it’s essential you find a way, to avoid overload and burn out.

More tips:

- find ideas for breaks and how to pay for them on our short
breaks page at mssociety.org.uk/care-and-support/everyday-living/breaks-and-holidays

- ‘Tourism for all’ is a charity dedicated to making tourism welcoming to all its members: tourismforall.org.uk
- The Respite Association offers help paying for care so you can have a break respiteassociation.org
- Revitalise is a charity providing short breaks at three centres in England (and sometimes funding) for carers and the people they care for revitalise.org.uk (search for ‘support fund’ for help with paying)
- wheelchairworld.org has travel resources and reviews of destinations in the UK and all over the world
- 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 at carers.org/article/days-out

“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

Someone with advanced MS might see a wide range of medical staff. 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.

Guidelines say this team should involve an MS specialist. And there should be one person in the team who coordinates all the care. You might find that, as the carer, it’s more likely you who takes on the 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 have 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 54 to 61 show who’s usually in it and other medical staff involved in the care of people severely affected by their MS. This helps you have a clearer picture of what sort of services might be 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 and the care team should be bigger.
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.

Unfortunately, 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. And 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 66–71, you can update this when staff change.

1 neurologist

A hospital-based doctor who specialises in nerve-related conditions. Some are specialists in MS, others treat a range of things, of which MS is one. 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.

2 MS nurses

They give advice about symptoms and treatment and can be the link between hospital and specialist services, including social care. They do home visits and answer questions by email or phone.

3 GP (‘general practitioner’)

Your family doctor looks after your general health. They may
have just one or two patients with MS, so 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 you on to specialist MS services.

4 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, and bowel and bladder issues. They give advice on symptoms, equipment and taking drugs (but they don’t usually prescribe them).

5 occupational therapist (OT)
They offer practical suggestions on how a person does everyday things, from eating, dressing or washing to work-related tasks and hobbies. They advise on equipment and alterations to the home or workplace that make life easier.

They also help with fatigue, balance and tremor and do assessments if you apply to have your home adapted. Ask a GP, nurse or other heath professional for a referral.  

6 physiotherapist
They use exercises and movements of the body so that someone can move around better, with 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.

7 pharmacist
He or she gives drugs (sometimes equipment) prescribed by your doctor or specialist and offers expert advice on them. They can discuss issues you or the person you care for are having with meds. NHS community pharmacists are based in hospitals, health centres or pharmacies but may visit patients at home or in
Meet the medical team

1. neurologist
2. neuro-rehabilitation team
3. GP
4. neuro-psychiatrist
5. occupational therapist
6. neuro-psychologist
7. pharmacist
8. spasticity specialist
9. GP
10. mental health nurse
11. dietitian
12. wheelchair services
13. wheelchair services
14. dietitian
15. wheelchair services
16. neuro-psychologist
17. neuro-psychiatrist
18. mental health nurse
Meet the medical team

1. neurologist
2. MS nurses
3. speech & language therapist
4. district/community nurse
5. physiotherapist
6. continence advisor
7. orthoptist
8. orthotics
9. palliative care
10. urologist
11. speech & language therapist
12. services
13. wheelchair services
14. with MS
15. orthopaedic
16. nurse
neuro-rehabilitation team
They help people get back their independence after a nerve-related injury such as a stroke or the effects of MS. They might do visits to homes or day centres and are usually based in a hospital or clinic.

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), and may include assessments by an OT and sessions with a physiotherapist. Self-referral may be possible or come via an MS nurse, neurologist or GP.

continence advisor
This is a bladder and bowel specialist nurse based in a hospital or clinic, with home visits possible. 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 and assesses people’s swallowing problems. 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.

neuro-rehabilitation team
They help people get back their independence after a nerve-related injury such as a stroke or the effects of MS. They might do visits to homes or day centres and are usually based in a hospital or clinic.
They offer physiotherapy, occupational therapy or speech and language therapy, and might include a dietitian, psychologist or social worker, too. A GP or MS specialist will make referrals to them.

13 **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.

14 **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.

15 **orthoptist**

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

16 **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 affecting the nerves (like MS), they’ll have ‘neuro’ before ‘psychologist’. Referral is through your GP or MS specialist.

17 **neuro-psychiatrist**

A medical doctor who treats more serious mental health problems and uses 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’ll have ‘neuro’ before ‘psychiatrist’. Referral is through your GP or MS specialist.

18 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.

19 orthotics
working in a hospital, they 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 is via a physio-therapist or MS specialist directly or be referred by an MS nurse or GP.

20 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 dying.
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.

others:

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, deal with emotional problems, including family relationships, depression and anxiety, and gets them through a difficult time. 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 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.

“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 and you don’t know what they mean, or if you disagree with their proposed actions.”

Paul

Contact details
On pages 66 to 71 you can make a note of the details of the medical staff who look after the person you care for. Either photocopy and use as a blank form you can fill in – or fill in with pencil so that 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
• 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.

Access to medical records
You can see the medical records of the person you care for if they let their surgery know this is OK by them (or if you have Lasting Power of Attorney – see page 155).

This is called their Online Patient Record or Personal Health Record (PHR). All GP surgeries now have these. It lets you book GP appointments and see test results and prescriptions.

Once you have access to these records you can get repeat prescriptions faster and cut out unnecessary trips to the surgery.

If you set up a repeat prescription service with a local pharmacy, you won’t need to see the GP.

Speak to your surgery about how to get this access. Read more about it at nhs.uk by putting in the search box ‘access someone else’s medical records’
‘Continuing healthcare’

In England, Wales or Northern Ireland, ‘continuing healthcare’ (CHC) is a package of free NHS care it’s possible to get 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 Health and Social Care Trust in Northern Ireland). It’s paid for by the Health Service (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 this 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. Page 82 has 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 the patient feels should be there. They go over the 12 needs on the checklist (plus another two). 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 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
In Scotland continuing health care was replaced in 2015 by 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 – 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.

Tips:
- download the assessment forms and fill them in before the assessment, using the scoring you’d give. Search gov.uk for ‘NHS continuing healthcare checklist’
- 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
- find out more about CHC, including how it’s paid for and how to appeal against a decision, from Beacon and Care to be Different and the websites listed on pages 169-170

Scotland
In Scotland continuing health care was replaced in 2015 by 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 – 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.

If you were getting CHC before June 2015, you’ll carry on getting it (if you still qualify for it).
Contact details 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:  

---

Advanced MS – a carers handbook
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

Name:
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**

Names: 
Based at: 
Phone number: Email: 

**Other**

Name: 
Based at: 
Phone number: Email: 

**Other**

Name: 
Based at: 
Phone number: Email: 

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Other

Name:
Based at:
Phone number:  Email:

Notes:
Managing three common symptoms

The person you care for has their own symptoms individual to them. But three are very common and often don’t go away: bladder and bowel problems, and pressure ulcers.

**Bladder**

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

MS can also stop their bladder emptying properly.

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

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

UTIs are very common in 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 pass urine
- 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 urine is dark, cloudy or has blood in it
- 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.

Check out our webpage on managing bladder issues at mssociety.org.uk/about-ms/signs-and-symptoms/bladder/managing-bladder-problems

You’ll find there our booklet ‘Managing bladder problems’. It also covers different types of catheters and Botox as a treatment for an overactive bladder.

**Tips:**

- lower someone’s risk of an infection by getting them to drink more (1.5 to 2 litres each day)
- avoid caffeine as it can irritate the bladder
- be sure to keep the catheter clean
- replace bags regularly (the leg bag each week, the night bag each day)
- keep your stocks of bags up so that you don’t run out
- drinking more helps stop a catheter getting blocked

“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
**Bowel**

Advanced MS often causes constipation. This can mean:

- not being able to have a bowel movement (to ‘poo’)
- having to strain a lot
- bloating
- if someone can go, their stools (‘poo’) 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, certain actions can help with a bowel movement. 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 bowel movements, what they look like, if there’s blood in them, and so on.

Download from the internet the ‘Bristol stools chart’. This helps you describe what you see in a way medical staff will understand. It’ll 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 stools 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, and meds for the bladder, heartburn, seizures or muscle spasms.

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

Fibre helps keep people regular, so their diet should have 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.

Being as active as possible stops the bowel getting sluggish. We have videos with exercises for people in wheelchairs here mssociety.org.uk/msactivetogether
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.

