MS Society

Supporting someone with MS

a guide for family and carers

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

Together we are a community. And together we will stop MS.

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

- Calling us on: **0300 500 8084**. Lines are open Monday to Friday, 9am – 5pm
- Visiting us at: **donate.mssociety.org.uk**
- Posting your donation to: MS Society, Carriage House, 8 City North Place, London N4 3FU.
- Please make cheques payable to the 'MS Society.'

Contents

A word from Paul, whose wife has MS

I'm a carer for my wife, Lesley. Life with multiple sclerosis is challenging, but we manage reasonably well thanks to the help we've been given.

It took me a long time to recognise that I was a carer. It crept up on me slowly. Looking back now, I can see I ought to have asked for help much sooner.

Just one example: it wasn't until I recognised myself as a carer that I applied for, and was awarded, Carer's Allowance. That delay had a bad effect on my State Pension. Yet if I'd known, I would've acted much sooner.

This booklet contains much wisdom from people who have first-hand experience of caring for someone with MS. I hope you can learn from them and pass the message on to others.

Paul

Five things to know

1. **Being a carer can take its toll on you, mentally and physically. This booklet tells you where you can get support**
2. **Some people don't see themselves as a 'carer'. But don't let that stop you using help that's available for carers**
3. **Claim all the financial support you qualify for. We cover what's available in this booklet**
4. **Carers can have an assessment of what help they need. This booklet can help you get ready for it**
5. **From 2024 carers who work can take up to five days unpaid leave each year. This is to help them with caring. It includes taking a break**

About this booklet

This booklet is for family, partners and friends who support someone with multiple sclerosis (MS). We talked to families and carers. And in this booklet you'll hear what help they said they needed, and how they got it.

There's a lot of information here to take in. So come back to it as and when you need it. And share it with others. For a shorter read, you'll find information for families and friends on our website. Search it for 'Supporting someone who has MS'.

This booklet will also point you towards where you can get more in depth information.

We have two other booklets for family members, partners and carers. Find out more about these on page 54.

Being there for someone with MS is such a valuable thing to do. It has its own rewards, but it can ask a lot of you.

We hope this booklet helps you to support the person in your life with MS. And, just as importantly, we hope it helps you to support yourself.

One last thing: if you see a word in **bold**, that means it's explained at the back of this booklet.

There you'll also find where you can get more help. That includes our MS Helpline on **0808 800 8000**.

> **"I found it difficult to identify as a carer. However, it's important to recognise that I am, and know that support is out there."**
>
> Alex

What do I need?

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

A lot depends on how much MS is affecting them. Even if there aren't many physical effects, there can be a major emotional impact on you both.

Families and carers told us they need:*

- information and advice about MS
- practical support, including help with money and care
- ways of sharing experiences with people in the same boat
- ways of solving problems, coping better or seeing things differently
- help with looking after themselves. That includes breaks and ways to ease the pressure and isolation
- support when relationships become difficult. And help to accept the situation they're in
- to be listened to (for example, by doctors)
- to have other people recognise and value the support they give - especially medical and health care staff

This booklet comes with an insert called 'Carer's assessment checklist'. It helps you work out what help you need. So you'll be better prepared for your assessment.

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* 'Scoping the Needs of Families and Carers of People with Multiple Sclerosis'. A 2017 study by Queen Margaret University for the MS Society of 49 family and carers.

Am I a 'carer'?

'Carer' isn't a word that everyone feels comfortable with. But what exactly do we mean when we say someone's a carer?

Often people think of a carer as a person outside of the family who's paid to look after someone. If it means that to you, it's understandable if you don't see yourself as a carer. Or perhaps you think that the amount of caring you do isn't enough to make you a carer.

But you're a carer if:

- without getting paid to do it, you give support to someone. And without it they'd not be able to manage

It's up to you whether you call yourself a carer. But don't turn down help or information just because it has the word 'carer' in front of it. Don't miss out on:

- extra money from welfare benefits, such as Carer's Allowance or grants for carers
- 'carer's leave' (time off from your job)
- the more flexible work hours that carers can sometimes ask for
- extra support from your local authority. But before you get this you need to have a 'carer's assessment' (see page 23)
- the help that the law gives carers. This includes protection from discrimination at work, and the right to carer's leave

> **"Recognising yourself as a 'carer' is a gradual process. It doesn't stop you also being a husband or wife, son or daughter, father or mother. Embrace it. It's a positive thing you're doing. So celebrate it."**
>
> Mark

I want to know more about MS

At some time or other you'll have questions. These could be about MS symptoms, treatments, or what the future might hold. Or you might need practical help with something.

MS changes over time. So the information and support you need will change too. You might feel overwhelmed. There can be lots to take in.

Sometimes you want medical information from a doctor, MS nurse or other expert. You can get reliable and easy to understand information from MS organisations. At other times what helps is hearing from people in the same situation as you.

Information can make you feel more prepared, confident and able to cope. It can make you feel less worried. It can lead you to the help you need. This could be care services, specialist equipment or more money. It might be a much needed break, or tips on support for yourself and the person you care for.

Maybe you need new skills. You might benefit from learning new ways of coping. Or training in how to do practical caring jobs. For example, how to lift or move someone without hurting your back or giving yourself a **hernia**.

> **"The best source of information has been talking to other people. I've read a lot, but none of it made sense until I could relate it to a real person or situation. Talking to others has helped to do that."**
>
> Liz

> **"It's good to question, and even to challenge, health care professionals, when needed. As carers we know much more about the person with MS and their needs, lifestyle and what they want than hospital staff can know."**
>
> Dan

Good places to start are support groups and online forums. Other people can share what worked for them. Details are on page 48.

These can help you lower anxiety levels and avoid the feeling you're overwhelmed:

- techniques you can learn from counselling such as cognitive behavioural therapy (CBT)
- **mindfulness** (see page 52)
- advice on how to handle relationships
- tips on how to communicate better (see page 15)
- advice on accepting the situation you're in

MS nurses are great sources of information and practical help. They're trained to talk in ways that are easy to understand.

If you don't have an MS nurse, find your nearest one on **mstrust.org.uk**. Put 'MS services near me' in the search box on the home page. You can also speak to an MS nurse on our MS Helpline.

Speaking to doctors and other medical staff

Going to health appointments with the person you support is an important way of getting information.

Make it clear if you want to be included in these appointments.

A word about MS support groups. Lots of people find these very useful. But you might find it difficult to see people with a lot of disability. So these groups might not be right for everyone.

