

A photograph of a middle-aged man and woman sitting on a black metal lawn chair on a grassy lawn. The man, on the left, has grey hair and is wearing a blue and white patterned short-sleeved shirt and khaki shorts. He is holding a small, scruffy grey dog. The woman, on the right, has brown hair and is wearing a light purple short-sleeved top and grey trousers. She is holding a wooden walking stick. They are both smiling at the camera. In the background, there is a brick house and some greenery.

Supporting someone with MS

a guide for family
and carers

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

Together, we are strong enough to stop MS.

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

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

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A word from 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.

A handwritten signature in black ink that reads "Paul". The signature is written in a cursive, flowing style with a large initial 'P' and a small dot at the end of the 'l'.

Five things to know

- 1 Nearly nine out of ten people with MS with care and support needs say friends and family give them some unpaid support with practical tasks*
- 2 One in three people with care and support needs say they rely totally on friends and family*
- 3 There's support out there for you from lots of different places. A lot of people are entitled to help but aren't claiming it
- 4 If you support someone with MS you can have an assessment of what help you need. This booklet helps you be ready for your assessment
- 5 The MS Society is campaigning for more money and practical support for carers

* My MS, My Needs 2016, MS Society survey



About this booklet

This booklet is for family, partners and friends who are supporting someone with multiple sclerosis (MS). You might find it especially useful if this is something you're new to.

We've been talking to families and carers about how they're getting on and what has helped. You'll hear what they have to say in this booklet.

This booklet tries not to overwhelm you with a lot about each topic. Instead it points you towards where you can get more in-depth information.

Being there for someone with MS is an incredibly valuable thing to do. You'll know that 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, to support yourself.

Just a couple of things. If you're the carer of someone who's very badly affected by MS then we have another booklet and other information for people in that situation that should be more useful (see page 46).

And where you see a word in bold in this booklet, it means you can turn to the back and 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 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, such as breaks and things that ease the pressure and isolation

- help with coping when relationships are difficult. Also, help with accepting the situation they're in
- to be listened to, for example, by doctors
- to have other people recognise and value the support they give

These might ring a bell with you, too. The insert that comes with this booklet called 'Getting ready for my assessment' should help you work out the help you need.

* '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 everyone feels comfortable with.

Maybe ‘carer’ makes you think of someone outside of the family who’s paid to look after someone, especially when they’re seriously ill.

If you do, you might not see yourself as a carer, too.

But do you, without getting paid, give the person with MS in your life support? And without it they’d not be able to manage? Then that describes what a carer does.

It’s up to you whether you call yourself a carer. But don’t turn down help just because it has the word ‘carer’ attached to it. For example, don’t miss out on things like:

- extra money from welfare benefits such as Carer’s Allowance or carer’s grants
- time off from your job (‘carer’s leave’) if you can get this

- the more flexible work hours that carers might be able to get
- extra support from your local council. But before you get this you need to have a ‘carer’s assessment’ (see page 22)
- protection the law can give carers, for example, from discrimination at work

“Recognising yourself as a ‘carer’ is a gradual process. It doesn’t stop you also being a husband or a wife, or son or a daughter, or a father or a 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 want answers to your questions. This might be about MS symptoms, treatments and what the future might hold – or practical help that you need.

The person you support will probably see their MS change over time. So the information and support you both need will probably change. There can be lots to take in, especially soon after a diagnosis of MS. Too much can make you feel overwhelmed or get you down.

Sometimes you want information from doctors, MS nurses and other medical experts. At other times what really helps is hearing what people in the same situation have to say.

Information can make you feel less worried, more prepared,

confident and able to cope. It can lead you to the help you need. This could be more money, care services, specialist equipment, a much needed break, or getting tips on supporting someone with MS (or yourself).

You might need new skills, too. Maybe you could benefit from learning new ways of coping or training in how to do practical caring jobs (like moving or lifting someone without risking back trouble or 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

Support groups and online forums are good places to start. Other people can share what worked for them and how they've solved a problem you're facing. Details of a few are on page 47.

These things can help both of you reduce anxiety and avoid you getting down or depressed:

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

MS nurses are fantastic sources of information and practical help.

If you don't have an MS nurse, find your nearest one on the MS Trust website (put 'map of services' in the search box on their home page).

