


A portrait of a middle-aged man with short grey hair, wearing glasses and a grey sweater over a dark shirt. He is smiling and holding a cane with an orange handle. The background is blurred, showing what appears to be an indoor setting with warm lighting.

Social care
getting support from
your Health and
Social Care Trust

Northern Ireland

A large orange triangle pointing downwards from the top left corner of the page, creating a diagonal split between the orange and white background.

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 Ralph, who has MS	4
Five things to know	5
About this booklet	7
Self Directed Support	8
What type of help might I get??	10
How do I get social care services?	16
My assessment	18
My care and support plan	22
Do I pay for social care?	23
Personal budgets and direct payments	26
I want to complain or appeal	29
What help do I need?	32
Assessments for carers	34
Useful organisations	36
New words explained	40
Further information	42

A word from Ralph, who has MS

I've had MS for 25 years. Over the past four years my physical condition and mobility have deteriorated. So I had to seek support from my local Health and Social Care Community Disability Team.

After an assessment by my social worker, I was given guidance on help available to me and my wife, who gives me most of my care. Very quickly lots of very knowledgeable professionals assessed me to see what I needed.

As my mobility got worse, I needed help with personal hygiene and getting from my wheelchair to my bed. The care manager, occupational therapist and the district nursing team drew up a care plan. A team of carers now provide help five times a day.

The occupational therapist and physio advised me on which adaptations for my home and equipment I needed. With these I could carry on being cared

for safely in my own home. They also helped me fill out applications for grants for them.

A Carer Coordinator arranged a carer's assessment for my wife. This looked at the support she needs to carry on being my carer. She now gets short breaks from caring.

The care I need changes. I have a review once a year (or more if necessary). That's central to all the support I get. And living with a long-term disability can lead to feeling isolated. So quick access to relevant up-to-date information and support is vital.

With this sort of information, a booklet like this will be extremely useful for people with MS and their families looking for support.

A handwritten signature in black ink that reads "Ralph". The letters are cursive and fluid, with a large 'R' and a long, sweeping tail on the 'h'.

Five things to know

- 1 Local Health and Social Care Trusts provide care and support services. People now have more control over which services they get and how they get them
- 2 You have an assessment from your Trust to see if you qualify for care and support and what services you need. This booklet helps you be ready for your assessment
- 3 If your assessment finds you qualify for help, you'll get a 'care and support plan'. This spells out what you need and the 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 and support for adults in Northern Ireland who have multiple sclerosis (MS). If you're the carer of someone with MS, you might benefit from these services and support too.

'Social care and support' means things your local Health and Social Care Trust offer such as services, money and equipment. These can help you live an independent, healthy, and active life – and keep your dignity, and feel in control.

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

Social care covers:

- equipment or changes to your home that make life easier
- someone to help at home. This might be help around your home or with your personal care, or help to go shopping and get out and about
- day care services
- short breaks
- moving into residential/nursing care or supported living instead of living at home
- information and advice
- support for family carers who look after you

Some services are free but you may have to pay towards others. 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, 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**.

Self Directed Support

Self Directed Support is a new way people in Northern Ireland get social care services from their Health and Social Care Trust.

It's how you plan your care with your Trust. It gives you more choice, control and flexibility over:

- how your needs are met and which services you get
- how money (your **personal budget**) is spent on the services you need

To get Self Directed Support you first must be assessed by a social worker or key worker from your Trust. This decides if you qualify to get social care support. What help you can have depends on what this assessment says (see page 18).

If it finds you don't qualify for help, you'll get information and support to look at other options. This could be advice on how to make yourself more independent - or help you can get from other organisations.

With Self Directed Support you have a **personal budget** to spend on your social care. You can use it in these ways:

- let your Health and Social Care Trust arrange services for you
- have a **Managed Budget**. Your Trust holds the budget but you're in charge of how it's spent
- use a direct payment (a cash payment). Instead of letting your Trust provide you with a service, you get a cash sum that you use to pay for it
- or choose a mix of these options

Tips:

- find out more from your Trust, from its Self Directed Support Implementation Officer or at **hscboard.hscni.net/SDS**
- the Centre for Independent Living also has information on Self Directed Support and direct payments at **cilni.org**
- learn more about direct payments and personal budgets on pages 26-27.



