



**Social care**  
getting support from  
your council

**England**

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](https://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 Carlyne, whose husband has MS

MS is unpredictable, with its ups and downs. For some people, like my husband Tony, it's got steadily worse. It was inevitable that at some stage we'd need help to carry on living in the family home and to cope with his increasing disability. After almost a year in hospital that need became immediate.

Tony had first class life-saving treatment in hospital. Every aspect of his care was catered for. It was like a big, cosy blanket of protection making us feel safe. Occupational therapists, physiotherapists, medical and nursing staff and a social worker worked with us to help Tony come home. Tony himself worked the hardest, with grit and determination at each therapy session.

You may need the same grit and determination when you journey into the social care system. It can be complicated and daunting at first. There'll be an assessment

of what help you need. There may be an assessment of your finances, because fees can be involved for some services.

The grant system for home adaptations can be a slow process. There can be a long wait for a community occupational therapist to prescribe equipment. But with patience it's worth it, so that you can carry on living independently.

My advice is: be clear at the assessment stage about what help you need to remain as independent as you can be.

This booklet will guide you and help you understand how needs are assessed and how the system works. I hope you find its information helpful and wish you all the best.

*Carlyne*

# Five things to know

- 1** The 2014 Care Act means you can now have more control over the care and support services you get
- 2** You'll have an assessment to see if you qualify for care and support and what services you need. This booklet helps you be ready for your assessment
- 3** After your assessment you'll get a 'care and support plan'. This spells out what care you need and which services you should get
- 4** You may have to pay towards the cost of some services
- 5** Do you look after someone with MS? If you do, you also have a right to have an assessment of what you need as their carer



# About this booklet

This booklet is about ‘social care’ for adults with multiple sclerosis (MS). If you have MS you might need social care, especially if your MS gets worse. If you’re the carer of someone with MS you might benefit from social care, too.

‘Social care’ means services, support, money or equipment from your local council. They help you live an independent life, hold on to your dignity and feel in control.

You get these services in the community you live in, either at home or in a day centre or residential care home.

Social care covers:

- equipment or changes to your home that make life easier
- someone to help at home with things like getting washed or dressed, cleaning,

going shopping and getting out and about

- moving into residential care instead of living at home
- information and advice services
- support for family carers who look after someone with MS

Some services are free but most people pay something towards them. In this booklet you’ll find out what support you might get, how to get it and how it’s arranged (and paid for).

This booklet is about social care in England. Much of it is true for other nations within the UK. You’ll find details in our separate booklets for Wales, Scotland and Northern Ireland.

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 type of help might I get?

A law called the 2014 Care Act brought in big changes to social care. You now have more choice and control over services that can help you keep your independence.

The help you qualify for depends on an assessment you'll have with someone from your local council (see page 14).

Social care services can cover:

## Equipment and changes to your home

You might need special equipment or small changes to your home to make it safer and easier to get around. Examples are hoists, grab rails, ramps or wider doors. An **occupational therapist** is the person who looks at what changes or equipment you need. Your council can arrange for you to have alterations.

Your council may charge you if you need a change to your home that costs more than £1,000, such as a stairlift or walk-in shower.

If you want equipment that costs more than what your council offers you may have to pay the extra yourself. For example, you might want a bath seat in the same colour as your bathroom. You might choose to pay for it yourself.

If you own your home, you can apply to your council for a Disabled Facilities Grant (DFG) to pay for these changes. You'll first have an assessment of your money situation. You may not get the full cost of what you want. In some places waiting lists for these grants can be long.

If you live in a council or a housing association property, your landlord should carry out adaptations for you. Ask your housing officer how to apply. If you rent privately your landlord must make changes that are



'reasonable adjustments' - or let you pay for them. Private landlords can get help (such as a DFG) to pay for alterations. Our booklet 'Adaptations and your home' has details.

## Home care

Care at home gives you support to stay independent. You arrange it yourself or your council can.