More tips:

- our MS Helpline is a great place to get information or talk to an MS nurse. Call **0808 800 8000**. You can email **helpline@mssociety.org.uk** or make contact through its Facebook page
- visit our online discussion forum at **forum.mssociety.org.uk**
- get tips and information through our local groups. Our MS Helpline knows which ones are near you
- our LivingWell programme of services offers support events and online talks ('webinars'). Search our site for 'virtual support events' to check what's happening
- our booklets and factsheets cover things like symptoms, treatments, diet, welfare rights, and working with MS. They cover emotional issues too. Page 54 tells you how to order. Find our catalogue by searching our website for 'information resources list'
- we have a magazine called 'MS Matters', often with articles about the latest research. Search our website for 'MS Matters'. You'll see how you can download copies or sign up to receive them
- other reliable sources of information are the MS Trust, Shift MS or the blog written by the MS team at Bart's hospital **multiple-sclerosis-research.blogspot.com**

Does your GP know?

Let your GP know that you support someone with MS. It'll help them offer you the right support, like:

- free flu jabs
- letters to support claims for a benefit
- help getting appointments and repeat prescriptions

How MS might affect our relationship

Lots of people have positive stories to tell. Relationships can get stronger and deeper. And MS doesn't mean that everything changes overnight. But over time MS can change your relationship.

Family and carers often find themselves full of admiration at how the person with MS is managing. It can feel a privilege to help them stay as independent, active and in control as possible.

If you're part of a couple, this can be a real help when dealing with MS. It's not just practical things you do that help your partner. It's things like your sense of humour or positive attitude, too.

Roles might change

In families and relationships we tend to take on certain roles. One of you might be the talker, or the practical one, the planner, or provider. One might look after the other, or be the one who gets looked after.

Over time MS can change these roles. That can be a challenge. It can disappoint or frustrate one or both of you. It can leave you feeling you're losing something important. It can lower self-confidence.

You might notice changes in the other person's mood, like depression or anxiety. Maybe they're having difficulty thinking or doing certain tasks. This could be a natural reaction to their diagnosis. Or it could be MS affecting their brain. Talk to their MS medical team to help work out what's going on.

Keep communicating

Communication makes all the difference. This is especially true when you're both coming to terms with the diagnosis. Or when you're adjusting to changes, and need to plan ahead.

It can be tough to keep communication open. But we need to keep working on our connections with other people.

Talk to others in a similar situation. Support networks will help you find solutions (see page 48).

> **"Keep talking, be honest about your feelings and try to forgive each other for being upsetting, difficult and constant hard work. Corny but it's true! Think about seeing a counsellor."**
>
> Yasmin

How to communicate better

Here are tips on how to talk to someone without upsetting them or making them angry:

- an honest chat needs a safe place and time
- turn off the TV, your phone and other distractions
- don't have important conversations if you're angry, tired or in a bad mood
- before you begin, know what you're going to say. And how you're going to say it
- body language makes a big impact. Avoid crossing your arms. And it helps to look the other person in the eye
- listen how you'd like to be listened to. Give the other person space to answer. Let them finish before you reply
- don't be afraid of silences
- ask questions that start with 'why?', 'how?' and 'what?' These need a full answer and they can't answer with only a 'yes' or 'no'
- reword and repeat back what they've said to check you've understood
- say how you feel. But in a way that doesn't make them feel guilty or responsible. For example: "I'm feeling angry with MS, not with you"

Find solutions through counselling. You can talk to someone on your own, as a couple or a family. Each of you can see a different counsellor if it helps.

The specialist MS team can often see you together if you all agree. They'll help unpack the tensions or misunderstandings. They can put you in touch with counsellors and other support.

Family time

This has helped a lot of people...

A regular meeting or 'family time'. Everyone's encouraged to ask questions, so they understand 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.

Sex and intimacy for couples

MS means you might need to plan sex a bit more. By making some changes you can hold on to what you enjoyed before. MS symptoms can make someone lose interest in sex. Things like muscle weakness, spasms and pain can be passion killers. So can bladder issues and MS fatigue.

Treatment might have side effects that get in the way. The emotional impact of having MS can affect someone's sex drive, too.

But MS can affect you as well. After a day spent caring you might be too tired. Or worry that getting intimate could cause discomfort, or make their symptoms worse.

All this can cause anxiety, stress, feelings of guilt or sadness (maybe even depression). Either of you might feel confused, rejected, angry or isolated. It might leave you feeling that you're no longer attractive.

It can be difficult to talk about personal things like this. Especially if there are communication barriers already. But put off facing up to them, and it can make it harder in the long run to put things right. Don't wait until a problem has become established before you reach out for support.

You could speak to your GP. Or look for a therapist who specialises in sex and relationships. An MS nurse or neurologist can refer you to a counsellor or other kinds of help. That can build the confidence you need to talk to each other about sensitive subjects.

Search our website for 'sex and relationships'. There you'll read about physical problems related to MS and where to turn for help.

More tips:

- talk to someone anonymously on our MS Helpline. Or ask people on our online forum what worked for them
- choose times and positions for sex that are more comfortable and less tiring for your partner
- some couples find they enjoy intimacy more from kissing, cuddling and touching. Try less focus on penetration
- talking about sexual problems isn't easy. Try writing things down and handing it to your partner or a health professional
- or bring up sexual problems as part of a wider chat about bowel and bladder issues
- try counselling from a sexual and relationship therapist. Details are on page 49. Ask your GP or your partner's MS nurse what's available on the NHS or privately
- many counsellors can see you in your own home using video call services like Zoom, Skype or FaceTime
- the MS Trust has two booklets on sex. Download them from

"I felt I couldn't talk to him about my problems. What have I got to complain about when he's got MS? It took us a long time to recognise that this was causing a big gap between us. We try to talk to each other about everything now"

Leslie

Looking after myself

Being a carer can take up much of your time. It can drain your energy, and maybe leave you unwell. You might stop taking care of yourself.

These can lead to problems:

- lack of sleep or poor diet
- lifting someone in a way that gives you a back injury or hernia
- stress, feeling down or depression

You might also develop negative feelings like guilt. This could be about your situation or the person you care for.

These reactions are natural, but can be hard to live with. Getting help to face up to them will take the pressure off you.

More tips:

- give yourself ‘me time’. Go for a long walk. Meet up with friends. Walk the dog
- build ways to de-stress and relax into your routine
- many people find **mindfulness** helps
- call the MS Helpline to talk through negative feelings
- if you’re feeling down or struggling to cope, speak to your GP. Acting now could avoid depression later
- don’t become isolated. Get in touch with people through online forums or your local MS Society or carers group
- have a carer’s assessment (see page 23)
- if you smoke, quitting could help you both. Smoking makes MS worse. It can make relapsing MS turn into progressive MS sooner. Quitting smoking can slow down how fast someone’s disability gets worse. It quickly goes down to the same rate seen in people who’ve never smoked. And if you quit, it should make it easier for the person you care for to give up.