What type of help might I get?

Social care and support services covers a range of services. Let's look at what the types of support are.

Equipment and changes to your home

You might need special equipment or **adaptations** to your home to make it safer and easier to get around. Examples are hoists, special chairs, or aids that help you walk or bathe.

An **occupational therapist** from your Health and Social Care Trust will carry out an assessment of your needs.

Aids are free but if you need adaptations to your home, you might need to pay for some of the work. You'll have an assessment of your income to work out if you need to pay anything. You might qualify for a grant to pay for the work.

The Northern Ireland Housing Executive (NIHE) carries out adaptations for people. They can

do this whether you rent privately, own your home or live in council or housing association property.

They also give people grants (such as Disabled Facilities Grants) to owner occupiers, landlords or private tenants to help pay for alterations (see page 37).

You don't need to go through an occupational therapist to get some smaller adaptations. Examples of these include:

outside – handrails at front or back of your home, widening of paths around the property and outdoor lighting.

inside – an extra stair rail, changing door knobs to lever handles, fitting extra power points, moving electrical sockets or lowering cooker switches, changing or adding lighting, accessible window openings, changes to your kitchen such as lowering or replacing cupboards and more storage space.

You also don't need a referral from an occupational therapist for smaller adaptations to your home such as:

a level access ('walk in' or 'wheel in') shower, a shower over the bath, ramps, special baths, fitting non-slip surfaces, and space in your shower for a wheelchair.

If you need nursing equipment like **commodes**, specialist beds or mattresses, you'll get these after an assessment from a district nurse from your Health and Social Care Trust.

Tips:

- explain the type of adaptation you want to your District Housing Executive Office. They'll advise you on how to get it
- the NIHE website **nihe.gov.uk/adaptations** has information on adaptations, including on funding for home owners, council tenants and those who rent privately
- check out our booklet 'Adaptations and your home'

Care in your own home (domiciliary care)

These services help keep you healthy, clean and safe at home. You get them from your Health and Social Care Trust or from organisations your Trust pays to provide them.

A social worker or other **key worker** from your Trust will assess you to see if you qualify for this. They'll look at what you need, and support you get from a carer or from your family.

If you qualify for this, you'll get a home care worker who can help with:

- **personal care**
- taking medication
- laundry
- shopping
- meals

Home Help is free if you're on certain benefits and over 75. Otherwise you'll need to have your money situation assessed to see what you'll have to pay. If you get care in your own home that

Personal care

This means things done for you of a personal nature such as:

- getting dressed and undressed
- having a bath or shower, washing your hair, shaving, nail care and keeping your mouth and teeth in good shape
- **continence** management. This could be help with going to the toilet, taking care of a catheters, skin care, **incontinence** laundry and changing the bed
- help with eating
- help with medication, including simple treatments such as eye drops, putting on creams and lotions
- using hoists and getting in and out of bed, also help with surgical appliances and aids

has personal care as part of it, you won't have to pay for that.

You could hire a **personal assistant (PA)** to come to your home to help with personal care. A PA may work for only a few hours a week, or several hours each day (or night).

You pay for this with a **direct payment** (a cash payment you receive instead of getting a social care service).

Employing a personal assistant may give greater flexibility. You can decide when and how you get a service and who provides it. You decide who comes into your home and who becomes involved in very personal parts of your life.

There's more about direct payments, budgets and hiring personal assistants on page 27.

Nursing care isn't personal care. That's something only a qualified nurse can give you. This includes things like giving injections or

looking after pressure sores. If you need nursing care to stay in your own home, your GP will get arrange a district nurse for you.

Day care services

Every Health and Social Care Trust offers day care settings in special centres or in the community.

They offer care, support, supervision, education, employment support, the chance to learn new skills, rehabilitation or **reablement**.

A social worker can talk over your options when you have the assessment of what care services you need.

Short breaks

If a partner, friend or someone in your family looks after you, your Trust might help arrange a break ('respite care'). Options include:

- you get support in your own home with a domiciliary care service or **sitting service**
- you get support from a worker to go to a day care centre for a while so your carer gets a break
- 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 34 looks at this in more detail

Residential care and nursing home care

If your assessment shows you need a lot of care, you and your family might feel more confident and safer if you go into a residential care or nursing home.