You could hire a 'personal assistant' (PA) to come to your home. You pay for this with money your local council gives you (a '**direct payment**'). A PA may work for only a few hours a week, or several hours each day (or night), helping with things like:

- **personal care** (getting in or out of bed, washing, showering, dressing or using the toilet)
- eating or preparing meals
- cleaning your home, for example, vacuuming
- food shopping
- help with taking medication
- driving you or helping you get out and about
- supporting you so that your family carer can have a break

If you don't hire a PA you could get help directly from your council or from a local care agency (arranged by your council). But things like cleaning, shopping or transport might not be included.

With a care agency your council will tell them what times and days you need help. In some areas you can choose which agency you use.

You can pay for this kind of home care from the money the council gives you as your '**personal budget**'. There's more about personal budgets and direct payments on page 25.

Whether you hire your own PA or the council arranges your care, be clear from the start about what support you expect and when.

## Day services

Some councils run day centres, with social and leisure activities. If you qualify for support with things like these, your council can arrange for you to visit one to help you decide if you'd like this.

## Short breaks and respite care

If a partner, friend or someone in your family regularly looks after you, your council might help arrange a break ('respite care'). This could be for a morning or afternoon each week or longer.

The options include:

- your carer goes on holiday and someone else looks after you while they're away
- you stay at a care home until they come back
- you get support in your own home
- you go to a local day care centre during the day
- you and your carer or family get help to go on holiday (together or separately)

Our booklet 'Short breaks' has more on this and how the MS Society might help pay for a short break or holiday.

**Social care also looks at other ways of helping carers. Page 30 looks at this in more detail.**

## Residential care

If you need a lot of support, your council might suggest residential care. You'll move out of your home permanently to live in a new one where more help is available.

This could be a care home with 24 hour care or a house or bungalow adapted to meet your needs. You keep some independence but get the care and support you need.

You shouldn't be forced into a care home. You have the right to stay in your own home and have your needs met there – if that's what you want and it's practical. You might be able to have 24 hour care in your home instead. If you do decide to go into a care home you should be offered a choice of places.

Page 23 looks at paying for a care home. Our booklet 'Residential care and your options' will tell you more.

## Information

Your local council must help you get the right information and advice about care and support

when you need it. Information should be easy to get hold of and understand and be tailored to what you need. That's true whether or not you've had an assessment. And it's true whether or not your assessment decides that you qualify for support.

Council-funded information services include their website, leaflets, advice centres, libraries, independent living centres or their special social care helplines or contact centres.

### **'Continuing healthcare'**

'Continuing healthcare' is a package of care for people at home (or in a care home). To qualify for this you must have very complicated health needs that aren't going to go away. It can support you with things like bathing, getting dressed and laundry. It can pay for your care home, too.

This isn't part of social care, so it's not dealt with by your council. It's paid for by the Health Service (NHS) but some parts of it might be paid for by your council. You won't be charged for any care you get from the NHS.

This type of care is hard to get. First you need to have an

assessment of your needs. It doesn't matter how much money or 'assets' (property, pensions and so on) you have.

If your MS gets worse and social care is no longer enough to cover the support you need, ask your social worker about being assessed for continuing healthcare.

For more information visit **nhs.uk** and search for 'continuing healthcare'.

For advice and tips of getting this kind of care, check out this organisation's website and publications:

**caretobedifferent.co.uk**

# How do I get social care services?

Before you can get these services your local council must find out what care and support you need and what you qualify for. They do this by giving you a 'needs assessment'.

## What should I do first?

Contact your local council's Social Services department or its contact centre and say you want to be assessed for social care. Their details are on your council's website, in local libraries, doctors' surgeries or the phone book.

They might send you a form to fill in and send back or ask some questions over the phone. If they decide you might qualify for help, you should get a visit later from someone who'll do the full needs assessment.

Don't let your council put you off asking for an assessment. They

can't decide whether you need care services unless you have one.