Social care - getting help from the council

Social care covers a range of services that you and the person you support might get. These services come from the council of the person you're caring for.

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

- specialist equipment, technology and changes to their home to make life easier (like ramps, grab rails, or making doors wider to let a wheelchair through)
- someone who comes to the home. They help with things like getting washed and dressed
- day centres
- residential care
- support for family and carers, such as **respite care**
- information and advice

The person who you support can ask to have an assessment to see what services they need.

As their carer, you can have an assessment of your needs too. The next chapter looks at that.

Contact the Social Services department of the council of the person you care for. They'll arrange an assessment for them. They'll send someone to see what help they need.

In Northern Ireland

If you live in Northern Ireland, social care doesn't come from your council. It comes from your local Health and Social Care Trust. Where we mention the council on these pages, for you this means your local Trust.

If they qualify for help, they'll get a **care and support plan**. This says what services the council is willing to offer, and how much they'll pay towards this. Most people pay something themselves towards these services. How much will depend on their money situation.

Many people feel social care isn't organised well. And there's not enough money spent on it. They feel it doesn't meet people's needs.

All you can do is apply for help and hope you get the support you need. There's a right to appeal if you feel they've not offered you enough support.

Social care can take some of the pressure off you. If the person you care for goes to a day centre or is offered respite care, you get a much needed break. See page 41 for more on this.

Equipment or changes to your home can make life easier for both of you. Or the council might arrange for someone to come and provide some care at home. That means you no longer need to do everything on your own.

Another part of social care is support for carers. See what help you could get on page 23.

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

More tips:

- the person you support can have their assessment at the same time that you have your carer's assessment
- but you can both have your assessments separately if that helps you talk more openly
- Carers UK have a booklet about technology that can make carers' lives easier. Download it at: **carersuk.org/help-and-advice/technology-and-equipment/tech-for-you**
- keep a list of the care services you get (plus letters and emails) to share with the healthcare team or hospital staff

Looking out for each other

Being a carer can put people under a lot of pressure. The person you care for might get abusive. This could be physically or emotionally. If this is happening to you, look for support.

On the other hand, carers might sometimes feel anger, frustration or resentment. They might take this out on the person they care for, physically or through words. If this might be you, talk to someone before things escalate.

Or maybe what's worrying you is how a paid carer or medical staff are behaving. Speak to someone if you feel something's not right about how they're treating the person you care for.

Whatever's on your mind, you can confide in someone on our MS Helpline. Call **0808 800 8000** or email them at **helpline@mssociety.org.uk**. You could also contact the adult services department of your local council (or Trust in Northern Ireland). And if you're struggling with caring and the feelings it can bring up, seeing a counsellor can help. They'll know who you can turn to for help. Ask if your council has a Carer Support Team and what they can do to help.

My carer's assessment

The law says the council of the person you support must look at how they can support you. They must ask what help you need to care for them.

This is a carer's assessment. You might not see yourself as a 'carer'. You might think you don't need help right now. But a carer's assessment could help you out. And it's good to know they exist in case you might want help in the future.

If your assessment shows you qualify for help, a **support plan** is made for you. This looks at ways a range of social care services can help you (we explain social care on page 20).

An assessment could help you get things like:

- a break from looking after the person you support
- 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)

If the person you care for gets support, that makes your life easier.

The assessment could give you money to spend on things that your support plan says you need. This money is called **direct payments**. Or the council itself might provide what you need.

Whether you pay for any of this depends on whether the council charges. They don't all charge. The council will look at the money situation of the person you care for. Then they'll decide how much of the costs they should pay.

In Northern Ireland

Carer's assessments here are arranged by the Health and Social Care Trust of the person you care for, not their council. Where we mention the council in this chapter, for you this means the local Trust.

What happens during the assessment?

Someone from the council of the person you're supporting will ask you questions that cover:

- your role as a carer and how it's affecting you
- your health, including physical, mental and emotional issues
- your feelings about being a carer. And what choices you want to have over 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

"What if the person I look after had their own assessment and was told they don't qualify for support?"
You can still have your own carer's assessment.

"What if the person I look after decides not to have their own assessment?"
As their carer, you still have a right to your own assessment.

"What if I have an assessment, and they decide I don't qualify for help?"
You can appeal against their decision. And the council must at least give you information and advice on other services that could help you. And if your caring role later changes a lot, you can ask to be assessed again.

How long does this take? And will it make a difference?

A large survey by Carers UK in 2016 found that half of carers got an assessment within six months. But almost one in three waited longer than that.

There's no guarantee a carer's assessment will give you all that you need. Some people have found them very useful, others haven't. You'll only find out yourself if you ask for one.

More tips:

- to get assessed, get in touch with the Social Services department of the council of the person you care for, or that council's contact centre (in Northern Ireland contact the Health and Social Care Trust)
- be prepared for your assessment. The insert that should be inside this booklet will help
- Carers UK has more information on carer's assessments at **carersuk.org** Click on 'Help and advice', then 'practical support', then 'having a carer's assessment'

In Scotland

What a carer's assessment recommends is written up as an Adult Carer Support Plan. If you're a young carer (under 18), it's called a Young Carer Statement.

Confused about assessments?

There are two assessments you need to know about:

1. The care and support needs assessment. This looks at what support the person with MS needs from their council's social care services. Our website has more about this. Search it for 'social care services'.

2. The carer's assessment. This looks at what help you need to support the person with MS that you care for. This help will come from that person's council. Our website has more about this. Search it for 'support for carers'.

In Northern Ireland the local Health and Social Care Trust carries out both assessments and provides the services.

If you apply for the Carer's Allowance benefit, you might hear people talk about being assessed for that. The benefits authorities look at whether you qualify for this benefit. It has nothing to do with the other assessments.

Juggling caring with my other responsibilities

You spend a lot of your time supporting the person in your life with MS. But you have other responsibilities, too.

Running a home. Looking after other family members. Holding down a job. Hospital appointments. From time to time, there'll be a crisis to manage, too.

Juggling all this can be hard. It can leave you exhausted, stressed and perhaps feeling a failure.