The time to start thinking about these sores is before they start. This is 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

Tips:

• caffeine, spicy food, chocolate, alcohol, milk products and high fibre can make stools 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
• organisations that can help with bladder and bowel problems are listed at the back of this booklet
• call 111 if you need medical advice from the NHS out of hours (see page 167 for more details)
• visit our webpage at mssociety.org.uk/about-ms/signs-and-symptoms/bowel/causes-of-bowel-problems
• you’ll find there our booklet ‘Managing bowel problems’
• call or email the MS Helpline for our ‘I need some help’ card. for people to carry. The person you care for carries it, and it explains they have a medical condition and urgently need to use the toilet.
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 washing them
- moisturiser stops skin drying out
- make sure they bathe when they need to
- when 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/conditions/pressure-sores/](https://nhs.uk/conditions/pressure-sores/)

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

**Other symptoms**

We have 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 problems

Check the list of our booklets and factsheets. It tells you how to order, or call the MS helpline for copies.

Find the list by putting ‘information resources list’ in the search engine on our website.
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’)? And when they come home (is ‘discharged’)?

Sudden, unexpected trips to hospital can be upsetting. They can also lead to infections which might cause lasting disability. These infections might be avoided if action is taken sooner.

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 72 to 78.

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 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 (you both 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 at mssociety.org.uk/msactivetoegether

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 to excess 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 142.

“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 relevant information on it. Staff say how useful they find this.”

**Nigel**

Getting ready for hospital

No-one knows the person you care for as well as you. 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 86 to 89. Fill it in using pencil so that you can change details. Or create your own version on a computer.

Use pages 90 to 92 to let paid carers know what they should know when they come to care for the person with MS in their home.
**Tips:**

- back up the form on pages 86-89 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

**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 coordinator’. 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 the section on Continuing Healthcare on page 63.

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. So 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 health service 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, this service is free.

Tips:
- read more about leaving hospital by searching ‘discharge from hospital’ 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:

<table>
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<tr>
<th>Evening:</th>
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Weekly routine:

<table>
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<td>Things the patient likes to eat:</td>
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<td>Details of personal items (such as false teeth, glasses, hearing aids):</td>
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Equipment and technology

A huge range of equipment 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 and 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 page 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 buying equipment, check to see if you can get it from the Health Service (NHS) or local council (or, in Northern Ireland, 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, prosthetics and orthotics services, and 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 Health Service 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 121 for more on social care assessments.
If the person you care for gets **direct payments** or a **personal budget** (see page 147) 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 might qualify for help getting equipment or technology if it makes your caring easier. Page 127 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, including the MS Society, and benevolent societies might help you get or pay for equipment. Check out page 143 for 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 173).

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

Disabled Living Foundation and Living Made Easy

The Disabled Living Foundation (DLF) has over 20 factsheets to help you choose equipment. The full list is here:

dlf.org.uk/content/full-list-factsheets

They have centres where you can see things demonstrated. Find where they are at livingmadeeasy.org.uk/contacts_edc.php

Their specialist website Living Made Easy covers in depth equipment and technology. This includes things to help with the home, communicating, walking and mobility, and personal care, as well as alarm systems.

livingmadeeasy.org.uk/

The Research Institute for Disabled People (previously RICA) have reviews of lots of equipment on their website, too.

ridc.org.uk/
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, themobilitymarket.co.uk and disabledgear.com
- independentliving.co.uk is a website featuring things that support daily living, mobility and independence
- across the UK are Equipment Demonstration Centres where people try disability equipment and get professional advice before they buy. Find them at livingmadeeasy.org.uk/contacts_edc.php
- 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
- other organisations that help disabled people with technology are Abilitynet, Everyone Can and Disabled Living. Details are on page 169.
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/financial-help-disabled/vat-relief](http://gov.uk/financial-help-disabled/vat-relief)

For a full list of equipment exempt from VAT go to [gov.uk](http://gov.uk) and put ‘VAT relief disabled’ in the search box and look for the help sheets.

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 [asksara.dlf.org.uk](http://asksara.dlf.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 these: dlf.org.uk/factsheets/stairs
**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 also 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 factsheets to help you choose which equipment for bathing and showering is right for you and the person you care for:

dlf.org.uk/factsheets/showering
dlf.org.uk/factsheets/bathing

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 pages 110 (Disabled Facilities Grant).

**Using the toilet**

Before choosing equipment get advice from a continence service, your GP, occupational therapist or MS nurse. They’ll 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

“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
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 about equipment, with tips for using the toilet [dlf.org.uk/factsheets/toileting](http://dlf.org.uk/factsheets/toileting)

**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 at [livingmadeeasy.org.uk](http://livingmadeeasy.org.uk) (go to ‘House and home’ section on the front page, then click on ‘Kitchen and household’)

**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
For seats and wheelchairs
You might need:
• pressure relieving cushions
• riser/recliner chair and chair raisers
• portable wheelchair ramp
• head and side supports

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.

Our booklet ‘Adaptations and your home’ has ideas for equipment and advice room by room and in the garden. Find it at mssociety.org.uk/care-and-support/everyday-living/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 next page) 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 Health and Social Care 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 121).

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 private or from the council, 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 check out [nhs.uk/Conditions/social-care-and-support-guide/Pages/telecare-alarms.aspx](nhs.uk/Conditions/social-care-and-support-guide/Pages/telecare-alarms.aspx)

The Disabled Living Foundation also has a factsheet on this: [dlf.org.uk/factsheets/factsheet_telecare.pdf](dlf.org.uk/factsheets/factsheet_telecare.pdf)

Carers UK have a booklet called ‘What can tech do for you?’ It covers technology, including telecare, alarm systems and telehealth. Download it here [carersuk.org/help-and-advice/technology-and-equipment/tech-for-you](carersuk.org/help-and-advice/technology-and-equipment/tech-for-you)
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 Home 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, and the TV, 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 work (see page 173).

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 for more details. 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: abilitynet.org.uk/factsheets/controlling-computer-tablet-or-smartphone-your-voice

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 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 on the cards 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 121). Or you might get help from charities, such as an MS Society health and wellbeing grant.

You don’t have to own your own home to get adaptations made. If you rent from a private landlord, they must by law make ‘reasonable adjustments’. They can get financial help to do this (see ‘Disabled Facilities Grant’ on the next page).

“I’ve had to have a hoist put up in the lounge … a hoist put up in the bedroom … a shower room built.”

Lana
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

“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

• moving a bathroom or toilet downstairs
• extensions or conversions to the building (such as turning a garage into a bedroom or bathroom)

**Paying for adaptations**

Pages 95 to 97 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 has a separate system. Find information on the Scottish Government website. Go to **gov.scot** and put ‘equipment and adaptations’ in the search box. There you’ll find more on equipment and adaptations including funding guides for home owners, council tenants and private renters.
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.

Northern Ireland
Here help with adaptations is arranged between the local Housing Executive and Health and Social Care Trust.

nidirect.gov.uk/articles/disabled-facilities-grants-0

Disabled Facilities Grants
These are available in England, Wales and Northern Ireland (Scotland has its own scheme – see previous page).

They may be given by councils 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 Disabled Facilities Grant is usually means-tested. By law you should get a decision on an application within six months and, if 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. Get legal advice if you still don’t get a decision, or if you’ve been stopped from applying for the grant. Go to the Local Government and Social Care Ombudsman.

Scotland
The Scottish Government has information on help with adaptations for all types of housing. Go to gov.scot and put ‘funding adaptations’ in the search box

We have a booklet ‘Adaptations and your home’ that has more information about these grants.
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 read more about these grants at nidirect.gov.uk/articles/disabled-facilities-grants-0

• as of July 2018 the highest a DFG grant can be is £30,000 in England, £25,000 in Northern Ireland and £36,000 in Wales

• Disability Rights UK have a factsheet about grants available to pay for adaptations disabilityrightsuk.org/housing-grants

• they also have a factsheet on complaining if you’re turned down for a DFG disabilityrightsuk.org/complaining-about-local-authority-decisions

• this web site has more info about adaptations, including DFGs: foundations.uk.com

What if we don’t qualify for a DFG?

You could think about taking out a loan, selling your home to buy something smaller or look into ‘equity release’.

This means borrowing money against the value of your house, or selling it (or part of it) for a lump sum or regular income but without having to leave it.

