

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.'

Contents

A word from Alan, who has MS	4
Five things to know	5
About this booklet	7
Help that's available	8
How do I get social care services?	12
My assessment	14
My care and support plan	19
Do I pay for social care?	21
Personal budgets and direct payments	24
I want to complain or appeal	27
What help do I need?	28
Assesssments for carers	30
Useful organisations	31
New words explained	33
Further information	34

A word from Alan, who has MS

I've had MS for 14 years. Not everyone with MS will feel they need help from the social care system but many do, and I'm one of them.

I've had wonderful help from lots of sources without giving it the label 'social care'. For example, my occupational therapist has helped me find – and often fund – adaptations to my home as my needs have changed.

My wife and I realised we could no longer cope with my personal care. Washing, dressing, getting in and out of bed became too demanding and unsafe. Calling in a social worker was a difficult step but one I had to make. After a false start with someone new to the job who didn't know the regime, I had an assessment of my needs and got 'into the system'.

I have to pay for care myself, which puts a strain on the family budget. And learning new concepts like Self-directed Support or Direct Payments was a struggle, too. This booklet will help.

I think I've got the hang of it. I now realise how varied care needs can be. Every individual is unique and their needs change over time. Keeping your needs assessment under review is crucial.

There's a lot of help out there.
The welfare state is a wonderful thing. The first big step is being motivated to ask and understanding how the system works. This booklet will help you take it.



Five things to know

- New laws* passed by the Scottish Parliament mean social care in Scotland has changed. You now have more control and choice over the social care services you get
- 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
- After your assessment you'll get a 'care and support plan'. This spells out what care you need and which services you should get
- You may have to pay towards the cost of some services
- 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

^{*} The Social Care (Self-directed Support) (Scotland) Act 2013 and the Public Bodies (Joint Working) Scotland Act 2014.



About this booklet

This booklet is about social care for adults in Scotland with multiple sclerosis (MS). If you have MS you might need social care, especially if it 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. These 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. This will be either at home or in a day centre or care home.

Social care covers:

 equipment or changes to your home that make life easier

- having help at home with things like getting washed or dressed, cleaning and getting out and about
- moving into a care home instead of living in your own home
- information and advice services
- support for family carers who look after someone with MS

Some services are free but many 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).

Where you see a word in bold in this booklet, turn to the back and you'll find it explained.

There you'll also find where you can get more help such as from the MS Helpline on **0808 800 8000**.

Help that's available

There's a new way of getting social care services to people in Scotland. It's called **Self-directed Support (SDS)**.

This involves planning your social care with your council in a way that gives you more control and choice over the services you use.

You only qualify for these services if an assessment decides your needs are big enough. You have this assessment with someone from your council (see page 14).

What 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 of equipment are walking sticks, commodes and leg raisers. Examples of adaptations include hoists, grab rails, ramps or wider doors. Our booklet 'Adaptations and your home' has more details.

Home care

Home care (or 'home help' or 'home support') is something you get in your own home that helps you keep your independence.

This could be regular visits from a home care worker sent by your council or by a care agency. It could also be someone you hire yourself (a 'personal assistant', see page 25).

Home care can help with things like:

- personal care (see next page)
- general cleaning, heavy housework and gardening
- shopping
- 'meals on wheels' or having frozen meals delivered
- collecting pensions and prescriptions
- paying bills
- washing clothes and ironing (in your home or a laundrette)
- equipment and adaptations
- 'reablement'. This is up to six weeks of personal care from your council after you leave hospital. It helps you live

independently again at home

Care workers from the council or a care agency might not do things like cleaning and shopping.

Personal care

Personal care is a part of home care that deals with things of a personal nature. In Scotland personal care provided by the council is free if you're 65 or over. The Scottish Government has said that from April 2019 personal care will be free for people under 65 too.

Personal care can include help with:

- baths, showers, washing your hair, shaving, keeping your mouth and teeth clean, and nail care
- bladder or bowel-related things. This includes help with going to the toilet, taking care of a catheter, skin care, incontinence laundry and changing the bed
- eating, special diets and preparing food
- moving around
- simple treatments such as eye drops, putting creams and lotions on, simple dressings

- and oxygen therapy
- getting dressed, using hoists, getting in and out of bed, and help with surgical appliances
- counselling and support. This covers gadgets that remind you to do things

Nursing care involves a nurse doing things like giving injections or looking after pressure sores. You or the council arrange nursing care.