Tips:

- talk to people in online forums or carers support groups. They've been through this and found solutions
- find carers groups near you on the Carers UK website. Search for 'support where you live'
- need to let off steam or vent your feelings? People on our MS Helpline are trained to listen and give support
- 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

Work

Being a carer and holding down a job can be a tricky balancing act. But there's help. And the law can protect you if an employer is harassing you or discriminating against you because you're someone's carer.

Flexible working

For a time you might need to change your normal work patterns.

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

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

Carers leave

From mid 2024, under the Carers Leave Act, carers have the right to take leave. They can take up to five days unpaid leave each year from their employer.

This leave is to help them with caring. It covers taking a break. For more details search our website for 'carer's leave law'.

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

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

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

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 if your workplace has extra support for carers. You might need this one day.

Some employers have a carer's policy that offers (paid or unpaid) carer's 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.

If you let people at work know you have extra responsibilities at home, hopefully they'll be more understanding.

Support while you're at work

When you're away at work, could you do with more help? This could be for you or for the person you care for. A carer's assessment could identify what extra support you need from the local council (or Trust in Northern Ireland). Page 23 has more on this.

An assessment for the person you support looks at what care and support they need. This could help them to live more independently (see page 20 for what kind of support). That could make it easier for you to stay in work.

Private care

If money isn't an issue, you could arrange private care and support while you're at work. Your local council will have details of providers of care that they've approved.

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.

But before you do 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. So if you stop work and don't pay these contributions, this will affect your pension. Stopping work will also affect any private pension you have.

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.

Carer's Credit won't give you any money. But it can fill the National Insurance gaps in your pension record. This lets you look after someone while still protecting your right to a State Pension.

Read more about Carer's Allowance and Carer's Credit on our website. Search for 'financial support for carers'.

“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

More tips:

- search our website for ‘carers’ rights at work’
- read more about Carer’s Credit at **gov.uk/carers-credit**
- encourage your workplace to put a carer’s policy in place if it doesn’t have one
- for help with work-related questions, search the Carers UK website for ‘work and career’
- search the Carers UK site for ‘pension help’ for information on that topic
- for your workplace rights, search the same site for ‘Your rights at work’ and download the factsheet with that name

Money and benefits

MS can hit finances hard. The person you care for may need to work less or stop working. One day you might have to do the same, so that you can look after them.

A disability means more expense. There are extra costs from things like getting around, special equipment, insurance and extra heating.

You have every right to help from the benefits system. Don’t feel bad about making a claim. You’re only getting back money that you both paid into the system for years.

Benefits could be available to you and the person you care for. That’s true whether you work or not.

Check for changes in what benefits you both qualify to get. Especially if the MS of the person you support gets worse.

The system can be hard to find your way around. See what’s available by searching our website for ‘brief guide to benefits’. Our booklet ‘Benefits and MS’ covers disability benefits and work-related benefits.

The booklet also covers pensions, loans, and help with fuel and transport costs. It looks at tax credits that people with MS and their carers can claim. Download it from the benefits page, or order it free from our shop (online or by phone).

MS Benefits Advice Service

For free and confidential advice, get in touch with one of our MS benefits advisers. Call our MS Helpline on **0808 800 8000** or email **msbenefitsadvice@dls.org.uk**

These other websites can tell you what benefits and tax credits you qualify for:

turn2us.org.uk

entitledto.co.uk

Tip:

- Disability Rights UK have a web page which lists all the benefits carers can claim at **disabilityrightsuk.org/benefits-checklist**

Carer's Allowance

You could get this if you're 16 or over and look after someone for at least 35 hours a week. You don't need to be living with the person you care for.

The person you care for must be getting one of these benefits:

- Attendance Allowance
- the daily living component of PIP (Personal Independence Payment)
- or the middle or highest rate of the care component of DLA (Disability Living Allowance)

Some less common benefits are on the list too. See the full list, exactly who qualifies for Carers Allowance and how to claim it at **gov.uk/carers-allowance**

Are you claiming Carer's Allowance, but still don't have enough to live on? You may be able to get this topped up with a **means-tested** benefit like Universal Credit or Pension Credit.

More tips:

- read more about Carer's Allowance in our 'Benefits and MS' booklet. Or search our site for 'financial support for carers'
- if you get Carer's Allowance, you might also get Carer's Premium (or Carer Addition if you're of State Pension age). If you get Universal Credit, you might be able to get extra money called the Carer Element. For more on these benefits search their names on **carersuk.org**.
- If the person you support goes into hospital or residential care, their disability benefits usually stop after 28 days. When that happens, your Carers Allowance will also stop. You must tell the benefits authorities when they go into hospital or residential care and when they come out

Extra help in Scotland

Carers in Scotland may qualify for extra money called the Carer's Allowance Supplement.

You get this payment twice a year as a lump sum if you receive Carer's Allowance on a particular date.

Read more about Carer's Allowance Supplement and how much you get at **mygov.scot/carers-allowance-supplement**

Young carers aged 16,17 or 18 might get the Young Carer Grant. Read more about it at **mygov.scot/young-carer-grant**

Pensions

Your pension can be affected if you work fewer hours, or give up your job to care for someone. Read more on page 29.

Other sources of financial help

Search our website for 'other financial help'. There you'll find details of places that can help with the cost of living.

Help with fuel costs

Several schemes might help with your gas or electricity bills.

England

Get money off your winter electricity bill with the Warm Home Discount. This reduction could be made on your gas bill if you get gas and electricity from the same company. Read more about this scheme, who can use it and how much the discount is at **gov.uk/the-warm-home-discount-scheme**

Northern Ireland

The Warm Home Discount isn't available in Northern Ireland. For details of a similar discount there visit **nihe.gov.uk**. Search for 'Affordable Warmth Scheme'.

Wales

The Warm Nest Scheme offers advice on cutting heating bills. Find details at **nestwales.org.uk**. Or call **0808 808 2244**.

Scotland

The Scottish Government offers help with heating bills. Find out more at **netzeronation.scot**, including help from the Warmer Homes Scotland scheme. Search for 'make your home more energy efficient'.

More tips:

- You might be able to get the Winter Fuel Payment and Cold Weather Payments. Read more about these at **gov.uk** by searching for the names of these payments
- Scotland doesn't have Cold Weather Payments. Instead you might get an annual £50 Winter Heating Payment. Find out more at **mygov.scot/winter-heating-payment**
- low income households might get help with bills from the Household Support Fund of the local council. Check your council's website
- contact your local Citizens Advice or your energy company to see if any trusts can help you pay your bills
- check out **energysavingtrust.org.uk** or **gov.uk/improve-energy-efficiency** for tips on reducing your heating bills.