Get independent financial advice before doing this. Read more at moneyadviseservice.org.uk/en/articles/equity-release

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 find them here (England only) findmyhia.org.uk
• in Scotland there’s [careandrepairscotland.co.uk](http://careandrepairscotland.co.uk)
• if you live in Wales check out [careandrepair.org.uk/en/](http://careandrepair.org.uk/en/)
• Northern Ireland has [nihe.gov.uk/index/advice/disability/agencies.htm](http://nihe.gov.uk/index/advice/disability/agencies.htm)
• 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

Our booklet ‘Adaptations and your home’ looks at alterations room by room, how to fund these, 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 121 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
Wheelchairs are provided on 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.

Who can have a wheelchair is different from area to area. No matter where the person lives, they’ll need to be referred to the service.

This is usually done by a GP, an occupational therapist (OT), or their hospital doctor. They’ll then have an assessment, usually by an OT.

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. You can only get a powered chair if you can’t use a manual one. The wheelchair must be for use indoors and outdoors. Ones made only for outdoors aren’t provided.

The person you care for might get an NHS voucher. It covers the cost of a standard wheelchair from the NHS range of chairs that’s been judged as meeting their needs. It might not be possible to use the voucher to get a powered wheelchair.

If the person wants a higher standard one from a slightly wider NHS range of chairs, they can get that using the voucher. They then make up the difference with their own money. This is called the ‘partnership’ option. Repairs are free.

The ‘independent option’ is to own the wheelchair, using the voucher to pay towards it, with the owner making up the difference. The owner is responsible for repairs, although the voucher covers some of that.

To give people more choice, vouchers are slowly being replaced by a personal budget scheme. They can use their budget to pick a wheelchair from the NHS range or add their own money to buy something different.

Most people wait over three months for a wheelchair. The rest wait even longer. Remember adaptations or replacement chairs can also take a long time to get.

Some people buy a wheelchair if they don’t qualify to get the type of chair they want on the NHS (or they want a special one not available on the NHS). Examples are ultra-lightweight wheelchairs or powered ones.

For people who are very severely affected by their MS, there are electric wheelchairs that don’t need a joystick control.

These wheelchairs have a touch pad instead. Or they’re controlled by breathing (called ‘sip’n’puff’) or by movement of head, voice or their tongue.

When choosing something like a wheelchair, also get input from an occupational therapist, the family and the carer.
A wheelchair needs to be tailored to the individual and situations where it’ll be used. They need to take account of how the MS is likely to develop in the future.

A wheelchair must provide proper support and pressure relief. It may need carer controls or be a ‘tilt-in-space’ chair so the person using it can change position if they can’t move their body weight.

**Scotland**

The wheelchair voucher scheme doesn’t operate in Scotland. 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.
Insurance

Wheelchairs from the NHS voucher scheme are insured against damage but not if its owner chooses the ‘independent option’. Then they must insure it.

To protect against it being stolen or damaged in a fire, the chair can be added to your household insurance. Or it can be insured separately through a range of companies. The MS Helpline has details.

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 your 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. You must register it 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 ‘choosing mobility equipment’ in the search box.

RiDC (Research Institute for Disabled Consumers, before 2018 known as Rica) is a charity that gives advice and reports on things like:

- making a car wheelchair accessible
- wheelchair accessories
- getting wheelchairs in and out of cars
- powered wheelchairs, scooters and buggies
- using wheelchairs on public transport and when flying

Tips:

- ridc.org.uk has lots of useful info on mobility, travel and technology for use in the home
- read more about rules for scooters and wheelchairs, including tax and insurance, at gov.uk/mobility-scooters-and-powered-wheelchairs-rules
- this site themobilitymarket.co.uk is for people buying or
serving used mobility and disability products

- the Disabled Living Foundation has factsheets to help you choose which mobility aid is right for you. These cover wheelchairs:
  dlf.org.uk/factsheets/manual-wheelchairs
  dlf.org.uk/factsheets/powered-wheelchairs

**Other walking aids**

For information on crutches, walking sticks, and wheeled walking frames (rollators), check out the RIDC webpage ridc.org.uk/content/walking-aids

On that link you can download their guide to wheeled walking aids. The Disabled Living Foundation has a factsheet on choosing walking aids at:

dlf.org.uk/factsheets/walking
Public transport

Using public transport is getting easier but include extra time for travel.

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

The RIDC website has lots of advice if you need to use public transport, broken down by how you’re travelling.

ridc.org.uk/content/accessible-public-transport

Buses

RIDC have tips on bus travel with someone in a wheelchair at ridc.org.uk/content/buses

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/apply-for-disabled-bus-pass

In 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/disabled-bus-pass](mygov.scot/disabled-bus-pass)

Get half fare bus and train travel in Northern Ireland with a Smartpass. Learn more at: [nidirect.gov.uk/articles/free-and-concessionary-bus-and-rail-travel](nidirect.gov.uk/articles/free-and-concessionary-bus-and-rail-travel)

**Trains**

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 ticket when they travel with them. Call [0345 605 0525](tel:03456050525) or visit [disabledpersons-railcard.co.uk](disabledpersons-railcard.co.uk)

Find helpful tips on train travel with someone using a wheelchair at [ridc.org.uk/content/trains](ridc.org.uk/content/trains)

**Motability**

This charity works with people with disabilities to use the parts of their benefits that help with getting about.

If the person you care for needs an outdoor electric wheelchair, scooter or a car, they can use the Motability scheme to pay for it if they get:

- the higher rate mobility component of Disability Living Allowance (DLA)
- the enhanced rate mobility component of Personal Independence Payment (PIP)
- or War Pensioner’s Mobility Supplement

They can hire a car (including specially adapted ones), powered wheelchair or mobility scooter. The PIP or DLA mobility component will be paid directly to Motability.

Contact Motability for details on [0300 456 4566](tel:03004564566) or visit [motability.co.uk](motability.co.uk)
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. They 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 to have an assessment to see what services they need.

To arrange one, contact the social services department of their local council. Someone will be sent 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. To decide whether they pay, and, if they do, how much, the council will look at their finances.

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

This amount in July 2018 was £23,250 in England, £24,000 in Wales and £26,500 in Scotland.
If someone has assets under these amounts they may have to pay some, but not all, of the costs.

When social care services make things easier for the person you care for, they make your life easier, too.

He or she might go to a day centre, or have a short break or some respite care. This gives you a much needed break (see ‘I need a break’ for more on page 47).

The person you care for might also qualify for a sitting service or for someone to come and provide care in their home. That means someone can do jobs that you were doing on your own.

Help for carers is part of social care, too. Read more on what help you might get on page 127 (‘Carer’s assessment’)

Whether you get what you need also depends on what part of the country you live in and how your local council (Health and Social Care Trust in Northern Ireland) manage their finances.

Personal care in Scotland

Personal care is free in Scotland to people 65 and over no matter how many assets they have. But first their local council will assess them and decide if they need it.

The Scottish Government has said that from April 2019 personal care will be free for people under 65 too. Page 177 explains what personal care covers. People of any age can get free nursing care if they’ve been assessed as needing it.
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 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’ll probably be surprised to find how medical and health care professionals don’t work together like you’d expect.

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.

We have booklets about social care, one for each of the four countries of the UK.

They have tips for someone with MS on preparing for an assessment. Find them on our website by searching ‘social care booklet’ or get one from the MS Helpline.

**Tips:**

- to save time, the person you care for can have their assessment at the same time you have your carer’s assessment
- you can have your assessments separately 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

**Our 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 80 for more on this).

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

**Tips for self-funders**

Do you or the person you care for may have more assets than the limits allow and need to pay for care yourselves (‘self-fund’)? Or the council decides you don’t need help. What then?

You have the right to appeal against a decision not to give you help. You’ll find more about challenging a decision on page 130.

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 176)
- seeing if you qualify for NHS Continuing Healthcare (see page 63) 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 these two websites:

nhs.uk/Conditions/social-care-and-support-guide/Pages/funding-your-own-care-self-funder.aspx

and

moneyadviceservice.org.uk/en/articles/self-funding-your-long-term-care-your-options
My carer’s assessment

The law says carers now 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 the council’s contact centre.

Having an assessment could help you out. If it decides you qualify for help, then a support plan is made for you. It looks at ways of helping you with a range of social care services (social care is explained on page 121).