Speaking to doctors and other medical staff

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

But you might feel left out of the picture. Make it clear you want to be included.

“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

A word about MS support groups. Lots of us find these very useful but seeing people with quite a lot of disability can upset some people. So they might not be right for everyone.

Finally, lots of useful information is aimed at carers. Even if you don't see yourself as a carer, that information could be really useful to know.

More tips:

- the MS Helpline is a great place to get information. Call **0808 800 8000** or email **helpline@mssociety.org.uk**
- we offer information through our local groups, the MS Life event every two years and the Living with MS or recently diagnosed events or training that some local groups organise. The MS Helpline can put you in touch with your local group
- check out our website **mssociety.org.uk** with its blogs, online talks ('webinars') and lively discussion forums
- MS Society booklets and

factsheets cover everything from diet, symptoms, welfare rights and work, to the emotional side of MS. Find our catalogue at **mssociety.org.uk/ms-resources/publications-list**

- check out our magazines 'MS Matters' and 'Research Matters'. Download them, get a free copy through our website or email **supportercare@mssociety.org.uk**
- other sources of information include the MS Trust, Shift MS (it has a forum for younger people with 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. This includes a free yearly flu jab, letters to support claims for a benefit, help getting appointments, repeat prescriptions, and so on.



msmatters
LIVING WELL WITH MS

"I was diagnosed live on air"
How Mary McAleese did it
and why MS is making headlines
in our first Year

MS 60
FIND OUT HOW TO LIVE WELL WITH MS

THE MS SOCIETY IS ON
THE COVER

FAMILY LIFE
Living with MS and a young child

How MS might affect our relationship

MS doesn't mean everything changes overnight. But when you're supporting someone with MS, over time it can change your relationship.

Lots of people have really positive stories to tell. Relationships can get stronger and deeper.

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 with an MS diagnosis. It's not just practical things you do that help a partner to cope. It's things like your sense of humour or positive attitude, too.

Your roles might change

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

It can be a challenge how MS can change these roles over time. These changes can disappoint or frustrate either of you or leave you feeling that you're losing something.

You may notice changes in the other person's mood. They may become depressed or anxious, perhaps have difficulty thinking and doing certain tasks. This could be a natural reaction to their diagnosis. Or it could be how MS is affecting their brain. Talk to their MS medical team to help work out what's going on.

Keep communicating

Communication in a relationship makes all the difference, especially when you're both coming to terms with the diagnosis, adjusting to changes and to the need to plan ahead. Our connections with other people need to be worked on. It can be tough to keep communication open.

Support networks help you find solutions. Talk to others in a similar situation who'll understand.

“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

Our booklet 'For family and friends' has more useful tips on how to communicate better.

Our 'Living with the effects of MS' booklet can help you understand what the person with MS in your life might be going through.

More tips:

- speak to others on online forums
- hear what's worked for others at your local MS Society group
- talk things over with someone on the MS Helpline

Family time

This has helped a lot of people.

Have a regular meeting or 'family time' when 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.

For husbands, wives and partners

MS in a couple's relationship can affect sex and intimacy. But like other parts of life, you might just need to plan a bit more and make some changes to hold on to what you enjoyed before.

MS symptoms can affect sex drives, both yours or the person you care for. Pain, bladder issues, muscle spasms or weakness and the extreme tiredness of MS fatigue can be passion killers. MS treatment may have side effects that get in the way. The emotional impact of MS can, too.

This can all cause anxiety, stress, guilt feelings or sadness (maybe even depression). Either of you might feel confused, rejected, angry or isolated. Or that you're no longer attractive.

If there are already communication barriers, talking about these personal things could be hard. But if you put off bringing them up it can make it harder in the long run to put things right. It's better not to wait until a problem

has become established before you reach out for support.

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

We have a booklet 'Sex, intimacy and relationships' that looks at these issues in more detail (see page 54 for how to get it). It covers physical problems related to orgasms, erection problems, dryness and where to turn for help.