The law says anyone who seems to need care must have an assessment. You may be told you don't qualify to have one but you can appeal against this decision (see page 27).

## The assessment: what you can expect

The assessment is designed to find out what care and support you need. It'll look at the effect on you if nobody takes care of these needs. It'll look at whether you can do a range of things and how this is affecting your well-being.

You'll qualify for support from your local council if your assessment shows that **all three** of the following are true for you:

1. What you need is a result of a physical or mental health problem or illness (such as MS).

2. You find it very hard, or impossible without help, to do two or more things in the numbered list on pages 14 and 15.

3. Not being able to do these things is likely to have a significant impact on your well-being.



# My assessment

You should feel properly involved in your assessment, with enough time to say what you want to.

The assessment is between you – and anyone you'd like with you – and someone from your local council. This is a trained person, often a social worker. He or she will ask what's important to you and what support you need to live how you'd like to.

You'll also be asked about:

- your personal circumstances. For example, do you live alone? Does anyone support you already?
- what everyday things you can do without help
- what you can't do – and the effect this has on you. For example, if you can't leave your house without help this means you can't get to the shops to buy food
- things you'd like to do, but need support with. Examples would be being able to go out, see friends or exercise
- the risks to you if you can't do these things. For example, if you can't make your own meals, your health and well-being could be at risk

There'll be questions about ten things in particular.

## 1. Eating well

How does your MS affect how you can prepare meals and get drinks?

## 2. Keeping clean

How easy is it for you to wash yourself and your clothes?

## 3. Using the toilet

Do you have difficulties getting to a toilet and using one?

## 4. Getting dressed

Can you put on the clothes you need, such as warm clothing in cold weather?

## 5. **Moving around your home**

Can you do this safely, including getting into your home?

## 6. **Keeping your home clean and safe**

## 7. **Staying in touch**

How easily can you keep in contact with family and friends and meet new people so that you don't get lonely?

## 8 **Keeping busy**

How able are you to start work, stay in a job or get to work, education, training or volunteering?

## 9. **Using local services**

How easy and safe is it for you to use things like public transport or leisure facilities?

## 10. **Looking after others**

Do you have difficulties caring for people who rely on you, such as a child?

If you need help with two or more of these your council must support you. They could do this by giving you information about local support. Or give you gadgets to help you do things (like open jars

or tins) or make changes to your home (like putting in handrails). Your assessment might show that you need more help at home to get washed or dressed.

If you don't have MS but look after someone who does, as their unpaid carer you can have an assessment of what you need, too. Read more on page 30.

## **Doing the assessment**

Some councils might ask you to fill in the assessment on your own and post it back – or do it online or over the phone. An assessment over the phone should only happen if:

- your needs aren't complicated
- or if your council already knows you
- or if you've had an assessment before and there's been a change in what you need

It would help if your assessment is face to face. MS can cause problems with your memory or thinking, so face to face assessments can work better.

It's also good to have a partner, friend or family member with you for help and support.

Need help understanding or filling in the assessment? Don't have someone you feel you can ask? Then the council should provide you with an **advocate**. See below for more on this.

The person assessing you will be trained but they're not always a social worker. Don't expect them to know a lot about MS.

That's why it's important before your assessment to prepare what you want to say. That way it's clear what support you need.

## Who can help me with my assessment?

Perhaps you don't have a partner, friend or someone in your family

who you'd like to ask for help. In that case, you have the right to ask for an independent **advocate**.

An advocate can help you apply for social care services and when you're assessed. He or she is someone who supports you through the process from start to finish. They'll help you understand what's happening and to say what your needs are.

To find an advocate contact your local council or Voiceability (details at the back of this booklet).