Your assessment could help you get things such as:

- 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.

The assessment could give you 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 charge). If the person you care for gets services, their money situation will be looked at as part of their assessment.

Northern Ireland

If you live in Northern Ireland, your local Health and Social Care Trust arranges carer’s assessments. Where 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. Or 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?
In 2016 Carers UK found that half of carers waiting for an assessment got one within six months. But almost one in three waited longer than that.

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. Some people have found them very useful, others haven’t.
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 those carers got.

“*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

**Tips:**
- before your carer’s assessment make sure you’re prepared. Inside this handbook you should find an insert (‘Carer’s assessment checklist’) that helps you to be ready
- Carers UK has more information on carer’s assessments at [carersuk.org](http://carersuk.org) (click on ‘practical support’ in the Help and Advice section)
- if you’ve had an assessment, it should be reviewed regularly because what the person you care for needs, can change

“My hubby was my sole carer for 11 years, before we got help in. He was dead against the idea of having in 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

* ‘Prepared to Care?’ by Carers Week, 2013
I want to complain or appeal

You can complain about a medical service from the Health Service (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 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 (get details from the MS Helpline). Or use an advocate

• Disability Rights UK has a factsheet about appealing against decisions about social care here disabilityrightsuk.org/complaining-about-local-authority-decisions

• the MS legal officer at the Disability Law Service helps people in England and Wales with welfare benefit appeals and legal issues with services and community care (see page 172)
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 making a complaint healthwatch.co.uk/help-making-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 page 168)
• your local councillor or Member of Parliament (or member of the devolved parliaments and assemblies) might take up your complaint, too

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 167-168.
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](http://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](http://nhs.uk) (put ‘make a complaint’ in the search box on the front page)

**Tips for England and Wales:**

- how to use the PALS system is explained at [nhs.uk/NHSEngland/complaints-and-feedback/Pages/nhs-complaints.aspx](http://nhs.uk/NHSEngland/complaints-and-feedback/Pages/nhs-complaints.aspx)
- if you’re not happy with the response from PALS and you live in England, POHWER gives
free advice (details on page 167) or gives you an advocate

- Healthwatch can also find someone to advise you about making a complaint at healthwatch.co.uk/help-making-complaint

**Tips for Scotland:**

- 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 168)

**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:**

- you normally 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 page 167 and 168)
- unhappy with how your complaint has been handled locally? Contact your ombudsman (see pages 167-168)

**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 previous page). You’ll find some useful information here, too: which.co.uk/consumer-rights/advice/how-to-complain-if-youre-unhappy-with-your-gp-or-gp-surgery

If you’re not happy with the response, try the ombudsman. Their details are on pages 167 to 168.

You might be able to register with another GP locally. For details on how, visit nhs.uk and put in the search box on the home page ‘how do I change my GP?’

“I want a second opinion

If you’re not happy with answers or treatment the person you care for gets in hospital or from a GP, you have a right to a second opinion. For details go to nhs.uk and put ‘second opinion’ in the search box.

If you’re having problems getting MS drugs check out the ‘I’ve been denied an NHS treatment’ sections of this web page at mssociety.org.uk/about-ms/treatments-and-therapies/getting-treatment-for-ms

“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
Money and benefits

MS hits finances hard, with extra costs to deal with and maybe lost incomes.

The person with MS might have to stop working. If you need to give up work to help care for them, that’s two incomes lost. You can find yourself raiding your savings or getting into debt.

Disabilities mean additional expense, such as extra costs of getting around, special equipment, changes to the home, insurance costs, extra heating and so on.

Lots of 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 is.

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

Benefits are changing. So it pays to check now and again if there have been changes to what 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](http://turn2us.org.uk) [entitledto.co.uk](http://entitledto.co.uk)

Our booklet ‘Benefits and MS’ goes into detail about benefits and tax credits that people with MS and their carers can claim. It covers disability benefits, work-related benefits, pensions, loans, and help with fuel and transport costs.

In **Scotland** certain benefits, including ones for carers, are going to be run differently to other parts of the UK. This will start to happen from mid-2018.
A Blue Badge will help with parking if you drive someone with MS around.

You might also get reduced bus and train fares when you travel with them. Your council or local transport operators have details.

**Tips:**

- Disability Rights UK have a web page that lists all the benefits carers can claim [disabilityrightsuk.org/benefits-checklist](http://disabilityrightsuk.org/benefits-checklist)
- if you need help filling in benefit claims or having assessments, people at a local Citizens Advice, carers group or MS Society group can help
- the MS Helpline, Citizens Advice, charities, professional benevolent funds and online organisations can all help you through the benefits system.

You might find the following benefits especially useful to know about.

**Carer’s Allowance**

Carer’s Allowance is a benefit you might get if you look after someone for at least 35 hours a week

**Who’s it for?**

To get it, you must:

- be at least 16 (there’s no upper age limit)
- spend at least 35 hours a week caring for a person who gets one of the following: Attendance Allowance, the daily living component of Personal Independence Payment or the middle or highest rate of the care component of Disability Living Allowance
- earn no more than £120 a week from employment (correct in July 2018). This is taken into account after taking away the tax you pay, National Insurance contributions, half of any payment you make towards a pension and certain care costs
- not be in full-time education (that’s 21 hours or more a week)

*You don’t need to be living with the person you care for.*
What can I get?
The Carer’s Allowance is a set amount, you pay tax on it and, depending on your circumstances, it may be affected by the benefit cap. From November 2016 Carer’s Allowance became a benefit that exempts you from the cap.

If you’re claiming Carer’s Allowance, you may be able to get this topped up with Income Support (see page 139) or 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?
To claim Carer’s Allowance, you need to fill out a claim form. To get one:

- call the Carer’s Allowance Unit (0345 608 4321); textphone 0345 604 5312
- in Northern Ireland call 0800 220 674; textphone 028 9031 1092
- download a form from gov.uk/government/publications/carers-allowance-claim-form, or claim online at gov.uk/apply-carers-allowance

Tips:
- read all about Carer’s Allowance in our ‘Benefits and MS’ booklet. Get one by calling the MS Helpline or find it under ‘further information’ at mssociety.org.uk/care-and-support/financial-help/brief-guide-to-benefits
- Carers UK have an advice line that tells you which benefits you can claim 0808 808 7777 (Mon–Wed)
- information on Carer’s Allowance (and other benefits) when you’re of pension age can be found at carersuk.org/help-and-advice/financial-support/help-with-benefits/other-pension-age-benefits
Other benefits
Before you claim Carer’s Allowance, check to see if the person you care for gets a severe disability premium.

This is extra money paid with benefits such as Income Support, income-related Employment and Support Allowance (ESA) or Housing Benefit. If they do get this premium, they may lose this extra money if you’re given Carer’s Allowance.

If you’re claiming Carer’s Allowance, you may be able to get this topped up with Income Support or Pension Credit.

‘Overlapping benefits’ rule
There’s no upper age limit for claiming Carer’s Allowance, but you can’t get the full amount of both Carer’s Allowance and your State Pension at the same time.

You also can’t get Carer’s Allowance at the same time as you get contributory Employment and Support Allowance. If you’re entitled to more than one of these ‘overlapping benefits’, you’ll be paid the higher one.

Even when you can’t get Carer’s Allowance, if you have what’s called an ‘underlying entitlement’ to it, you might be able to get extra payments in other benefits (like the extra money in Pension Credit).

So it’s worth applying for Carer’s Allowance, even if you can’t actually be paid it.

Income support
You may be able to claim Income Support if you care for someone and don’t get enough to live on. It can top up Carer’s Allowance. Income Support is means-tested.

Income Support is one of the benefits that’s being replaced by Universal Credit. The benefit cap applies to Income Support.

• to claim Income Support, call the Jobcentre Plus claim line on 0800 055 6688 or textphone 0800 023 4888.
• download a claim form at [gov.uk/government/publications/income-support-claim-form](gov.uk/government/publications/income-support-claim-form)

**Pensions**
Thinking of working fewer hours or giving up your job to care for someone? This could affect your pension. Read more on page 34.

**Other sources of money**

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

They must be paid back within two years. You or the person with MS you support may be able to get one if you’ve been claiming for at least 26 weeks any of these:

- Income-related Employment and Support Allowance
- Income Support
- Income-based Jobseeker’s Allowance
- Pension Credit
You can borrow from £100 to £348 if you’re single, £464 if you have a partner and £812 if you or your partner claim Child Benefit (limits as of July 2018).