More tips:

- talk to someone anonymously on the MS Helpline or ask for advice from our online forum
- choose times and positions for sex that are more comfortable and less tiring for your partner
- if talking about sexual problems is hard, write it down and hand it to your partner or a health professional

- mention sexual problems as part of a wider chat about bowel and bladder issues. That can make it easier to talk about
- look into counselling from a sexual and relationship therapist (see page 49). Ask your GP or your partner's MS nurse what's available on the NHS or privately
- the organisation Relate can give you advice or counselling on your relationship, face to face, by phone or through its web site (see page 49). Many counsellors offer counselling using Skype
- some couples find that they enjoy intimacy more from kissing, cuddling, touching and foreplay, with less focus on penetration
- the MS Trust has two booklets on sex, 'Sexuality and MS: a guide for women' and 'Sex and MS: a guide for men'. Download them from this part of their site mstrust.org.uk/a-z/talking-about-sexual-problems

“We have to constantly keep communication open and respect how each other might be feeling. MS is difficult and affects many aspects of life, but through honesty and open discussion, we learn to adapt and change”

Alan

“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

Supporting someone with MS can take much of your time and drain your energy. Looking after your own physical and emotional health can slip.

But if you become exhausted or ill yourself, how well can you look after the person you want to support?

Lack of sleep, back problems from lifting someone, a poor diet, stress and feeling down (maybe depressed) could mean you're not there for them in the way you'd like to be.

You might develop negative feelings about your situation and the person you care for. Guilt is one example.

These reactions are totally natural but can be hard to live with. Getting help in facing up to them can take the pressure off you.

More tips:

- give yourself 'me time' away from MS. Even if it's just going for a long walk, walking the dog or meeting up with friends
- build into your routine ways of de-stressing and relaxing
- '**mindfulness**' is a big help to many people (see page 52)
- call the MS Helpline to talk through negative feelings you're struggling with
- speak to your GP if you're feeling down or that you're struggling to cope. Acting now could avoid depression later
- don't become isolated. Carers groups, your local MS Society group or online forums can put you in touch with people who know just what you're dealing with
- look into having a carer's assessment (see page 22)

Social care - getting help from the council

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

Social care services help people with an illness or disability 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
- information

The person with MS you support 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 come to talk to them about the help they need.

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. Most people pay something themselves towards these services, depending on their money situation.

By making things easier for the person you support with MS, social care services can make your life easier, too.

In Northern Ireland

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

If he or she goes to a day centre, or has a short break or some respite care, this means you get a much needed break (see 'I need a break' for more on p 40).

Equipment or changes to your home will make it easier for you to do things for them. They might qualify for someone to come and provide care in their home. That means someone can do jobs 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 22.

The MS Society booklet 'Social care – getting support from your council' has more details on social care, including tips for someone with MS on preparing for their assessment.

More tips:

- to save time the person you support 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 about how you feel 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
- 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

“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

My carer's assessment

The law says you now have the right to have the council of the person you support look at what help you need to care for them.

This is called a 'carer's assessment'. You might not see yourself as a 'carer' or think you need one now. But having one could really help you out. And it's good to know they exist in case you feel you'd benefit from one in the future.

If your assessment 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 20).

Your assessment could help you get things such as:

- 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)

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 in your support plan. Or the local council might provide what you need.

Whether you pay for any of this depends on whether the council charges (they don't all charge). If the services are provided to the person with MS that you care for, then their money situation will be assessed.

In 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'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 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 to save time. But you might prefer to be assessed separately.

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 your assessment decides you don't qualify for support, the council must at least give you information and advice on other services that could help you. You can appeal against the decision. And if your caring role changes a lot you can ask to be assessed again.

How long does this take? Will it make a difference?

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

There's no guarantee a carers 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)
- before your carer's assessment make sure you're prepared for it. The insert that should be inside this booklet will help
- Carers UK has more information on carers assessments at carersuk.org (click on 'practical support' in the Help and Advice section)

Confused about assessments?

There are two assessments you need to know about:

1. The carer's assessment – this looks at what help you need to support the person in your life with MS. This help will come from that person's council
2. The care and support needs assessment – this looks at what support the person with MS needs from their council's **social care** services. Our booklet 'Social care' has more on this.

In Northern Ireland the local Health and Social Care Trust does both assessments and offers the support.

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



Juggling caring with my other responsibilities

At the same time as you're giving support to the person in your life with MS, you'll have other responsibilities. Holding down a job and running a home can add to the strain. There might be hospital appointments and, from time to time, a crisis or two.