You'll move out of your home permanently to live in a new one where more help is available.

You shouldn't be forced into a residential or nursing 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 and safe to do so.

If you decide to go into residential care or a nursing home, you should be offered a choice of places. Page 24 looks at paying for a care home.

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

Information

Your Trust must give you information and advice about care and support when you need it.

This should be easy for you to get hold of and understand, and be tailored to what you need.

You’re entitled to information whether or not you’ve had an assessment. You can have information even if your assessment decides that you don’t qualify for support.

Information services are included in each Trust’s website (listed at the back of this booklet).

Information is also available from Citizen’s Advice and the Centre for Independent Living (see page 36).

Supported housing

Supported housing is another option. You become a tenant somewhere that’s been specially built or adapted, with 24 hour care. You keep some independence but get the care and support you need.

This is provided by housing associations or voluntary associations. Care comes from staff employed by the local Trust or other organisations.

Apply for it through your local housing executive office.



How do I get social services?

First your local Health and Social Care Trust must find out what you need and qualify for. They do this by giving you an assessment.

What should I do first?

Contact your Trust. Say you want an assessment for care and support. Their details are on page 39.

You can contact the Trust yourself – or a family member, friend or carer can. Your GP or someone from a voluntary agency can do this too.

When you phone your Trust, ask for the Physical Health and Disability team or Integrated Care Team. They can:

- do an assessment of your needs
- do an assessment of what your carer needs
- give you advice about **Self Directed Support** which includes direct payments
- give you information about local support

- agree a care and support plan to meet you or your carer's needs
- give social work support to you and your family carer
- offer you emotional support
- work with other professionals involved in your care
- help you be more independent

You'll be asked questions to find out how urgent your needs are. If they're not urgent, you might wait a few weeks to be assessed. Someone will visit you later to do the full assessment.

Don't let anyone put you off asking for an assessment. Nobody can decide whether you need care services unless you have one.

The person who carries out your assessment could be a:

- social worker
- district nurse
- **occupational therapist**
- another care professional

A friend, relative or **advocate** can be with you during your assessment.



My assessment

You should feel properly involved in your assessment, with enough time to say what you want to. It might take more than one visit.

The person assessing you will ask questions to help them understand:

- what you can do
- what you find hard to do
- what you'd like to be able to do
- what help you already get from family, friends or other carers
- what care services you need
- how suitable your home is
- if you have special needs because of a disability
- any risks to your health and well-being if you don't get the right support

They'll talk to you about what matters most to you. The focus will be on what you can do, rather than what you can't. It'll concentrate on support to help

you keep living like you are now. When this isn't possible, it can identify the right care for you.

What you say during the assessment goes into your care and support plan. It sets out how your needs can be met.

There'll be questions about ten things in particular.

1. Your physical health

and its effect on your daily life. Can you eat well? How does MS affect how you can prepare meals and get drinks?

2. Your mental health and emotional well-being.

This looks at your mood, motivation and confidence

3. Your awareness and decision-making.

Does anything affect this? Does that make day-to-day life difficult?

4. Your medicines.

Can you take your medications safely?

5. **Communication.**

Do you need help with your hearing, speech or sight?

6. **Walking and moving.**

Can you easily and safely get into your home and move around it? Can you keep it clean and safe? How easy and safe it is for you to use public transport or leisure facilities?

7. **Personal care.**

How easy it is to wash yourself and your clothes? Do you have difficulties getting to a toilet or using one? Can you put on clothes you need, such as warm clothing in cold weather?

8. **Where you live**

Do you have problems with where you live?

9. **Your relationships**

How easily can you keep in contact with family and friends or meet new people? Do you have difficulties caring for people who rely on you, like a child?

10. **Work, money and leisure time**

Can you keep yourself busy, start work, stay in a job or get to work, education, training or volunteering?

If you don't have MS but look after someone who does, as their carer you can have an assessment of what you need, too. Read more on page 34.

Having the assessment

You can have a partner, friend or family member with you for support. This could be important if MS affects your memory or your thinking.

The person assessing you will be trained but may not know a lot about MS. That's why it's important to prepare what you want to say, so it's clear what support you need.