How much you can borrow depends on your circumstances, such as whether you have savings or a family. If you claim Universal Credit, you may be eligible to apply for a similar ‘Budgeting Advance’ instead.

**Tips:**

- find more on these loans in our ‘Benefits and MS’ booklet
- if you’re a member of a credit union and have saved a bit over a period of time, you can often get very low interest small loans
- the website [disability-grants.org](http://disability-grants.org) can identify grants available for people with MS and their carers (for things like equipment, holidays, housing and bills)
- apply for a loan by filling in the claim form from your local Job Centre Plus office or download it from [gov.uk/budgeting-help-benefits/how-to-claim](http://gov.uk/budgeting-help-benefits/how-to-claim)
- in Northern Ireland some details about budgeting loans are different. Find out more at [nidirect.gov.uk/articles/budgeting-loans](http://nidirect.gov.uk/articles/budgeting-loans)

**Grants**

**Help from the MS Society and other places**

The MS Society has two grant funds for people with MS and their carers:

- our health and wellbeing grant
- our carer’s grant

Health and wellbeing grants can help towards equipment, adaptations to the home, respite breaks and other things that improve the health and wellbeing of someone with MS.

Carer’s grants offer support for carers with leisure activities or personal development.

You don’t have to be a member of the MS Society to apply.
Benefits and hospital stays

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

Personal independence payment (PIP), Attendance Allowance and Disability Living Allowance (DLA) stop after a total of four weeks (either in one stay, or several stays, where the gaps between stays are no more than four weeks each time).

With the person with MS too ill, it’s usually the carer who tells the DWP 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

Your local MS Society group may give grants from their own funds.

If there’s a group in your area, we’ll send your application on to them to consider first, or you can contact them directly. If they can’t help, or can’t cover the whole cost, they’ll ask our grants team to consider a top up.

Tips:

- find details of these grants, what they can and can’t be used for, plus the form you fill in, at mssociety.org.uk/grants
- or contact the Supporter Care team on 0300 500 8084 or email grants@mssociety.org.uk
Other grants and trusts

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 local council about what help you might get from them.

In Wales search for ‘Discretionary Assistance’ on gov.wales.

In Northern Ireland check out nidirect.gov.uk/articles/finance-support.

In Scotland the Scottish Welfare Fund gives vulnerable people on low incomes emergency and crisis grants. Apply through your local council. More details are at beta.gov.scot (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.

Tips:

• your local MS Society group or Citizens Advice might know of trusts or benevolent societies that help people with MS or their carers.

• Carers Trust also gives grants. Enter ‘grants available’ in the search box on their website carers.org.

• Carers Trust has a factsheet with details of around 40 other trusts, benevolent funds and charities that give out grants carers.org/sites/default/files/media/grants_and_other_sources_of_funding.pdf.

• the Turn2Us site has a grants checker on this link turn2us.org.uk/Your-Situation/Carers.

• this site could help you find money if you’re suffering hardship grantsforindividuals.org.uk.
• Disability Rights UK have details of benefits and grants and other help you might be able to claim at [disabilityrightsuk.org/benefits-checklist](disabilityrightsuk.org/benefits-checklist)

**Disabled Facilities Grants**
These are available to help with the cost of making changes to the home. Read more about them on page 110.

**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 four items in three months or 14 items in 12 months? Then they may save money if they buy a prescription pre-payment certificate (PPC).

They can also get free prescriptions if they can’t leave home without help. You’ll need a FP92A form from your doctor, hospital or pharmacist. You or they might also qualify for free prescriptions if 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 ‘prescription costs’ at [nhs.uk](nhs.uk)
• the Pharmacy 2 U service delivers repeat prescriptions to your door for free
• this will save you endless trips and chasing prescriptions

**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 paying a bill or help towards making the home use less energy.

There are trusts that help people pay gas, electricity and water bills. Contact your local Citizens Advice or the company who sends the bills.

The Warm Homes Discount Scheme could cut £140 off the electricity bill if you or the person with MS gets Pension Credit or are...
on a low income. Details of who qualifies and how to claim are at [gov.uk/the-warm-home-discount-scheme/what-youll-get](https://gov.uk/the-warm-home-discount-scheme/what-youll-get)

For people born before 5 August 1953 the Winter Fuel Payment might give from £100 to £300 to help pay heating bills. This is paid automatically once a year to people getting the State pension.

But if you or the person you care for aren’t getting it this way, you can claim it separately. More details at [gov.uk/winter-fuel-payment](https://gov.uk/winter-fuel-payment)

The Cold Weather Payment is paid to people on certain welfare benefits. If the temperature drops – or is forecast to drop – below zero degrees Celsius (freezing) for seven days in a row, then £25 is paid automatically along with any benefits.

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/cold-weather-payment](https://www.gov.uk/cold-weather-payment)

**Tips:**

- find help with fuel bills and using less energy across the UK at [gov.uk/energy-grants-calculator](https://www.gov.uk/energy-grants-calculator) and [energysavingtrust.org.uk](http://energysavingtrust.org.uk)
- for help cutting heating bills in Scotland, call 0808 808 2282 or visit [energysavingtrust.org.uk/scotland/grants-loans](http://energysavingtrust.org.uk/scotland/grants-loans)
- in Wales the Warm Nest scheme offers similar help. Call 0808 808 2244 or visit [nestwales.org.uk](http://nestwales.org.uk)
- in Northern Ireland the Affordable Warmth scheme offers grants to make homes use less energy. Call 0300 200 7874 or visit [ nidirect.gov.uk/articles/affordable-warmth-grant-scheme](http://nidirect.gov.uk/articles/affordable-warmth-grant-scheme)
- most water companies also offer help with their bills. Find details by searching for ‘help with water bills’ at [citizensadvice.org.uk](http://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 must get either the highest rate of the care component of Disability Living Allowance or the higher rate of Attendance Allowance or Constant Attendance Allowance

You don’t have to be getting Carer’s Allowance to claim a discount.

If you normally live somewhere else
Do you usually live elsewhere but need to move in with the person you care for? Then you can be made exempt from paying 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 a factsheet about council tax in England, Wales and Scotland. carersuk.org/help-and-advice/get-resources/our-factsheets
• for more on discounts in Northern Ireland contact Carers Northern Ireland Advice Line – 028 9043 9843. Or email advice@carersuk.org or search for ‘rate relief’ on the Carers UK site.

Personal budgets and direct payments
If the person you care for had a social care assessment (see page 121), 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 social care services that their assessment said they need. In Northern Ireland it’s the local Health and Social Care Trust that does this, but we’ll refer to councils in this section.

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.
Then the council will 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 decide to take on the responsibility of managing direct payments for them, 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.

**Tips:**

- read more about personal budgets and direct payments in our booklets about social care. There are separate ones for the four nations of the UK
- keep careful records and files so that the reporting doesn’t become an overwhelming job (including tax returns as the ‘employer’)

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Advanced MS - a carers handbook
Thinking ahead

With advanced MS you might prefer not to think too much about the future. But it can store up problems for later if you just ‘take each day as it comes’.

Planning for emergencies
What if you’re suddenly taken ill or an emergency means you can’t look after the person you 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 with a phone number for you or others to call in an emergency.

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 carersuk.org/search/planning-for-emergencies

The tipping point
This is when you reach the point where the needs of the person you care for are more than you can cope with. This can be emotionally, physically or financially.

Maybe you’ll get to this point while the person with MS is still at home or after they’ve gone into a care home. But it doesn’t mean you have to completely give up being their carer.

You might get support that helps you delay reaching this stage or helps you avoid it ever happening.

For example, Continuing Health Care might be an option (see page 63). 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 pages 121 and 127. 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 37 suggests ways of getting support that might boost how you’re feeling and protect your health. This could delay the tipping point.

This tipping point can be something you’re afraid of or feel guilty about. This period can be especially tough if MS is causing mental health problems in the person you care for.

“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 residential care home**

This may be a short-lived solution or it could be permanent. If it’s for keeps, then your role as a carer doing practical things for them will be largely over. But you might still want to help with things like feeding at meal times. Ask the staff how you might stay involved in their care.