Personal care could come from your council or a care agency (arranged by your council). With a care agency your council tells them what times and days you need help. In some areas you can choose which agency you use. You can pay for this from the money the council gives you as your 'personal budget'.

Another option is to hire a 'personal assistant' (PA). 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). How long they work depends on what your assessment said you need. Read more about personal budgets and direct payments on page 24.

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 this, your council can arrange a visit to help you decide if you'd like this.

Short breaks and respite care

If a partner, friend or family member looks after you, your council might arrange a break ('respite care'), maybe 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 where more help is available. This could be a care home with 24 hour care or a house or bungalow adapted to your needs. You keep some independence but get the care and support you need.

You shouldn't be forced into a home. You have the right to stay in your own home and have your needs met there – if it's practical.

You might get 24 hour care in your own 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' has more on this.

Information

Your council must help you get tailored, easy to understand information and advice about care when you need it. This should be true whether or not you've had an assessment – and even if the assessment decided you don't qualify for support.

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

Hospital Based Complex Clinical Care

Before 2015, something called Continuing Healthcare could be provided to those with very complicated long term health problems, either at home or in a care home rather than in a hospital. In Scotland, this has now been replaced by Hospital Based Complex Clinical Care.

Whether you qualify for this depends on your answer to the question: Can your care needs be properly met in anywhere other than a hospital? If, after a full assessment, the answer's

yes, you'll be discharged from NHS care into:

- · your own home with a care plan
- a care home
- or supported accommodation

You may then have to pay towards the cost of your care or care home. Your local council's charging policies will apply.
After you leave hospital the NHS will still look after your medical needs free of charge.

More information can be found at **careinfoscotland.scot** (put 'hospital based complex clinical care' in the search box).

How do I get social care services?

Your council must first find out what help you need and what you qualify for. They do this by giving you an assessment.

What should I do first?

Contact your local council's health and social care department or its contact centre. Tell them 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.

When you phone the council, you'll be asked questions to find out how urgent your needs are. If they're not, you may have to wait a few weeks for your assessment. You should get a visit later from someone who'll assess you.

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 person who carries out the assessment with you may be a:

- social worker or care manager
- district nurse
- occupational therapist
- another care professional

You can have a friend, relative or **advocate** with you during the assessment, even if they're not directly involved in caring for you.

The next chapter looks at assessments in more detail.



My assessment

The assessment is a chat with someone (like a social worker) from your council. You should feel fully involved in your assessment, with enough time to say what you want.

The person who assesses you will visit you (maybe more than once) to find out what care and support you need. They'll look at what might happen to you if nobody takes care of these needs.

They'll ask questions about:

- things you find hard to do
- what you'd like to be able to do
- help you get from family, friends or other carers
- what your care needs are
- specialist needs you have because of your MS
- risks to you if you don't get the right support
- and how suitable your home is for you

They should ask you what matters most to you. The information goes into creating your care and support plan. This sets out how the council can help you with what you need.

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?

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?

This will help the council decide what support you need. This could be information about services or gadgets to help you do things (like open jars or tins). It might mean changes to your home, like putting in handrails. Your assessment might show that you need more help getting washed or dressed.

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

MS can cause problems with your memory or thinking. So it's good to have a partner, friend or family member with you for support.

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.

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.

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. If not, you have the right to ask for an independent **advocate**.

An advocate can help you apply for social care services and help during your assessment. They'll support you 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 Scottish Independent Advocacy Alliance (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's 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. They 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 and support plan needs to cover what happens if there's a time when they can't

After

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

If you qualify for help, you and the council will draw up your **care and support plan**, describing help you can have.

Within the first three months your council should look at your plan again and then review your care plan at least once a year after that.

Who qualifies for help is different from council to council. You might be told that you don't qualify for social care under your council's rules. If the assessment decides you can't have help, you should get a letter explaining why not.

More tips

- write down what support you need. Use a diary or the table on pages 28-29
- list equipment or technology you need to help you do things
- think what you might need if your MS gets worse, such as equipment, changes to your home or a move to a more suitable place to live
- collect evidence about your medical needs. If your doctor or other professionals 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

If your council can't help you directly, they should at least tell you about organisations that might help. If your assessment decides you don't qualify for help, you can appeal (see page 27).