## Before

Here are some things to think about before your assessment:

- don't pretend you don't need help when you do. If it's a struggle to do something, make that clear, even if it's something you can manage
- be realistic about what you can manage. Maybe you can manage to do something but how does this leave you feeling for the rest of the day?
- don't underestimate how long something takes. If you're not



- sure, time it. If a bath takes an hour, put down one hour
- if doing something takes longer on a bad day, say so
  - life is more than getting up, getting food and going to bed. You can ask for help to visit family and look after your children. It covers having a social life, such as going to the pub, visiting friends, going on a course or whatever you'd do if you had support to do it
  - don't assume the person assessing you will really understand MS or how it affects you. He or she might have assessed other people with MS but their needs may be very different to yours

## During

During your assessment:

- be honest. Some people try to hide their condition and problems they have. If you do that you won't get the help you need
- say what you'd like to happen. For example, say what you need to be more active or to feel safer

- make clear what support you get from carers and family. Even if your family will keep doing this, your **care plan** needs to cover what happens if there's a time when they can't give this support

## More tips

- write down what support you need. Use a diary or the table on pages 28–29
- list equipment you need to help you do things
- think what you might need in the future if your MS gets worse, such as equipment
- collect evidence about your medical needs. For example, your doctor or other professionals may want to say something to back you up. Make sure you hand this over during your assessment
- write down your medication and why you take it
- if you want someone you know at your assessment, make sure they can be there when it happens

## After

Afterwards your local council should give you a copy of the results of your assessment. They must offer you help with needs your assessment has identified.

If you qualify for help, you and the council will draw up your **care and support plan**. This describes the help you can have. Within the first three months your council's social services department should look at your plan again and then do this at least once a year after that.

You might be told you don't qualify for social care. You can appeal against this decision (see page 27). If the assessment decides you don't qualify for support you should get a letter explaining why not. If your council can't help you directly, they should at least tell you about organisations that might help.

Your council has a duty to stop (or delay) your need for support getting worse. Here's an example: at the time of your assessment you might not qualify for a carer

to support you at home. But if the council agrees to fit a ramp in your home that could mean you're less likely to fall and need care at home in the future.

**If at any time you feel your needs have got bigger or things have got more difficult, you have the right to ask for a review of your care plan.**

On pages 28 and 29 you'll find a table that you can fill in. It will show which everyday things you have difficulty doing. This will help you work out what support you need.



# My care and support plan

If your assessment shows that you have things the council must help you with, you'll agree with them what will be in your **care and support plan**.

This plan puts in writing:

- what your assessment decided that your needs are
- what support the council will put in place to meet these
- your personal budget. That's the amount of money the council will spend on meeting your needs
- any needs that your council won't meet

Your social worker can help with your plan – so can friends and family or an **advocate**.

You should be given a copy of your plan that you can understand and refer to.

The plan should answer questions such as:

- what's important to me?
- what do I want to change?
- how will I arrange the support I need?
- will I manage my own **personal budget**?
- how will I stay in control?
- what will I do next?

If the council say you have to pay for all of your care yourself, they should still provide information and advice about how to get support and how much it will cost.

You'll find useful guides to help you think about your support plan at **[in-control.org.uk](http://in-control.org.uk)**

Put 'Making your support plan' in the search box on the front page. You'll then find a booklet with that name. Or you can call them for one on **01564 821 650**.



# Do I pay for social care?

Information and advice services are free. But most people pay something towards other care services.

This will depend on the assessment of what you need and of your money situation. The assessment looks at:

- your income. This won't include wages you earn from a job. But it does count pensions or money you get from renting out a property
- savings
- investments
- whether you get benefits or other financial support. This includes Disability Related Expenditure (see the next page)
- your expenses, such as bills or rent

If you own a home, this won't be taken into account – unless you want to move into a residential care home (see the next page).

Your council will then give you a **personal budget** to pay for services. How big this is depends on your money situation and the cost of the services you need. You shouldn't be asked for more than you can pay.

You'll have to pay the full cost of your care if your 'capital' or 'assets' are worth more than a certain amount. In England this is £23,250.\*

Your assets include your savings, income, pensions, or investments. If your assets are worth less than £23,250 you'll get help from your council to pay for services.