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 and Northern Ireland they’ll have to pay for all the cost of the care home if the value of what they have is over £23,250. In Wales the amount is over £40,000 and in Scotland it’s over £26,500 (figures correct as of July 2018).

If the value is less than this, they’ll get 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 up to pay care home costs, they can arrange with their council to delay paying for their care (‘deferred payment’).

The council can pay their costs and 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 (which could be you)
- a relative under 16 or over 60
- a relative who’s disabled

**Tips:**

- get advice from an independent financial adviser before making any decisions
- put ‘residential care’ in the search box on our website’s home page to find more on finding a home and paying for it
- check out our booklet ‘Residential care and your options’. Find it on the web pages above

**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 about the care home.
In Scotland
No matter how many assets a person has, their council can pay towards their personal care if:

- they’re 65 or over
- they’ve been assessed as having personal or nursing care needs which need to be met in a care home
- they’re funding their own care

People of all ages can receive payments for nursing care if they have been assessed as needing this.

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 here: careinfoscotland.scot

The Scottish Government has said that from April 2019 personal care will be free for people under 65 too.
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 and 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.

Legal matters

Making wills can be a difficult thing to bring up. Another hard thing to raise is: what do you do when the person you care for can no longer make decisions or communicate their wishes?

That last point is especially important when decisions need to be made about what medical treatment to give them.

You need documents that record what the person with MS wants to happen. This could be things like wills or clear instructions about what medical care should be given in an emergency.

Things can get very difficult if you don’t sort out things like this in advance.

You might feel that talking about the future, especially death, will be too upsetting. But leaving things unspoken could be more upsetting in the long run.
And what if something happens to you? Many carers worry about what would happen if their own health fails, or if they’re not around any longer to be a carer.

You might worry much less once you have plans for a crisis in place - or plans for when the end finally comes.

Getting this sorted out way in advance means both of you have plenty of time to think things over. You have enough time to involve the rest of the family, too.

It can take a lot of worry off the shoulders of you both once you know wishes have been written down in a legal document. It’s reassuring to know things will happen the way you both want.

There’s a special 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.

Here we look at important legal documents you should know about. Decisions about care and treatment should involve you, others in the family, health and social care staff and, of course, the person you care for.
**Lasting Power of Attorney (LPA)**

In England and Wales this is when the person with MS chooses someone to look after their health and welfare, and make decisions when they no longer can.

An LPA can cover medical treatment a person does or doesn’t want to have, but also how and where they’re cared for. Without one (or an Advance Decision) a doctor will make these decisions in 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).

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. It needs to be registered before it comes into force.

**England and Wales**

Find out more, including downloading the forms, at [gov.uk/government/organisations/office-of-the-public-guardian](http://gov.uk/government/organisations/office-of-the-public-guardian)

**Scotland**

There are three different kinds of Power of Attorney.

- a Continuing Power of Attorney looks after money matters
- a Welfare Power of Attorney looks after health and personal welfare
- a Combined Power of Attorney looks after both money matters and welfare. Find out more at [publicguardian-scotland.gov.uk](http://publicguardian-scotland.gov.uk)

**Northern Ireland**

If you’re in Northern Ireland, you can make an Enduring Power of Attorney.

Find details at [nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney](http://nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney)
An Advance Decision

The full name of this is an ‘advance decision to refuse treatment’. 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 the person can no longer make a decision or communicate what they want to happen.

The kind of treatments it can cover:

- artificial feeding (through a tube)
- artificial ventilation (when breathing is taken over by a machine, also known as being on ‘life support’)
- CPR (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 and Wales. In Scotland and Northern Ireland it’s not, but should be taken notice of by medical staff.

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 has free forms that meet all the criteria to make an Advance Decision legally binding. [compassionindying.org.uk/choose-a-way-to-make-an-advance-decision-living-will/](http://compassionindying.org.uk/choose-a-way-to-make-an-advance-decision-living-will/)

An Advance Statement

An Advance Statement can be made if you live in England or Wales. It’s sometimes called a Statement of Wishes. It’s about what a person wants and what’s important to them.

It covers things not covered by a Lasting Power of Attorney or an Advance Decision, like food, religious wishes or daily routines.
It’s not legally binding. But if the person can no longer make their own decisions, the people looking after their care must take into account what’s in the document.

It can be written, recorded or told verbally to family and carers. Having it written or recorded is a better way to make sure it’s taken notice of.

**Tip:**

- Compassion in Dying has a factsheet explaining more about the difference between Advance Decision and Advance Statements and whether someone needs both
- to find it put ‘advance statement’ in the search box on their homepage at compassionindying.org.uk

**An Advance Care Plan**

This is only made with a person’s healthcare team near the end of their life. It covers their care and treatment wishes and should be attached to their medical notes.

It should mention if a person also has an Advance Decision, Advance Statement or Lasting Power of Attorney.

Read more about it in the Compassion in Dying booklet ‘Planning Ahead’.

**Court Appointed Deputies**

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).

This costs £400, with many more costs after that. It comes with much stricter regulation than with a Power of Attorney. This includes the need to provide exact accounts and an annual report.

Read more in the Compassion in Dying booklet ‘Planning Ahead’ or at gov.uk/become-deputy
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 and 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 the will for free if you donate to a charity. Visit willaid.org.uk (in Scotland willreliefscotland.co.uk) to find solicitors who will do this
- look at these documents again from time to time. 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

In Scotland if a person is no longer able to look after their own affairs, an intervention or guardianship order can be applied for. The Sheriff will decide on the period of the order. More information is available from the Office of Public Guardian Scotland website. publicguardian-scotland.gov.uk
End of life

It can be upsetting just thinking about planning for the last stage of life of the person you care for. Maybe you worry that bringing this up will upset them too.

Some people with MS want to face the fact that the end is getting nearer. They may want to talk about their death.

They might have wishes about where they want to be cared for during those final days (for example, in a hospice or to 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 you might find it.

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.

It can be written, recorded or told verbally to family and carers. Having it written or recorded is a better way to make sure it’s taken notice of.

After a death

On average people with MS die about seven years sooner than other people. This gap has been getting shorter as medical care gets better.

They may, of course, outlive you. But the expectation is that one day it’ll be you who takes care of their funeral.

When someone dies people are often surprised by the number of things that need doing. At this very
difficult time it can help to know what you’ll 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 who’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 this applies, you fill this in and hand it to your Jobcentre, Jobcentre Plus or social security office.

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**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 interested in doing this, contact them on **020 7594 9734** or visit [ukmstissuebank.imperial.ac.uk](http://ukmstissuebank.imperial.ac.uk)
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.

The funeral
The person you cared for may have left instructions in their will about how they wanted their funeral, so check this.

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.

If you use a funeral director, the average cost is now around £3,500 to £4,500 (almost £6,000 in London).

Burials are more expensive than cremations. Even the cheapest option (‘direct cremation’) costs at least £1,000. These prices don’t cover catering or legal fees connected to dealing with the will.

If there wasn’t a pre-payment plan to cover these costs, and you don’t have the money, you might qualify for help from the Social Fund if you’re income is low enough. Find out more from gov.uk/funeral-payments

If this Funeral Payment doesn’t cover the full cost, you might be able to apply for a Budgeting Loan (see page 140)

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.

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 it. 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, 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
director 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 has suddenly ended. This will be a major change in your life.

Look to family and friends for support with dealing with this change and for 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 tricky to cope with this sudden change, let alone 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 things like:
• bereavement and 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:

- the effect that going back to work can have on any benefits you’ve been getting
- how to identify your skills
- and where to get help with training.

Check out carersuk.org/help-and-advice/practical-support/when-caring-ends/life-after-caring

Find ideas for getting back to work here carersuk.org/help-and-advice/work-and-career/getting-back-into-employment

We have a factsheet on bereavement that you can download from our website. Put ‘bereavement’ in the search box of our home page.