Much of your time and energy can be taken up supporting the person with MS. If you have kids, looking after them and making sure they don't get neglected can be another worry. Juggling these things can be a hard. All this can leave you exhausted, stressed and feeling a failure.

More tips:

- talk to people in online forums or carers support groups who've been through this and found solutions
- find carers groups near to you on the Carers UK website [carersuk.org/help-and-advice/get-support/local-support](https://www.carersuk.org/help-and-advice/get-support/local-support)
- if you need to let off steam or vent your feelings, the MS Helpline is run by people trained in giving emotional 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 there for someone with MS while holding down a job can be a tricky balancing act. But there's help you can call on. And the law can protect you from an employer harassing you or discriminating against you because you're someone's carer.

There might be a period when you need to change your normal 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 requested this in the previous year.

Flexible working could cover things like flexible hours, working from home, going part time and job sharing.

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 could cover medical emergencies and accidents. It could also 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. Check this and your work's HR policies to see if you can get more than the basics guaranteed by law.

Should I tell work I support someone with MS?

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 these extra responsibilities at home will hopefully mean you'll get more support and understanding from them.

Support while you're at work

Could you do with more help, either for yourself or for the person you care for while you're out at work? A carer's assessment could identify how you might get extra support from the local council of the person you support (see page 22).

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 page 20 for what kind of support). That could make it easier for you to hold down your job.

Private care

If money isn't an issue, you could arrange privately for care and support while you're at work. Your local council will have details of local providers of care that they've approved. Under 'useful organisations' (page 47) you'll find places that list registered care services.

Should I cut my hours? Leave my job?

Depending on your circumstances, 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.

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

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.

**“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

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

More tips:

- read more about Carer’s Credit at www.gov.uk/carers-credit
- check out the part of the Carers UK website called ‘Help with your pension’
- visit the Carers UK ‘Work and career’ web page and booklet
- download the Carers UK Factsheet ‘Your rights at work’ from carersuk.org
- encourage your workplace to put a carer’s policy in place



Money and benefits

MS can hit finances hard. It can mean a lost income, perhaps two if you need to give up work to help support someone. When someone has a disability it can mean additional expense, such as extra costs of getting around, special equipment, insurance costs, extra heating and so on.

But you can get help from the benefits system. That's something you have a right to. You're only claiming back money you paid in for years.

Benefits could be available to both you and the person you care for with MS, regardless of whether you work or not. 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, especially if the MS of the person you support gets worse. Our 'Benefits and MS' booklet has up to date information of what's available.

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

turn2us.org.uk

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.

A Blue Badge, for example, 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.

Another tip

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

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

Carer's Allowance

You might get this if you're 16 or over and look after someone for at least 35 hours a week. They must be getting 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.

As their carer you mustn't be in full-time education and you mustn't earn more than £116 a week from employment after certain deductions are made (correct in May 2017). You don't need to be living with the person you care for.

If you're claiming Carer's Allowance, you may be able to get this topped up with a **means-tested** benefit like Income Support or Pension Credit.

More tips:

- read all about Carer's Allowance in our 'Benefits and MS' booklet. Get one by calling the MS Helpline, or download it from our website or order free from our online shop
- claim Carer's Allowance by filling out a claim form from the Carer's Allowance Unit (**0345 608 4321**); textphone **0345 604 5312**.
- in Northern Ireland call **0800 220 674**; textphone **028 9031 1092**
- or download a form from gov.uk/government/publications/carers-allowance-claim-form, or claim online at gov.uk/apply-carers-allowance

if the person you support goes into hospital or residential

care, your Carer's Allowance will stop after four weeks. You must tell the benefits authorities when they go into hospital or residential care and come out.

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**. It's being replaced by Universal Credit.

More tips:

- claim Income Support by calling 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](https://www.gov.uk/government/publications/income-support-claim-form)

Pensions

If you're thinking of working fewer hours or giving up your job to care for someone, this could affect your pension. Read more on page 28.

Other sources of financial help

Budgeting loans

These are short-term, interest-free loans 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. 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.