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.

Looking out for each other

People with MS often rely on others to look after them in their home or outside it. These carers (paid or unpaid) and family members usually do a great job.

But what if you feel something's not right about how they're treated? Maybe you feel this is making them unhappy and they need some support. Or perhaps you're the person with MS and you want to talk about how you're being treated.

Talk over your concerns by calling the MS Helpline on **0808 800 8000** or email them at **helpline@mssociety.org.uk**. You could also contact your local council's adult services department.

My care and support plan

If your assessment shows that you have things the council must help you with, you 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, they should still provide information and advice about how to get support and how much it will cost.



Do I pay for social care?

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

If your assessment finds that you need social care services, you might be charged for some of them. This depends on your council's charging policy. Their social care department will look at your money situation and work out if you must pay and how much.

This assessment of your finances looks at:

- money you have coming in
- savings
- investments
- whether you get benefits or other financial support.
- your expenses, such as bills or rent

Each council in Scotland has its own rules about how much you must have in assets before you start to pay for services. Personal care

services are free if you're 65 or over, no matter how much you have.

Before you say yes to a service, you must be told how much you'll have to pay. If you own a home, this won't be taken into account (unless you want to move into a care home – see page 23).

Your council will 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. Read more about personal budgets on page 24.

Some equipment comes free of charge, like walking sticks, commodes and leg raisers. You can use your personal budget if you want to choose equipment yourself. You'll pay the full cost and it'll be your job to get things installed, repaired and maintained.

How much this costs will be set out in your council's charging policy (ask their social care department for it).

Information about funding more expensive adaptations in your home can be found on the Scottish Government website. You'll find detailed information for home owners, council and private tenants at gov.scot/Topics/Health/Support-Social-Care/Independent-Living/Equipment-Adaptations

The assessment of your care needs is free. So are any medical services or equipment you get from the NHS.

Free personal care

Personal care provided by your local council is free in Scotland if you're 65 or over. Page 9 has more on what personal care covers.

If you're 65 or older you'll get this whether you're single or in a couple. It won't matter how much you have in 'capital' or 'assets' (what your savings, property or investments are worth).

If what you need isn't personal care, you may be charged for it. This may be for things like housework, shopping and making beds. Charges are different from council to council.

Nursing care from the NHS in your own home is free no matter what your age and should be provided by your GP surgery.

If you're 65 or over and need personal and nursing care in a care home, you can get a flat rate payment towards the part of the home fees that cover personal and nursing care. You must still pay towards your accommodation and living costs in the care home.

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

If I move into a care home, do I have to sell my home to pay for it?

If your council is arranging for you to move into residential care, first they'll work out how much you might need to pay.

Then they'll assess your finances 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.

The value of your home won't be counted if your partner is living in it or a relative who's under 16, over 60 or disabled lives there.

If your assets are under £17,000 you won't pay anything. If they're over £27,250* you pay all the costs of your care home. If you have between these two amounts, you'll pay some of the costs, based on a sliding scale.

Many people sell their home to pay for a care home but it's not always necessary. There may be alternatives to care homes, such as supported accommodation or sheltered housing.

If you do need to sell your house to pay care home costs, you can arrange with your council to delay paying them ('deferred payment'). The council can pay for you. You then pay them back when you decide to sell or when your house is sold after you die.

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

*correct as of April 2018.

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

When it comes to managing your personal budget, you've four options:

- manage it yourself as a direct payment or ask someone else to manage it 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)

- 3. ask your local council to do this for you
- 4. or you can choose a mix if these options

More information can be found at the Scottish Government website about Self-directed Support at selfdirectedsupportscotland.org.uk

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. You'll 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.

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 things like further education, leisure activities or getting to the shops are mentioned in your care and support plan, you can pay for them with a direct payment, too.

How direct payments work

Direct payments aren't benefits and don't affect any 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.

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

Help managing them

Direct payments and hiring personal assistants bring real benefits but extra responsibilities. Before your council offers you this, they should make sure you can manage it and offer support. Ask about help to manage direct payments.