If you own a home and want home care, how much it's worth won't be taken into account when deciding how much to charge you.

\* This was the limit in March 2017 but it will go up.

## If I move into residential care do I have to sell my home to pay for it?

If your council is arranging for you to move into residential care, the first step is for them to work out how much you might need to pay.

They'll give you a means test to see what assets you have. This includes savings, income (from pensions or renting out property) and the value of your home if you own it.

In England you'll have to pay for all the cost of your care home if the value of what you have is over £23,250. If the value is less than this you'll get help from your council to pay for your care home.

Many people do sell their home to pay for a care home. But it doesn't automatically have to happen.

If you need to sell to pay care home costs you can arrange with your council to delay paying them ('deferred payment'). The council can pay for you and you pay them back when you decide

to sell or when your house is sold after you die.

**Your home won't be part of your means test if your partner or a relative under 16 or over 60 or who is disabled is living there,**

Our booklet 'Residential care and your options' will tell you more.

## Disability Related Expenditure

When your council decides how much you must pay towards your services, they should take into account your 'Disability Related Expenditure'.

This is money you spend because of the extra costs of having a disability. It's also what you'd spend if you weren't worrying about the high cost involved.

Here are some examples:

- the cost of extra heating, laundry or electricity
- special clothes. Using a wheelchair might cause extra wear and tear. Or you may need special clothes because

of bowel or bladder problems

- wheelchair insurance
- paying for a gardener
- travel. For example, taxis to medical appointments or day centres (or places where no accessible alternatives exist)

This can protect your savings.

An example would be if you can show you need to save to replace an adapted vehicle or specialist equipment. Then you could ask your local council to take these costs into account.





# Personal budgets and direct payments

If you qualify for social care services you'll be given a **personal budget** to pay for your care. This is how much money your council will spend on meeting your needs. It's part of your **care and support plan**.

You use your personal budget to pay for things that help meet the goals in your plan. For example, if it says you need to exercise, your budget could pay for gym fees.

## Managing my personal budget

There are three ways of managing your personal budget. You can:

- ask your local council to do this for you
- manage it yourself as a **direct payment** or ask someone else to do this, such as your partner, family member or a **'broker'**
- ask the organisation that gives you a service to manage your budget. This is called an Individual Service Fund (ISF)

## Direct payments

If your council agrees to pay for your care services you can choose to get your **personal budget** for this as a direct payment. This means you can get some or all of your personal budget as a payment that goes straight to you. How much you get depends on the results of your assessment.

Direct payments can give you more control and flexibility over the support you get. You can choose who comes to help you, what they do and when. You can use direct payments to help with things that a care agency provides such as **personal care**. But direct payments can also help with further education, leisure activities or getting to the shops.

## How direct payments work

Direct payments aren't benefits and don't affect benefits you get. They're not seen as income, so won't put you over any limit you must be under to get a welfare benefit. You pay no tax on them.

They must go into a separate bank account, not your normal one. You can only use them to meet needs in your **care and support plan**. You must keep records of how you spend them.

Most people use their direct payments to hire one or more 'personal assistants' ('PAs'). They support you with the care and help you need. You employ them, so you're in charge of the rules, times and standards.

You can also use a direct payment to pay for care from an agency or to pay for short-term residential care. If you want, you can use a mix of direct payments and services from the local council.

**If you need residential care all the time then direct payments aren't for you.**

## Help managing direct payments

Direct payments and hiring a personal assistant can bring real benefits but extra responsibilities. Before your council offers you direct payments, they should make sure you can manage this and offer support with it.

Your council's social care services department can put you in touch with support with direct payments. Find support on the **Disability Rights UK Resource Directory** (see page 32).

Your carer, partner, someone in your family or a friend can manage your direct payments for you. Or use an independent **broker** or **advocate** from a disabled people's organisation. You could manage some of your direct payments yourself while someone else manages the rest.