More tips:

- if you qualify for one, you and the person you support can apply for a budgeting loan
- before you get this loan your circumstances will be looked at
- apply by filling in the claim form from your local Jobcentre Plus office or download it from [gov.uk/budgeting-help-benefits/how-to-claim](https://www.gov.uk/budgeting-help-benefits/how-to-claim)
- read more in our 'Benefits and MS' booklet
- in Northern Ireland some details about budgeting loans are different. Find out more at nidirect.gov.uk/articles/budgeting-loans
- 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

Grants from the MS Society

The MS Society has two grant funds for people with MS and their carers. There's the carer's grant and the health and wellbeing grant.

Grants can help towards equipment, adaptations, **respite** breaks and support for carers and families. You don't have to be a member of the MS Society to apply.

Some grants your local MS Society group can give from their own funding. If there's a group in your area, we'll send your application on to them to consider first. If they can't help, or can't cover the whole cost, they'll ask the grants team to consider a top up.

More tips:

- you'll find more details of these grants, what they can and can't be used for, plus the form to fill in at mssociety.org.uk/grants
- for more about MS Society grants contact the Grants 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.

If you have an urgent financial need you weren't expecting, you might be able to get local help. This is called local welfare assistance.

In England, contact your local council about what help they might be able to give you. In Wales search for 'Discretionary Assistance' on gov.wales. In Northern Ireland search for 'Help from the social fund' on nidirect.gov.uk/

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

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 grants to carers. Enter 'grants

available' in the search box on their website carers.org

- details of around 40 other trusts and charities that give out grants can be found in this Carers Trust factsheet: carers.org/sites/files/carustrust/grants_and_other_sources_of_funding_0.pdf
- the Turn2Us site has a grants checker on this link: www.turn2us.org.uk/Your-Situation/Carers

Help paying council tax

You and/or the person you care for may be able to apply for a reduction in your Council Tax bill if you're on benefits or have a low income, and little or no savings. In Northern Ireland this is called Rate relief. Councils can set their own rules around who qualifies for help, so it's worth checking with them.

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. But 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

If you usually live elsewhere but have to move in with the person you care for, you can be made exempt from paying council tax on your own home (as long as no-one is living there 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: www.carersuk.org/files/helpandadvice/4039/factsheet-uk1024-help-with-council-tax-2017-2018.pdf
- 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

Disabled Facilities Grants

Disabled Facilities Grants are available in England, Wales and Northern Ireland. Scotland has its own scheme (see below). They may be given by councils to people with a disability so that they can make changes to their home, for example, having a ramp fitted or doors made wider.

To get this, 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 the length of the grant period (five years).

A Disabled Facilities Grant is usually **means-tested**.

More tips:

- your local council can give you advice about the scheme in your area and how to apply
- the Scottish Government has information on help with adaptations. Go to **gov.scot** and put 'funding adaptations' in the search box
- wherever you live in the UK, the MS Society booklet

'Adaptations and your home' has more information

Personal budgets and direct payments

If the person you're supporting had a social care assessment (see page 20) and was judged to qualify 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, not the council, but we'll refer to councils in this section.

The council can arrange and pay for these services itself. Or, if the council agrees, the person with MS can pay for services using their personal budget. They pay using a **direct payment**. If the person you're supporting prefers, you can manage this budget for them as their carer.

A direct payment gives more control and flexibility over the services you get. You can only use this money to buy something that'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 must keep records of how it's spent.

If you decide to take on the responsibility of managing direct payments for the person you support, your council's social care services department can put you in touch with places to help you with this.

Another tip:

- read more about personal budgets and direct payments in our booklet 'Social care - getting support from your council'

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 qualify for free prescriptions if you get some benefits, have a low income or certain conditions (such as epilepsy).

More tips:

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

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 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.

Another tip:

- contact your local council or Carer's Centre to see if there's an emergency scheme locally



I need a break

Having a break can be a life saver – whether it's with or without the person you support. A break doesn't have to be a holiday. It could be just 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 you support, either the two of you together or separate holidays.

'Respite care', on the other hand, gives you and the person with MS you support a break from your usual routine but with help provided by a paid care worker arranged by the council or another care organisation. Respite can happen at home or in a special centre. In some centres, as their carer, you can stay too.

Paying for a break or respite care

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

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

Tell the council when you have your assessment 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 the person you support gets a **personal budget** from their council as part of their social care, then they could use this to pay for a break for themselves if this is in their **care plan**. Or, if they pay to

have a personal assistant, they could use their funding package to pay for them to come on holiday with them.