That second site has special advice for people in Scotland and Northern Ireland

Budgeting loans

These are short-term, interest free loans for people on a low income. The money is for basic costs like furniture, clothing or advance rent. You must pay the loan back within two years.

You, or the person with MS you support, may be able to get one if you've been claiming any of these for at least six months:

- Income Support
- Income-related Employment and Support Allowance
- Income-based Jobseeker's Allowance
- Pension Credit

How much you can borrow depends on your circumstances.

This includes whether you have savings or a family.

If you claim Universal Credit, you may qualify for a similar 'Budgeting Advance' instead.

More tips:

- find details of these loans, how much you can borrow and how to apply at **gov.uk/budgeting-help-benefits**
- read more about budgeting loans in our 'Benefits and MS' booklet

Grants

The MS Society no longer has a national grants programme. Some of our local groups offer grants. Your local group can tell you if they accept grant applications. If they do, they'll explain how to apply.

Other grants and trusts

Our MS Helpline can tell you about places like charitable trusts and other organisations that offer financial help. So give them a call.

Welfare schemes give grants to cover emergencies or a crisis. Check your local council's website to see what their scheme provides, and how to apply.

You might be able to get help if you have an urgent and unexpected financial need. This is called local welfare assistance.

In **England**, contact your local council about what help might be on offer.

In **Wales** search for 'Discretionary Assistance' on **gov.wales**

In **Scotland** the Scottish Welfare Fund gives emergency and crisis grants to vulnerable people on low incomes. Apply through your council. For more details search for 'Scottish Welfare Fund' at **gov.scot**

In **Northern Ireland** there are Discretionary Support grants or loans. For more on Discretionary Support search that phrase at **nidirect.gov.uk**

More tips:

- your local MS Society group might know of trusts or benevolent societies that help people with MS or their carers
- the Carers Trust also gives Carers Fund grants. These come from its local Carers Trust Network Partners. Search 'grants and discounts' on **carers.org**. This link has details of other trusts and charities that give out grants
- The Turn2Us site has a grants checker at **turn2us.org.uk/Your-Situation/Carers**

Help with council tax bills

You or the person you care for might get a reduction in your Council Tax.

To qualify you must be on certain benefits, or have a low income. Councils set their own rules around who qualifies for help. So it's worth checking with them.

In Northern Ireland this help is called Rate Relief. Read about this at **nidirect.gov.uk/rates-help**

If you live with the person you care for

You can't get a Council Tax discount if the person you care for and who lives with you is your:

- husband, wife or civil partner
- or a child under 18

And you must give them care for more than 35 hours per week. The person you care for must be getting one of these benefits:

- Disability Living Allowance (DLA) with the care component at the middle or high rate
- Personal Independence Payment (PIP) with the daily living component at any rate
- Adult Disability Payment with the daily living component at the highest rate
- Child Disability Payment with the care component at the highest rate
- Attendance Allowance at any rate
- Armed Forces Independence Payment

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

If you think you meet these conditions, talk to your council about applying for the discount.

If you normally live somewhere else

Do you normally live somewhere else but need to move in with the person you care for? Then you can avoid paying council tax. But only if no one's living in your home who should pay council tax.

More 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. Find it by searching **carersuk.org** for 'help with council tax'

Disabled Facilities Grants

Disabled Facilities Grants are available in England, Wales and Northern Ireland. Scotland has the Scheme of Assistance.

If a disabled person needs to make changes to their home, their council gives them money to pay for it. This could cover things like fitting a ramp, or making doors wider for a wheelchair. You can be renting or home owners, but you must intend to live in the property for five years.

You or your landlord can apply for a Disabled Facilities Grant. In some places waiting lists for this grant are long.

An **occupational therapist** will visit to see what changes are needed. A **means test** works out the size of the grant and whether you pay some of the costs. If your landlord applies, they don't have a means test.

Don't start making changes before your application is accepted. If you do, you risk not getting any money.

In Northern Ireland

In Northern Ireland, it's the local Housing Executive office and your Health and Social Care Trust (not councils) that arrange these grants. Search **nidirect.gov.uk** for 'disabled facilities grants' for more information.

In Scotland

Scotland doesn't have Disabled Facilities Grants. But if you live in private housing, you can get grants from your local council through the Scheme of Assistance. For more on all types of housing grants go to **gov.scot** and search for 'funding adaptations'.

More tips:

- ask your council about the scheme in your area and how to apply
- for more on making changes to your home, search our website for 'home adaptations'.

Personal budgets and direct payments

Has the person you care for had a social care assessment (see page 20) and qualifies for help? Then they'll get a personal budget.

This is how much their council will spend on the social care services their assessment said they need.

In Northern Ireland it's the local Health and Social Care Trust that does this, not the council. So for you, in this section when it says the council, it means your Trust.

The council can arrange and pay for these services itself. Or, if the council agrees, the person with MS can use their personal budget to pay for services. They pay using direct payments.

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

They can only use this money to buy something that's been agreed in their care and support plan. The money must go into a separate bank account. They have to keep records of how it's spent.

If the person you care for prefers, you can manage this budget for them as their carer.

There's help if you decide to manage direct payments for the person you support. The council's social care services department can put you in touch with places to help you with this.

Tip:

- read more about personal budgets and direct payments on our website. Search for 'paying for social care'

Prescription charges

Prescriptions are free in Northern Ireland, Scotland and Wales.

If you're in England, does the person you support have to pay for more than three items in three months? Or 11 items in 12 months? 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 certain benefits
- have a low income
- or have some conditions (such as epilepsy).

More tips:

- find out more by searching **nhs.uk** for 'prescription charges'
- the Pharmacy 2 U service delivers repeat prescriptions to your door for free

Travel

Do you travel with the person you're a carer for? Some railcards or concessionary cards give both of you reduced bus and train fares.

Your council or local transport operators have details. You'll find lots of ideas if you search our website for 'getting around'.

A Blue Badge helps with free parking if you drive someone with MS around. Search 'blue badge' on **gov.uk** for how to apply.

Planning for an emergency

Do you worry that one day you might suddenly be taken ill? Or an emergency means you can't look after the person you care for?

In some areas free 'carers emergency card' schemes will quickly put back-up care in place. You carry a card with a phone number that you or others call in an emergency.

Contact your council or Carer's Centre to see if there's an emergency scheme locally.

I need a break

Regular breaks can be a lifesaver. They can stop you feeling overwhelmed, and prevent 'burnout'. You can get back your strength, hope and the ability to enjoy life. Life can have a better balance again.