Your carer, partner, a family member or friend can manage direct payments for you. Or use a **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 and health department about local brokers or advocates. Disability Rights UK also offer help with direct payments (disabilityrightsuk.org).



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 (0300 555 1525 Tue and Thurs).

Complaints

First take your complaint to whoever gives you the service, your social worker (if you have one) or local social care 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 quickly 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 the Scottish Parliament might take on your complaint, too.

If you don't get a reply, report it to the Scottish Public Services Ombudsman. Details at **spso.org.uk**

What help do I need?

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

My personal needs
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
My needs at home
Making meals and getting drinks
Shopping for food
Shopping for other things
Keeping my home clean and safe
Essential gardening
My needs to do with everyday life
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		

Assessments for carers

A carer is a partner, family member of friend who looks after someone with MS without getting paid. Without this help the person with MS 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. If you qualify for help, then a **support plan** is made for you. It could arrange for you to have a break, pay some transport costs, or help with housework or gardening. Or it could arrange for support for the person you care for and that will make your life easier.

The assessment should cover:

- your role as a carer and how it affects your life and what you want from life
- your health, including physical, mental and emotional issues

- your feelings and choices about being a carer
- a plan in case of emergencies

You can also talk about support, such as a short break or planned regular breaks from caring. You'll agree how often your support plan is reviewed and whether your plan is meeting your personal goals.

You and the person you care for can both be assessed at the same time – if you're both happy with this. You can have an assessment even if the person you look after had one and it was decided they didn't qualify for support.

We have a carers assessment checklist to help you get ready for the assessment. You'll find it in the print and online versions of our booklet 'Supporting someone with MS'.

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

Useful organisations

Care Information Scotland

Information and support on Social Care and Health in Scotland. Helpline and web chat available.

Helpline 0800 011 3200 careinfoscotland.scot

Care Inspectorate

Regulates and inspects care services in Scotland to make sure that they meet the right standards.

0345 600 9527 enquiries@careinspectorate.com careinspectorate.com

Carers Trust Scotland

Information and support for carers. Includes listings of local carer groups across the UK.

0300 123 2008

carers.org/country/carers-trustscotland

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/scotland

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/scotland**

Disability Information Scotland

Disability related information and advice in Scotland.

0300 323 9961 info@disabilityscot.org.uk disabilityscot.org.uk

Independent Living Fund Scotland

After the UK Independent Living Fund closed in 2015, the Scottish Government set up this fund. Its

job is to run the fund for people already getting money from the old one. A new fund is now available but only to provide money for a year for physically or mentally disabled young people (16 to 21).

0300 200 2022 www.ilf.scot

Scottish Independent Advocacy Alliance

A membership organisation that makes sure that Independent Advocacy is available to any vulnerable person in Scotland. Provides information on advocacy available across Scotland.

siaa.org.uk

Scottish Personal Assistant Employers Network

Offers a range of support and services to self-directed support users across Scotland. This ranges from HR and employment related advice and guidance for employers of personal assistants, to Managed Account Services and Support Planning.

0845 601 1156 info@spaen.co.uk spaen.co.uk

Scottish Public Services Ombudsman (SPSO)

Offers help when a complaint to an organisation that provides a service hasn't been sorted out.

0800 377 7330 spso.org.uk

Self-directed Support

A one-stop-shop for information about self-directed support for people who use social care services. selfdirectedsupportscotland.org.uk

Shelter Scotland

Provides information on housing and homelessness including information on adaptations for all housing types. Web chat available.

Helpline **0808 800 4444** scotland.shelter.org.uk

New words explained

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

advocate/advocacy – independent person who helps 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. The plans carers have are called 'support plans'

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 some of your personal budget to a service you use. With ISFs you have control over your services without the responsibility of direct payments supports you to do daily tasks and keep your independence. They suggest practical changes to how you do things and 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 – money in your care plan that your council will spend on 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)

Self-directed support (SDS) – the name for how people who need support and care services get these. SDS gives more control over how you get support and how you pay for it

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 or you can complete our short online survey at 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**

Photography

Photography: Davie Dunne

This resource is also available in large print.

Call **020 8438 0999** or email **shop@ mssociety.org.uk**

Contact us

MS Helpline

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This title will be reviewed within three years of publication.