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

The MS Society might also 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

Our booklet 'Short Breaks – a guide to holidays, short breaks and respite' has details of charities that might help pay for a holiday for you or the person with MS you support. It also lists accessible travel agencies and respite companies.

“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:

- for details of help from the MS Society in having a break check out our 'Short breaks' booklet, call **020 8438 0700**, email **grants@mssociety.org.uk** or visit **mssociety.org.uk/grants**
- you can apply for a grant through your local MS Society group. They'll also know places locally and beyond that are suitable for a respite stay
- your local MS Society group will know about other charities that help with the cost of breaks

- ‘Tourism for all’ is a charity dedicated to making tourism welcoming to all to its members. Its website has a guide to getting help paying for a holiday: tourismforall.org.uk/news.htm
- a section on our website covers having a break. Find it at mssociety.org.uk/shortbreaks
- local carers’ centres may give grants for carers to take a respite break. Search for your nearest carers’ centre here carers.org/search/network-partners
- 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 carers.org/article/out-and-about



Young carers

If your mum or dad has MS, looking after them can bring you closer together. It can feel good to know you're helping them stay active and you're doing things that make life easier for them.

Mum or Dad may be worried, feeling down or might get angry. They're probably not angry with you but with their MS.

But you're dealing with your own feelings about their MS as well as theirs. How you feel counts, too. You might feel better if you talk about your feelings and get some support.

Being there for them can put pressure on you. You might be doing things for them like housework, shopping, cooking or looking after any brothers or sisters you have.

Juggling this with school and wanting to be with your friends can be tricky. But when you're under 18 and supporting someone with MS, there's help you can get from your local council.

“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

You can have an 'assessment'. Someone from your council will come and talk to you to see what help they can give you (and any brothers or sisters you have).

If you want a break, or don't want to look after your mum and dad anymore, you can ask for help with that, too. For example, after you leave school you might want to go to college or get a job. An assessment can help work out what the family needs to support you to do that.

To get an assessment you or an adult (like your mum, dad or social worker) should contact the Social Services department of your local council or its Children's Services department. If you're in Northern Ireland, contact your local Health and Social Care Trust.

The MS Society has a booklet 'MS in your life – a booklet for young carers'. Put 'MS in your life booklet' into the search box on our website.

More tips:

- de-stress with long walks, exercise, the gym or listening to your favourite music
- ask relatives or friends of your mum or dad to spend an evening with them so you can

have time off with your friends

- the Carers Trust has a guide for young carers called 'Know Your Rights'. It has more about the assessment you can have. Download it from [carers.org/know-your-rights-support-young-carers-and-young-adult-carers-england](https://www.carers.org/know-your-rights-support-young-carers-and-young-adult-carers-england)
- the Carers Trust Network Partners support young carers and young adult carers. They offer support such as breaks, activities and someone to talk to. Call 0844 800 4361 or visit Carers.org or email support@carers.org
- watch videos of people who are supporting their mum or dad with MS here: [mssociety.org.uk/ms-resources/life-young-carer-zenas-story](https://www.mssociety.org.uk/ms-resources/life-young-carer-zenas-story)

Telling school

Speak to your mum or dad about telling school about their MS. Letting school know you look after them could be a big help. Teachers will be more understanding if it's having an effect on your life at school



Thinking ahead

There can come a time when the care needed by the person you support is more than you can give.

You might wonder ‘what if the person I support eventually needs a lot more care?’ Then a range of care is available.

A team of health care workers will provide this care. They could get this at home, or for short time in a respite care centre.

If necessary, the person with MS could move into a residential care home. Also, the more affected by MS someone becomes, the more help they can claim in welfare benefits.

Our booklet for carers of people very badly affected by MS will be available from September 2017. Our ‘My MS, My Choices’ booklets about the issues that people with advanced MS face will be available by then, too. Get them from our website or the MS helpline.

Tip:

- if you’ve got worries or questions about what might happen in the future, call the MS Helpline or talk it over with an MS nurse if you have one
- there’s more about the advanced stage of MS in the ‘severely affected’ section of our website: mssociety.org.uk/ms-support/people-severely-affected-by-ms

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 for lots of information in one place on our website.

Chat to other carers on our forum: community.mssociety.org.uk/forum

MS Helpline (see back cover for details).