Tips:

- talk things over with someone at the 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. See page 174 for more on this and the service for Scotland
- Work Preparation Support offers advice and training for carers and ex-carers. It’s available through your local Jobcentre Plus office or by calling on 0845 6060 234
- your local carers group or centre will help with training and getting into work
- the MS Society can give grants to former carers so they can learn a new skill that could help them get back into work
Useful organisations

Support
Forums, blogs and discussion boards for people with MS or their families, partners, friends or carers:

**MS Society**
Visit [mssociety.org.uk/ms-support/for-carers](http://mssociety.org.uk/ms-support/for-carers) for lots of information covering help and support, money, work, looking after yourself and end of life issues. Chat to other carers on our forum: [community.mssociety.org.uk/forum](http://community.mssociety.org.uk/forum)

MS Helpline – get information or emotional support at every stage of MS (see back cover for details)

Grants – call 0300 500 8084, email grants@mssociety.org.uk or visit [mssociety.org.uk/grants](http://mssociety.org.uk/grants)

**Shift MS**
A social network for people with MS. Popular with younger people: [shift.ms](http://shift.ms)

**MS Trust**
Useful information about MS, including where the nearest MS nurse is. Put ‘MS services near me’ in the search box on their website: [mstrust.org.uk](http://mstrust.org.uk)

**Carers Trust**
Information, advice and support through its carers centres, website and online forum. Also, has grants for carers.

Carers Trust has local Network Partners. These are 150 independent services for carers across the UK. They offer information, advice, practical support and/or care in the home. Find your nearest one on their website - search for ‘carers’ plus the name of the town or county you live in.

0300 772 9600 [carers.org](http://carers.org)

**Carers UK**
The UK’s national membership charity for carers. Information, advice and telephone and email support for unpaid carers (family or friends) from their advice line.
Advice Line 0808 808 7777 (Monday to Friday 10am-4pm)
Check out their online forum at carersuk.org/forum

carersuk.org - choose from the separate versions of their site for Wales, Scotland, Northern Ireland and England.

To find local groups check out carersuk.org/help-and-advice/get-support/local-support

**Scotland**

Care Information Scotland
Provides information and advice for carers and those they care for. Helpline and web chat available. 0800 011 3200 (Mon-Fri 8am to 10pm, Sat-Sun 9am to 5pm)
careinfoscotland.com

Crossroads Caring Scotland
One of Scotland’s leading providers of packages of support services for carers and their families so they can live independently at home. Local contact information on the website.
crossroads-scotland.co.uk

**England**

Carers Direct Helpline
0300 123 1053 9am-8pm Mon-Fri, 11am-4pm weekends. Closed on bank holidays. Has webchat and email enquiry services.

England-only information service to help you get the support needed by you and the person you care for. Covers assessments, benefits, direct payments and individual budgets. Advises on taking time off and staying in – or going back to or leaving – work or education. Also help with complaints about NHS and care services.
nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-direct-helpline.aspx

**Northern Ireland**

Crossroads Care Northern Ireland
A not-for-profit organisation that supports carers and those with care needs.
028 9181 4455
Email info@crossroadscare.co.uk
crossroadscare.co.uk

**Wales**

‘My MS, My Rights, My Choices’ Project
Big Lottery funded project that
provides information, advice and advocacy services across Wales for people with MS and their carers.

0808 800 8000
Email: mymscymru@mssociety.org.uk

**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.

If it’s an emergency (someone’s life is at risk), call 999.

**Care services regulators and complaints**

**England**

The Care Quality Commission
The health and social care regulator, with 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**
Helps people have a voice by providing advocacy services. Helps with complaints about the NHS (England only). Find details about complaining about the NHS at:
pohwer.net/nhs-complaints-advocacy-resources
0300 456 2370

**Wales**

The Care and Social Services Inspectorate Wales
Responsible for inspecting social care and social services. It has an online directory of registered care services

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0300 7900 126
cssiw.org.uk

Public Services Ombudsman for Wales
Independent body with legal powers to look into complaints about public services (including social care) and independent care providers.
0300 790 0203
ask@ombudsman-wales.org.uk
ombudsman-wales.org.uk

Scotland

The Care Inspectorate
Regulates and inspects care services. It has an online directory of registered care services.
0345 600 9527
enquiries@careinspectorate.com
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 9051 7500
Email: info@rqia.org.uk
rqia.org.uk

Office of the Northern Ireland Ombudsman
Offers help only when you’ve exhausted an organisation’s own complaints procedure.
0800 34 34 24
nipso@nipso.org.uk
nipso.org.uk

Bladder and bowel problems

Bladder and Bowel
This organisation has details of continence services across the UK and continence advisers on their
helpline on 0800 031 5412
bladderandbowel.org

Bladder and Bowel UK
Information and an online forum to talk over symptoms
bladderandboweluk.co.uk

Equipment and technology

Abilitynet
Helps people with any disability to use technology at home, work and in education. They run a free helpline on 0800 269 545 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.
disabledliving.co.uk

Disabled Living Foundation
Charity providing impartial advice, information and training on equipment and mobility products for disabled people
Helpline 0300 999 0004
(Mon–Fri, 10am–4pm)
dlf.org.uk

The DLF also run the website livingmadeeasy.org.uk. It shows you a large range of equipment, from clothing and personal care, to mobility products and things for the home, including alarms and other technology.

Continuing Healthcare (CHC)
For more information visit nhs.uk and search for ‘continuing healthcare’.

Also find information at ukcareguide.co.uk/chc-funding

Care to be Different has advice and tips on getting CHC. Check out their website and publications caretobedifferent.co.uk

If you’re turned down for CHC, find advice on appealing at caretobedifferent.co.uk/nhs-continuing-healthcare-appeals/
Beacon
In England the Beacon organisation offers free advice and information to help guide people through applying for CHC.
For a fee they can take on someone’s case (and be their advocate) or help with appeals. They have a free toolkit you can ask for or download to help you understand the CHC system.
0345 548 0300
beaconchc.co.uk

Counselling (relationships and sex)
British Association for Counselling and Psychotherapy
Details of counsellors can be found on their website:
bacp.co.uk/search/Therapists

Relate
Offers advice, relationship counselling, family counselling and support face to face, by phone or through its website.
relate.org.uk (England and Wales)
0300 100 1234

relateni.org (Northern Ireland)
028 9032 3454
The MS Society in Northern Ireland has a counselling service. Contact 028 9080 2802 for details.

Relationships Scotland
Similar service to Relate for people in Scotland.
0845 119 2020
relationships-scotland.org.uk

College of Sexual and Relationship Therapists
Has a list of therapists.
020 8543 2707
Email: info@cosrt.org.uk
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.mobi/

Sexual Advice Association
Charity that helps improve the sexual health and wellbeing of
men and women with information and a helpline.

Helpline: **0207 486 7262** info@sexualadviceassociation.co.uk
sexualadviceassociation.co.uk

**Sex and Disability Helpline**
07770 884 985 (11am to 7pm weekdays) or email sexdis@outsiders.org.uk

More information at outsiders.org.uk/outsidersclub/helpline

**Money and benefits**

**Carer’s Allowance Unit**
0345 608 4321

**Carer’s Allowance Unit in Northern Ireland**
0300 123 3356

**Disability Rights UK**

Information on benefits such as the Disability Rights Handbook and free factsheets are available from its website. It campaigns for improvements to the social security system. It can’t answer general questions over the phone but has a helpline for questions on personal budgets.

**Personal Budgets helpline:**
0300 555 1525
(Tue and Thurs 9.30am–1.30pm)

**Email:** personalbudgets@disabilityrightsuk.org

It can help 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:** 020 7250 8181
disabilityrightsuk.org

**Turn2us**
Charity that 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 0808 802 0020 (Mon-Fri 9am to 5pm). 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. Their work covers discrimination and issues with care services, including social care assessments.

0207 791 9800
advice@dls.org.uk
dls.org.uk

The MS Society helps fund an MS Legal officer at the DLS to give MS-specific advice to people in England and Wales. They can help with legal issues to do with work, discrimination, services, community care and welfare benefits.

0207 791 9800
msadvice@dls.org.uk

Find more information (and how to get legal advice in Scotland and Northern Ireland) at mssociety.org.uk/care-and-support/financial-help/legal-advice

Disability Rights UK
Campaigns for improvements to the social security system (see its entry on page 171 for more details)

Disability Information Scotland
Provides information to help guide people through the maze of disability information in Scotland.

Helpline 0300 323 9961
disability.scot.org.uk

Travel

Bus
Free off-peak travel on all local buses anywhere in England is available to disabled people who qualify for it. Similar schemes run in Wales. Application forms are available from local councils.
In Scotland you can get application forms for the National Entitlement card from local councils. Visit transport.gov.scot and put ‘concessionary travel’ in the search box for more information. Or call the ‘Concessionary travel and integrated ticketing unit’ at Transport for Scotland on 0141 272 7170.