Ask your council's social care services department about local brokers or advocates. **Disability Rights UK** also offer help with direct payments (see page 32).

# I want to complain or appeal

You have a right to appeal if you think your council made the wrong decision about your care. And you can complain if you're not happy with a service you get.

## Appeals

You can appeal if:

- your council decides you don't qualify for support but you feel you should
- you feel the council didn't look at all of your needs when they made their decision
- you qualify for services but feel enough isn't being offered

Find information on appeals at your local library or on some councils' websites. The Disability Rights UK Advice Line helps with appeals as well (see page 32).

## Complaints

First take your complaint to whoever gives you the service, your social worker (if you have one) or

local social services team. If that doesn't work, your council has a way of dealing with complaints (their 'complaints procedure'). It tells you how to complain, how this is handled and how fast the council should reply. Find your council's complaints procedure on their website or call them. Or get it from your library or social worker.

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

Find support from your local MS Society group (details from the MS Helpline) or local Citizens Advice - or use an **advocate**. Your local councillor or Member of Parliament might take on your complaint, too.

If you don't get a reply, report it to the local government and social care ombudsman. Details at [lgo.org.uk/adult-social-care](http://lgo.org.uk/adult-social-care)

# Thinking about what I need

Fill this in to help you be ready for your assessment. Find tips on pages 16–17.

<b>My personal needs</b>
Getting in/out of bed
Moving around safely at home (such as using stairs)
Having a wash, bath or shower
Getting dressed and undressed
Using the toilet
Looking after my personal hygiene (for example, cleaning teeth, washing hair and clothes)
Taking medication
(for women) Hygiene during my period
<b>My needs at home</b>
Making meals and getting drinks
Shopping for food
Shopping for other things
Keeping my home clean and safe
Essential gardening
<b>My needs to do with everyday life</b>
Staying in touch with my family, keeping up with friends or making new ones
Staying active (such as exercise, keep fit or gym)
Looking after money and bills
Looking after children
Getting around (driving or with public transport) and using public services
Having access to work, volunteering or college/university
Enjoying my hobbies and free time
Other things important to me:

I can do this without help	I can only do this with help	I need help with this every day/ week/month (say which)	I can't do this but want to

# Can carers have their needs assessed too?

A carer is a partner, family member or friend who looks after someone with MS on a regular basis without getting paid. Without this help they couldn't manage.

You might not like to see yourself as a carer but if you do it can get you a lot of help.

As a carer you now have the right to be assessed by your council. The assessment should cover:

- your role as a carer and how it affects your life and well-being
- your health, including physical, mental and emotional issues
- your feelings and choices about caring for someone
- 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 problems
- planning for emergencies

If you and the person you care for both agree, you can both be assessed at the same time.

You can have an assessment even if the person you look after had one and it decided they didn't qualify for support.

If your assessment decides you qualify for help, then a **support plan** is made for you. It looks at ways of helping you. For example, it could arrange for you to have a break from caring, pay some of your transport costs or help with housework or gardening. Or it could arrange for support for the person you care for that will make your life easier.

Organisations that support carers are listed on the next page. The MS Helpline has more information for carers, too.

# Useful organisations

## Care Quality Commission

The independent regulator for health and social care services in England.

03000 616161

[cqc.org.uk](http://cqc.org.uk)

## Carers Trust

Information, advice and support for unpaid carers (family and friends) through its carers' centres. Also has grants for carers.

0300 772 9600

[carers.org](http://carers.org)

## Carers UK

Information and telephone support for unpaid carers (family or friends) from their helpline

CarersLine 0808 808 7777

(Monday to Friday 10am–4pm)

[carersuk.org](http://carersuk.org)

## Citizens Advice

Free, confidential information and advice on money, legal, consumer and other problems. Local offices

are in the phone book and on their website. They also run an online advice guide.