Grants – call **0300 500 8084**, email grants@mssociety.org.uk or visit mssociety.org.uk/grants

Shift MS

A social network for people with MS. Popular with younger people: shift.ms/

MS Trust

Useful information about MS, including where the nearest MS nurse is. Put ‘map of MS services’ in the search box on their website: 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’ or ‘young carers’ plus the name of the town or county you live in.

0300 772 9600

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.

Care services regulators

England

The Care Quality Commission is the health and social care regulator and has an online directory of registered independent care services.

03000 616161

cqc.org.uk

Wales

The Care and Social Services Inspectorate Wales is responsible for inspecting social care and

social services and has an online directory of registered care services.

0300 7900 126

cssiw.org.uk

Scotland

The Care Inspectorate regulates and inspects care services and has an online directory of registered care services.

0345 600 9527

enquiries@careinspectorate.com

www.careinspectorate.com

Northern Ireland

The Regulation and Quality Improvement Authority (RQIA) is the independent health and social care regulator and has an online directory of registered care services.

028 9051 7500

Email: **info@rqia.org.uk**

rqia.org.uk

Counselling

British Association for Counselling and Psychotherapy

Details of counsellors can
be found on their website:
itsgoodtotalk.org.uk

College of Sexual and Relationship Therapists

Has a list of therapists.

COSRT

PO Box 13686

London SW20 9ZH

Tel: **020 8543 2707**

Email: **info@cosrt.org.uk**

cosrt.org.uk

Relate

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

relate.org.uk (England and Wales)

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

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

Turn2us

An online charity that helps people find out what benefits and grants they qualify for. It has some useful tools and resources to help you understand what your options are.

turn2us.org.uk

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 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

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. For information on cheaper travel in Scotland visit **transport.gov.scot** and put 'concessionary travel' in the search box.

For Northern Ireland concessions, 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

Young carers

MS Society

Information, and advice, including about grants.

**mssociety.org.uk/ms-support/
for-carers/young-carers**

Hear young carers talking at
**mssociety.org.uk/ms-resources/
life-young-carer-zenas-story**

Barnados

**barnados.org.uk/what_we_do/
our_work/young_carers.htm**

Crossroads Young Carers Project (Northern Ireland)

028 9181 4363

ycarer@crossroadscare.co.uk

crossroadsyongcarers.co.uk/

New words explained

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

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

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

direct payments – a way of using the money a council gives someone with MS to pay for their social care. It can only be spent on social care services and things that meet the needs in their **care plan**

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 allows you manage your emotions. Studies show it helps with stress, anxiety and depression

means-tested – you only get a welfare benefit that is 'means-tested' if you can show that the money you have coming in from wages, savings, and so on, is below a certain level

personal budget – the money set out in the care and support plan of a person with MS that their council will spend on meeting their social care needs. This budget can be managed by their carer

respite care – a break for a person with MS or their family carer where specialist care is provided (anything from a few hours a day or week to longer holidays)

social care – support and care services that the local council arranges. Includes help at home with personal care (washing,

dressing, going to the toilet), care homes, day centres, breaks for carers and advice. In Northern Ireland the local Health and Social Care Trust arranges social care

support plan - when the carer of a person with MS has an assessment of their support needs by the local council. It puts in writing what services they need

Further information

Library

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

020 8438 0900

librarian@mssociety.org.uk

mssociety.org.uk/library

Resources

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

020 8438 0999

shop@mssociety.org.uk

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

publications

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, especially Suzette Gregu and Jennifer Kelly from Carers Trust's Advice and Information team.

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

Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability

for any errors or omissions. Seek advice from the sources listed.

References

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

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

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This resource is also available in large print.

Call **020 8438 0999**
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](https://www.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

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Carers assessment checklist



Getting ready for my assessment

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

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

	Yes	No
Your health and mental well-being		
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 doing 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 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?

Information and advice

How do you like to get information and advice?

Such as leaflets, face to face, on the phone, on the internet, email, or in large print

Is there specific advice or information you need now?

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

Contact us



MS Helpline

Freephone 0808 800 8000

(closed on weekends and bank holidays)

helpline@mssociety.org.uk

MS National Centre

0300 500 8084

info@mssociety.org.uk

supportercare@mssociety.org.uk

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