For concessions in Northern Ireland, call Translink on 028 9066 6630.

**Train**

A Disabled Person’s Railcard can give a third off the cost of most UK train journeys for the person with MS and their carer.

0345 605 0525

Email disability@atoc.org

disabledpersons-railcard.co.uk

**Research Institute for Disabled Consumers**

RiDC (before 2018 called Rica) has information, guides and reviews about products and technology that help disabled people lead independent lives. Their information covers driving, public transport, wheelchairs and walking aids.

020 7427 2460

**mail@ridc.org.uk**

**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

0345 268 8489

Email: atwosu.london@dwp.gsi.gov.uk

**Dying and Bereavement**

**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–Friday 9.30–5pm (not bank...
Dying Matters
A coalition of 32,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

dyingmatters.org

Cruse Scotland
Helpline 0845 600 2227
Mon 10am–8pm Mondays to Wednesdays, 10am–9pm Thursdays, 10am–4pm Fridays

crusescotland.org.uk

Compassion in Dying
Help with decisions about healthcare, rights and planning in advance, including drawing up an Advance Decision. Their booklet ‘Planning Ahead’ explains the different legal documents we mention in pages 155–159.

End-of-life Rights Information Line 0800 999 2434

Call if you have questions about end-of-life rights or care, Advance Decisions or Lasting Powers of Attorney.

Email info@compassionindying.org.uk

compassionindying.org.uk
New words explained

adaptations – changes in the home that make life easier, from structural alterations to gadgets and changes to furniture and fittings

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 urine (wee) from the bladder and into a bag via the urethra (the body’s ‘pipe’ that takes urine from the bladder to outside the body). A suprapubic catheter is more comfortable and less likely to cause infections. The tube goes into the bladder through a cut a few inches below the belly button

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) 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

**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 where you train yourself to focus on the present, your breathing and how you’re feeling. You become more aware of your body, thoughts and feelings. It lets 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)** – 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.

**open appointment** – 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.

**personal budget** – the money set out in the **care and support plan** of a person with MS that their council (or HSCT) 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.

**sitting service** – when someone is paid to spend time with a person so that their carer gets a few hours’ break. They can’t give medical or personal care. Run by local health authorities, or private companies.

**social care** – support and care services that the local council (or HSCT in Northern Ireland) arranges. Includes help at home with personal care, care homes, day centres, breaks for carers and advice.

**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.
Further information

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

To order them email shop@mssociety.org.uk or visit mssociety.org.uk/publications

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

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

0808 800 8000
(closed on weekends and bank holidays)
helpline@mssociety.org.uk
About this resource

With thanks to all the people affected by MS and professionals who contributed to this booklet, including Wendy Wilson, Nicole Kirbyshire (Parkinson’s UK) and especially Mark Brightburn.

If you have any comments on this information, please send them to: resources@mssociety.org.uk

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 Simon Rawles (pages 17, 65, 126 and 154), Paul Moane (pages 25 and 148), Davie Dunne (p 140) and Ginny Lattul (p30).

This resource is also available in large print.

Call 0300 500 8084 or email shop@mssociety.org.uk
Contact us

MS Helpline
Freephone 0808 800 8000 (closed on weekends and bank holidays)
helpline@mssociety.org.uk

MS National Centre
0300 500 8084
info@mssociety.org.uk
supportercare@mssociety.org.uk

Online
mssociety.org.uk
facebook.com/MSSociety
twitter.com/mssocietyuk

MS Society Scotland
0131 335 4050
msscotland@mssociety.org.uk

MS Society Northern Ireland
028 9080 2802
nireception@mssociety.org.uk

MS Society Cymru
0300 500 8084
mscymru@mssociety.org.uk

BK37

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This title will be reviewed within three years of publication.
Carer’s assessment checklist

Let’s stop MS together
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.

<table>
<thead>
<tr>
<th>Day-to-day help</th>
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<tbody>
<tr>
<td>Cleaning the house</td>
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<tr>
<td>Shopping</td>
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<tr>
<td>Cooking meals</td>
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<tr>
<td>Washing clothes</td>
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<tr>
<td>Helping them wash or have a bath</td>
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<tr>
<td>Helping them go to the toilet</td>
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<tr>
<td>Helping them feed themselves</td>
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<tr>
<td>Helping them take their medicines</td>
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<tr>
<td>Helping with other medical care</td>
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<tr>
<td>Helping them use specialist equipment</td>
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<tr>
<td>Arranging appointments for them</td>
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<tr>
<td>Making sure they follow therapy routines (like physio exercises)</td>
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<tr>
<td>Helping with paperwork (mail, money, paying bills)</td>
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<tr>
<td>Getting them from A to B (help with walking, driving them, pushing their wheelchair)</td>
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<tr>
<td>Giving them emotional support</td>
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<tr>
<td>Helping them express what they want to say</td>
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<tr>
<td>Emergency care (you’re available by phone, or you have a house key)</td>
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<tr>
<td>Yes, I do this for the person with MS I’m supporting</td>
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<td>-----------------------------------------------------</td>
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### Your health and mental well-being

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<thead>
<tr>
<th>Question</th>
<th>Options</th>
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<tr>
<td>Do you have any health problems of your own?</td>
<td>Yes/No</td>
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<tr>
<td>Is caring for someone making these worse?</td>
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<tr>
<td>Do you feel anxious, stressed or depressed?</td>
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<tr>
<td>Do you get backaches or headaches?</td>
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<td>Does your GP know you’re a carer?</td>
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<td>Do you have to move or lift the person you care for?</td>
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<tr>
<td>Would you like any aids or adaptations to help you like a raised chair, bed, or hoist?</td>
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<td>Do you get enough sleep?</td>
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<td>Do you sometimes get a break from caring?</td>
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<tr>
<td>Do you eat healthily?</td>
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<td>Do you get enough exercise?</td>
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<tr>
<td>Can you leave the person you care for alone in the house?</td>
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<tr>
<td>Can you look after your own day to day needs? Are you getting support from other people?</td>
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<tr>
<td>Would you like to have any telecare equipment to help you like a pendant alarm, flood detector, bed occupancy sensor or door exit sensor?</td>
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How easy is it for you to get to appointments for yourself (GP/dentist/hospital/optician)?
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<th>No</th>
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<tr>
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<th>Very difficult</th>
<th>Fairly difficult</th>
<th>No problem</th>
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<tr>
<td>Family responsibilities</td>
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<td>Do you have family commitments as well as your caring role?</td>
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<td>If you’re a parent, is caring making this role harder?</td>
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<td>Do you feel you have time for your children?</td>
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<tr>
<th>Support and leisure</th>
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<tr>
<td>Does the person you care for have home care, or go to a day centre or lunch club?</td>
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<td>Does another family member or friend sometimes provide care?</td>
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<td>Do you get breaks where you have time for yourself, your leisure interests or time with friends? Or is caring getting in the way?</td>
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<th>Work, education and training</th>
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<tr>
<td>Are you struggling to be a carer and hold down your job?</td>
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<tr>
<td>Have you had to cut down how many hours you work?</td>
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<tr>
<td>Would you like to go back to paid work?</td>
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<tr>
<td>Is caring stopping you from doing any training or further education?</td>
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<tr>
<th>Money</th>
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<tbody>
<tr>
<td>Is being a carer giving you money problems?</td>
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<tr>
<td>Would you like advice on benefits or debt?</td>
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<tr>
<th>Risks</th>
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<tbody>
<tr>
<td>Does the person you care for sometimes show challenging behaviour?</td>
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<tr>
<td>Do you feel your housing and living conditions are suitable?</td>
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<tr>
<th>Culture and religion</th>
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<tbody>
<tr>
<td>Do you want to go to a place of worship or other regular religious and cultural activities?</td>
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<td>Do you have any specific religious or cultural needs?</td>
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<tr>
<td>Question</td>
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**Carer’s assessment checklist**
## Emergency planning
Do you need help planning what happens if either of you suddenly become 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?
Yes | No
---|---

<p>| | |</p>
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Carer's assessment checklist
### 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

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**Is there specific advice or information you need now?**

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**Any other problems or worries you’d like to bring up?**
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<th>Carer’s assessment checklist</th>
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Contact us

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This title will be reviewed within three years of publication.