Helpline 03454 04 05 06

[citizensadvice.org.uk](http://citizensadvice.org.uk)

## Disability Law Service

Free, confidential legal advice and support for disabled people, their families and carers. They deal with employment, welfare benefits, housing and disability discrimination law. They cover **legal issues** to do with:

- care needs assessments
- charges for care
- funding of care
- cuts to services
- **direct payments** and **personal budgets**
- Continuing Health Care
- adaptations
- Disabled Facilities Grants

Find more details at:

[dls.org.uk/free-advice/online-advice/community-care-law/](http://dls.org.uk/free-advice/online-advice/community-care-law/)

The MS Society funds a dedicated MS Legal Officer there who can give legal advice and information.

Telephone/textphone **020 7791 9800**.

Email: [msadvice@dls.org.uk](mailto:msadvice@dls.org.uk)  
[dls.org.uk](http://dls.org.uk)

## 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](mailto: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](http://disabilityrightsuk.org)

## Disabled Living Foundation

Free, impartial advice about all types of specialist equipment.

Helpline **0300 999 0004**  
[dlf.org.uk](http://dlf.org.uk)

[livingmadeeasy.org.uk](http://livingmadeeasy.org.uk)

## inControl

Information, tools and resources to help people take control of their own health and social care.

**01564 821 650**  
[in-control.org.uk](http://in-control.org.uk)

## VoiceAbility

Provides support in parts of England for people who face disadvantage or discrimination. Also has useful tools for people using the social care system.

Helpline **0300 330 5454**  
[imca@voiceability.org](mailto:imca@voiceability.org)  
[voiceability.org](http://voiceability.org)



# New words explained

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

**advocate** – independent person to help with care and support plans, assessments and making complaints

**broker** – someone you hire using your **personal budget**. They help manage budgets, give advice, write care plans and try to solve problems you have with services

**care and support plan (or ‘care plan’)** – you and your council write this if an assessment decides you qualify for help. It puts in writing what services you need. ‘Support plans’ are the plans that carers have

**direct payments** – a way of using the money your council gives you to pay for social care. It goes into a special bank account. You can only spend it on social care services

**Individual Service Fund (ISF)** – with an ISF your council gives your **personal budget** to an organisation that provides services. You tell them the services you need. With ISFs you have control over services without

the responsibility of direct payments

**occupational therapist** – someone who supports you to do daily tasks and keep your independence. They suggest practical changes to how you do things and alterations to where you work or live

**personal assistant** or ‘**PA**’ – a person you hire with your **direct payment** to help at home with **personal care**. They can also help you shop, cook, do laundry, get to work or visit friends

**personal budget** – the money set out in your care plan that your council will spend on meeting your social care needs

**personal care** – help with getting up, washed or dressed, eating and going to the toilet

**respite care** – a short break for you and/or a family carer (from half a day each week to longer holidays)

**social care** – support and care services that your local council arranges. Includes help at home with **personal care**, care homes, day centres, breaks for carers and advice

# 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/**  
**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.

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

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

## References

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

Contact the librarian on **020 8438 0900**, or visit [mssociety.org.uk/library](https://www.mssociety.org.uk/library)

## Photography

Photography: Amit Lennon (cover, p13, 19 and 24) and Simon Rawles (p6, and 21).

This resource is also available in large print.

Call **020 8438 0999**  
or email [shop@mssociety.org.uk](mailto:shop@mssociety.org.uk)

# Contact us



## MS Helpline

Freephone 0808 800 8000

(closed on weekends and bank holidays)

helpline@mssociety.org.uk

## MS National Centre

0300 500 8084

info@mssociety.org.uk

supportercare@mssociety.org.uk

## Online

mssociety.org.uk

facebook.com/MSSociety

twitter.com/mssocietyuk

## MS Society Scotland

0131 335 4050

msscotland@mssociety.org.uk

## MS Society Northern Ireland

028 9080 2802

nireception@mssociety.org.uk

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0300 500 8084

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