Carers can feel guilty about spending time on themselves. If they take a break, they worry about the standard of care while they're away.

But the price of neglecting yourself can be your physical and mental health. You could end up in no state to look after yourself or the person you care for.

A break can be with or without the person you care for. It doesn't have to be a holiday.

It can be a simple as building into your usual routine some time for yourself.

Tips:

- create time each day to pamper or treat yourself. Even better if it gets you out of the house
- make time for your hobbies, or whatever you enjoy and helps you unwind. Do things you know will make you laugh
- keep contact with friends. Invite them over if it's hard for you to visit them

Short breaks and respite care

A 'short break' usually means a holiday for you or the person you support. It can be the two of you together or separate holidays.

'Respite care' means a break from your usual routine for you and the person you support. It comes with help from a paid care worker.

The council (or Trust in Northern Ireland) or another care organisation might arrange this.

Respite can happen at home or in a special centre. In some centres you, as their carer, can stay too.

Carer's leave

Are you a carer with a paid job? From 2024 you have the right in law to take up to five days unpaid leave each year from your employer.

You can use this time off to help you carry out your caring responsibilities. Or you can use it to take a break from caring.

Find more details on our web site by searching for 'carer's leave law'.

Paying for a break or respite

You might qualify for support towards the cost of a holiday, short break or respite care.

Do you qualify for social care services from your local council (or Trust in Northern Ireland)? If you do, you may be able to use your funding package from them to help pay for short breaks and respite care.

When you have your carer's assessment, tell the council or Trust that you need respite care (and how often). If you've already had your assessment but now need respite, get back in touch with them and say you need this.

Does the person you support get a personal budget from their council or Trust as part of their social care? If so, they can use this to pay for a break for themselves. But only if this is already written into their care plan.

If they pay to have a personal assistant (PA), they can use their funding package to pay for the PA to go on holiday with them.

If you have a carer's assessment, your support plan can say you need breaks. You might get money to make these breaks happen.

> **"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 - not only on the person with it, but for those of us surrounded by it."**
>
> Sunita

More tips:

- search our website for 'breaks and holidays for people with MS' for more on breaks and paying for them
- call our MS Helpline and ask for information on short breaks. They can help with planning holidays or respite care in a residential home
- your local MS Society group might offer grants to pay for breaks. They'll know about other charities that can help with the cost
- our local groups know places locally and beyond that are suitable for a respite stay
- local carers' centres might give grants for respite breaks. Search for your nearest carers' centre at **carers.org/search/network-partners**
- the Carers Trust have practical tips for days out. These cover things like parking, transport, toilets, and free entry for carers. Find them at **carers.org/out-and-about/out-and-about**

Young carers

Looking after someone in the family with MS can bring you closer together. It feels good to know you're making their life easier. But being a young carer can be tough. Always remember: there's support out there for you

A 'young carer' is someone under 18 who helps look after a relative with a disability or health problem. They don't get paid for this. And without their help the person they care for couldn't manage.

It's usually Mum or Dad who has MS, but it might be another family member. The term 'young adult carer' covers people aged 18 to 25.

Young carers help with cooking, cleaning and shopping. You might help someone get dressed or move around. You'll give them emotional support. And you might help by looking after any brothers or sisters you have.

It's better if carers under 18 don't do some things. One is lifting someone. Without training or special equipment you could both get hurt.

Another thing is 'personal care'. That's things like washing or bathing someone, or doing things a nurse would do. Helping someone get to the toilet is OK. But if they need help to poo or pee, an adult should step in.

Young carers need time for school, homework and being with friends. You shouldn't feel your own life is on hold.

You have the right to go to college, get a job, and have a social life. Wanting this doesn't mean you're selfish or a bad person.

Young carer's assessments

This assessment works out what help you need. All carers under 18 can have one. It doesn't matter how much or how little caring you do.

> **"Knowing I can help her makes me happy. It's rewarding to know I can help her when she can't do things like get herself changed. I just know caring for mum is the right thing to do."**
>
> Tiana, MS Society's
> Young Carer of the Year, 2016

Your mum or dad (or your guardian) can ask for you to have an assessment. Or you can ask for it yourself. Contact the social services department of your local council (or Trust in Northern Ireland). If you're 18 or older, you'll have the version of the assessment that adults have.

Someone like a social worker will chat to you about how you're managing. They'll ask what kind of caring jobs you do. And how you feel about being a carer. If you don't want to do it, they can arrange for paid carers to take over.

The Carers Trust have a booklet for young carers that talks you through having an assessment. To download it google 'Carers Trust' and 'know your rights support for young carers'.

Find more help for young carers by searching our website for 'support for young carers'.

Support at school

It helps if school know you're a carer. The person you support can tell them. Or you can let a teacher or school counsellor know.

Teachers should then be more understanding if caring is affecting your schooling. If it does, your local authority's social care services can arrange help for your family.

Benefits you might qualify for

If you're a carer who's 16 or older, you might get welfare benefits. The main one is Carers Allowance.

Our web page 'Support for Young Carers' has more about who qualifies to get this and other benefits. That page has information about special support for young carers in the different nations of the UK.

Our young carers web page looks at how to deal with difficult emotions that can come up when MS is in the family. Feelings like guilt, anger, frustration and worry. There are also tips on looking after yourself as a young carer. And advice on where to turn to if you're bullied at school.

The Carers Trust has a network of local organisations. Many have groups for young carers. Check out **carers.org/our-network/the-carers-trust-network**. Call **0300 772 9600** or email **info@carers.org** for what's near you.

Also, go to the 'Help and Info' part of the Carers Trust site and you'll find a section on 'Getting support if you are a young carer'.

More tips:

- de-stress with long walks, the gym or listening to your favourite music
- the Children's Society has information for young carers. Search **childrenssociety.org.uk** for 'advice and support for young carers'

Thinking ahead

'Taking each day as it comes' might seem a good approach. But what if time comes when the care someone needs is more than you can give? It's better to think about this before it happens.

The stage might come when you reach a tipping point. You can't carry on as before. Then a range of care is available.

A team of health care workers will provide the care to the person you support. They might deliver this care at their home, or for short time in a respite care centre or care home.

If necessary, the person you care for might move permanently into a residential care home.

And don't forget: the more severely MS affects someone, the more welfare benefits are available.

There's a lot to think about when someone's MS enters a more advanced stage:

- adapting the home to meet their needs
- how to manage stays in hospital (and when they come home)
- their mobility getting worse
- planning for emergencies
- finding a residential care home, and how to pay for it
- specialised healthcare or palliative care

Legal matters

There are legal things to think about. For example, there are documents that give carers the power to make decisions on behalf of someone.

Other legal documents spell out what medical care someone is happy (or not happy) to have. These are covered in our advanced MS carers handbook (see page 54). Or download it at **mssociety.org.uk/care-and-support/advanced-ms advanced-ms**

Useful organisations

Support

MS Society

Search our website for 'Support for carers' for lots of information all in one place. Chat to other carers at **forum.mssociety.org.uk**

MS Helpline
Information and support for anyone with or affected by MS. Our operators include specialist legal and benefits advisers as well as MS nurses.

Freephone **0808 800 8000** 9am to 7pm (closed weekends and bank holidays)

Send a direct private message on Facebook messenger or email **helpline@mssociety.org.uk**

Shift MS

Community and support for people with MS.
shift.ms

MS Trust

Use their website to find your nearest MS nurse. Put 'MS services near me' in the search box.
mstrust.org.uk

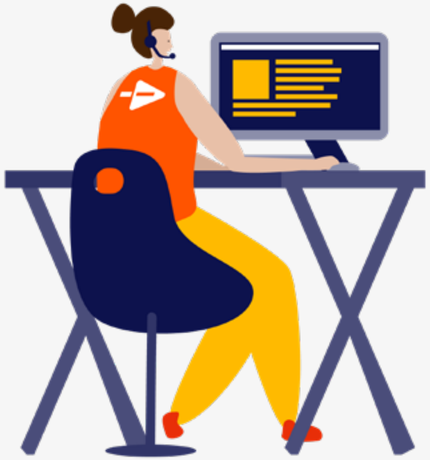
Carers UK

Information, advice and support for carers, including the Carers Connect forum
forum.carersuk.org
Helpline 0808 808 7777
advice@carersuk.org
carersuk.org

Carers Trust

Support, advice and resources for carers to live a fulfilling life alongside caring. Its network of carer organisations provide funding, help, advice and breaks from caring.

Find your nearest Carers Trust Network Partner on:
0300 772 9600
info@carers.org
carers.org



Counselling

Mind

Learn about talking therapy and counselling by entering those words into their website's search box. It'll tell you how to find someone to talk to.
0208 215 2243
supporterrelations@mind.org.uk
mind.org.uk

British Association for Counselling and Psychotherapy

Find details of counsellors on their website.
01455 883300
bacp@bacp.co.uk
itsgoodtotalk.org.uk

College of Sexual and Relationship Therapists (COSRT)

Has a list of therapists.
020 8106 9635
info@cosrt.org.uk
cosrt.org.uk

Relate

Advice, relationship counselling, family counselling and support face to face, by phone or through its website.

England and Wales
relate.org.uk
relateni.org
(Northern Ireland)
02890 323454

The MS Society in Northern Ireland also has a counselling service. Contact **028 9080 2802** for details.

Relationships Scotland

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

Pink Therapy

Counsellors and therapists for lesbian, gay, bisexual and trans people.
pinktherapy.com

Money and benefits

MS Benefits Advice Service

Part of our MS Helpline. For free confidential advice and help finding your way around the benefits system.
0808 800 8000 or email msbenefitsadvice@dls.org.uk

Turn2us

Online charity that helps people find out what benefits and grants they qualify for.
It has useful tools and resources to help you understand your options.
turn2us.org.uk

Citizens Advice

Advice on welfare rights, housing and disability. Find local offices and online information at **citizensadvice.org.uk**

Northern Ireland has the Independent Welfare Changes Helpline:
0800 915 4604.

Disability Rights UK

Information on benefits such as its Disability Rights Handbook and factsheets. They can't answer general questions over the phone but have a helpline for questions on **personal budgets**.

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

personalbudgets@disabilityrightsuk.org

This helpline 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:
0330 995 0400
disabilityrightsuk.org

Travel

Bus

Free off-peak travel on all local buses anywhere in England is available to disabled people.

Similar schemes run in Wales. Application forms are available from local councils.

Scotland
For information on cheaper travel in Scotland visit **transport.gov.scot** Search for 'concessionary travel'.

The National Entitlement Card allows free travel on most local and long distance bus services. Applications for this card can now be supported by a letter from an MS nurse instead of a neurologist.

Apply for a card from your local authority or at **entitlementcard.org.uk**

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

Train

A Disabled Person's Railcard gives a third off most UK train journeys for someone with MS and their carer.

0345 605 0525

disability@atoc.org

railcardhelp@nationalrail.co.uk

Young carers

MS Society

Search our website for 'support for young carers' for information.

Crossroads Together

Helps young carers meet others, take part in day trips and activities, and have fun breaks from caring.

0333 323 1990

headoffice@crossroadstogether.org.uk

crossroadstogether.org.uk/our-services/young-carers-services

Northern Ireland

Crossroads Young Carers Project

Social support, workshops and activities for young carers in Northern Ireland.

028 9181 4455

ycarer@crossroadscare.co.uk

crossroadscare.co.uk about-young-carers

Scotland
Call Carers Trust Scotland on **0300 772 7701** to see if there's a Young Adult Carer service in your area.

New words explained

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

care plan (or **care and support plan**) – the document that results from when someone has an assessment of their needs by their local authority. It puts in writing what services they need

CBT (cognitive behavioural therapy) – a technique a counsellor can teach you to reduce anxiety, negative thinking and depression. It helps you manage your problems by changing the way you think and behave

direct payments – a way of using the money a local authority gives someone to pay for their social care. They can only be spent on social care services that meet the needs mentioned in their care plan

hernia – an injury when part of your insides pushes through an opening or weak spot in the muscle or tissue in your groin or stomach area. This can happen when you lift someone using poor technique

mindfulness – a type of meditation. You train yourself to become more aware of your body, thoughts and feelings. Studies show it helps with stress, anxiety and depression

means-tested – when people look at your money situation (including wages, and savings) to decide if you qualify to get a welfare benefit

occupational therapist (OT) – someone (usually from a council or hospital) who helps people do everyday things. They advise on equipment, changes to the home or workplace, and can help with dealing with MS symptoms

palliative care – special medical care to improve the quality of someone's life towards the end of their life. But it can also be care that helps you live better with a serious illness over many years

personal budget – the money that someone's local authority will spend on meeting their social care needs. The amount is set out in their **support and care plan**. This budget can be managed by their carer

respite care – a break for someone or their family carer. Specialist care is provided from a few hours a day or week to longer holidays

social care – support and care services arranged by the local authority. It can include advice, help at home with personal care (washing, dressing, going to the toilet), staying in a care home, visits to day centres, or breaks for carers

support plan - when someone's carer has an assessment of their support needs by the local authority. The plan puts in writing what services they need

Further information

MS Helpline

Our MS Helpline gives emotional support and information to anyone living with MS. And through the helpline you can also access our:

- MS nurses
- MS benefits advisers
- MS legal advisers
- Physical activity service
- Short breaks service

We can provide information in different languages through an interpreter service. And by text relay and British Sign Language interpreters.

Find out more at **mssociety.org.uk/helpline**

0808 800 8000
(Mon-Fri 9am to 7pm except Bank Holidays)

helpline@mssociety.org.uk

Or direct private message us on **Facebook** (Mon-Fri 9am to 7pm)

Resources

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

You can read them online or download at **mssociety.org.uk/publications**

You can order printed resources from **onlineshop.mssociety.org.uk** or call **0300 500 8084**, select option 4

Two more booklets for family members and carers:

'**For Family and Friends**' is for when the person with MS isn't likely to need a lot of practical support (for example, because they were diagnosed recently).

'**Advanced MS – a carer's handbook**' is for people who look after someone who is severely affected by their MS and need much more support.

Search our website using those titles to download them. Or order them free as explained above.

About this resource

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

We'd love to hear what you think about this information at **mssociety.org.uk/yourviews**

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

References

Email us if you'd like to know the references for this information at **supportercare@mssociety.org.uk**

Photography

Photography: Amit Lennon (p18, 25, 34 and 46), Rebecca Cresta (p6, 13 and 30), Alex Grace (p43)

This resource is also available in large print.

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

MS Society

Contact us:

MS Helpline
Freephone 0808 800 8000
(weekdays 9am-7pm)
helpline@mssociety.org.uk

MS National Centre
020 8438 0700
supportercare@mssociety.org.uk

MS Society Scotland
0131 335 4050
enquiries-scotland@mssociety.org.uk

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

MS Society Cymru
0208 438 0700
mscymru@mssociety.org.uk

Online
mssociety.org.uk
f /MSSociety
X @mssocietyuk
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Registered with
FUNDRAISING REGULATOR

Trusted Information Creator
Patient Information Forum

BK36

This title will be reviewed within three years of publication (October 2026).

Carer's assessment checklist

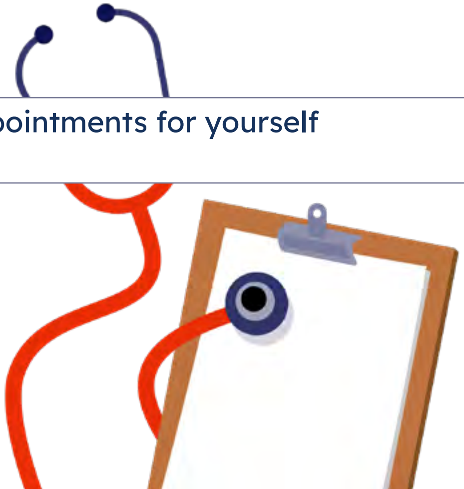
Getting ready for my assessment

If you have a carer's assessment, it's important to be prepared for it. Here's a checklist of things to think about. Fill this in for a week or so before your assessment. It could help you be clearer about the help you need. Have it with you during your assessment to jog your memory.

Day-to-day help	Yes, I do this for the person with MS I'm supporting	I do this for them every day/every week/every month (say which). Don't forget to include if you do this during the night	Each time I do this for them it takes me (say how long)
Cleaning the house			
Shopping			
Cooking meals			
Washing clothes			
Helping them wash or have a bath			
Helping them go to the toilet			
Helping them feed themselves			
Helping them take their medicines			
Helping with other medical care			
Helping them use specialist equipment			
Arranging appointments for them			
Making sure they follow therapy routines (like physio exercises)			
Helping with paperwork (mail, money, paying bills)			
Getting them from A to B (help with walking, driving them, pushing their wheelchair)			
Giving them emotional support			
Helping them express what they want to say			
Emergency care (you're available by phone, or you have a house key)			

	Yes	No
Your health and mental wellbeing		
Do you have any health problems of your own? Is caring for someone making these worse?		
Do you feel anxious, stressed or depressed?		
Do you get backaches or headaches?		
Does your GP know you're a carer?		
Do you have to move or lift the person you care for?		
Would you like any aids or adaptations to help you, like a raised chair, bed, or hoist?		
Do you get enough sleep?		
Do you sometimes get a break from caring?		
Do you eat healthily?		
Do you get enough exercise?		
Can you leave the person you care for alone in the house?		
Can you look after your own day-to-day needs? Are you getting support from other people?		
Would you like to have any telecare equipment to help you like a pendant alarm, flood detector, bed occupancy sensor or door exit sensor?		

	Very difficult	Fairly difficult	No problem
How easy is it for you to get to appointments for yourself (GP/dentist/hospital/optician)?			



	Yes	No
Family responsibilities		
Do you have family commitments as well as your caring role?		
If you're a parent, is caring making this role harder?		
Do you feel you have time for your children?		
Do you feel you have to ask your children to support you in your caring role?		
Support and leisure		
Does the person you care for have home care, or go to a day centre or lunch club?		
Does another family member or friend sometimes provide care?		
Do you get breaks where you have time for yourself, your leisure interests or time with friends? Or is caring getting in the way?		
Work, education and training		
Are you struggling to be a carer and hold down your job?		
Have you had to cut down how many hours you work?		
Would you like to go back to paid work?		
Is caring stopping you from getting any training or further education?		
Money		
Is being a carer giving you money problems?		
Would you like advice on benefits or debt?		
Risks		
Does the person you care for sometimes show challenging behaviour?		
Do you feel your housing and living conditions are suitable?		
Culture and religion		
Do you want to go to a place of worship or other regular religious and cultural activities?		
Do you have any specific religious or cultural needs?		

	Yes	No
Emergency planning		
Do you need help planning what happens if either of you suddenly becomes ill or have an emergency?		
Your views on caring		
Do you feel you don’t have a choice about providing care?		
Do you have particular concerns about the future for you and the person you care for?		

For you what’s the hardest thing about caring?

You may feel that you can’t carry on at all, or only if you reduce the amount that you do. What would you most like to change about your situation?

Who or what helps you at the moment, and is this enough?

Information and advice

How do you like to get information and advice? Such as leaflets, face to face, on the phone, on the internet, email, or in large print

Is there specific advice or information you need now?

Any other problems or worries you'd like to bring up?

MS Society

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This title will be reviewed within three years of publication (October 2026).