Help with your 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 advocate.

An advocate is independent of social services and of your local Trust. They can support you when you apply for social care services, and when you're assessed.

They'll help you to understand what's happening and to say what your needs are. Find one by contacting your local Trust (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, write 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 things like 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 really understands MS or how it affects you. They might have assessed other people with MS but their needs may be very different to yours

Tips:

- write down what support you need. Use a diary or the table on pages 32–33
- 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
- get evidence about your medical needs. For example, your doctor or other professionals may want to say things to back you up. Hand this over during your assessment
- write down your medication and why you take it
- want someone you know at your assessment? Make sure they're free to be there when it happens

During

During your assessment:

- be honest. Some people try to hide their condition and problems they have. Do that and 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 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

The person assessing you will fill in forms with the information you give and ask you to sign them. You'll be asked to sign permission for this information to be shared with other professionals.

When the results of your assessment are ready, your Trust should give you a copy. They must offer you help with the needs your assessment has identified.

If you qualify for help, you and your Trust will draw up your **care**

and support plan describing help you can have.

What you need might change. So your plan gets reviewed at intervals set out in the plan – or whenever it needs to be.

Your need for support can grow. Your Trust has a duty to stop (or delay) this if it can. For example, at the time of your assessment you might not qualify for a carer to support you at home. But if your Trust agrees to fit a ramp in your home, that could mean you're less likely to fall and then need care at home.

You might be told you don't qualify for social care. You can appeal against this decision (see page 29). If the assessment decides you don't qualify for help, you should get an explanation of why not.

If your Trust can't help you directly, they should at least tell you about organisations that might.

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

My care and support plan

If your assessment shows you have things your Health and Social Care Trust must help you with, you'll agree a care and support plan with them.

This puts in writing:

- what your assessment decided that your needs are
- what support your Trust will put in place to meet these
- any needs that your Trust 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 **direct payment**?
- how will I stay in control?
- what will I do next?



Do I pay for social care services?

You might be charged for social care services, such as some parts of home care, residential /nursing care and short breaks.

You don't pay to have your assessment of what services you need. Information and advice services are free too.

You also won't pay for any healthcare (or equipment for a health need) you get, either at home or in a residential care or nursing home.

Free personal care

Personal care is free, no matter how much you have in income or 'capital' or 'assets' (savings, property or investments). It's free whether you're single or married or in a civil partnership.

But you may be charged for care that's not personal care, such as housework, shopping and making beds.

An assessment will work out if

you have to pay towards other services. This will look at:

- your income
- savings
- investments
- whether you get benefits or other financial support
- your expenses, such as bills or rent

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

Nursing care

This is care from a registered nurse in a care home. It's different from personal care (help with things like dressing, eating, getting out of bed, using the toilet).

Nursing care is paid for by your local Trust through Health and Personal Social Services (HPSS)

payments. To get these you must be responsible for paying the full costs of your nursing home care. You must also be assessed as needing nursing care.

If you need nursing care in a care home, and if an assessment

decided you have to pay the full costs, you can get a flat rate payment towards the part of the home fees that cover nursing care. You still have to pay towards your accommodation and living costs in the care home.

If I move into residential care or nursing home, must I sell my home to pay for it?

Is your Health and Social Care Trust arranging for you to move into residential care or a nursing home? Then they must tell you 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.

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 Trust to delay paying them ('deferred payment'). The Trust pays for you. You pay them back when you decide to sell, or when your house is sold after you die.

You'll have to pay all the cost of your care home if the value of your assets is over £23,250. You pay nothing if the value is under £14,250 (correct as of August 2018).

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 lives there.

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



Personal budgets and direct payments

If you qualify for social care services, your Health and Social Care Trust will work out your personal budget.

Your personal budget

This is how much your Trust will spend on your social care. It's part of your **care and support plan**.

What you get depends on the what your assessment says you need.

Your **keyworker** will help you write your support plan. It'll include how you'll use your personal budget to meet your needs.

Once your plan is agreed you can pay for things like hiring a **personal assistant (PA)** or getting help at home.

Your Trust will give your personal budget to you (or someone who manages it for you). You can choose who you want to support you to manage your personal budget and organise your support.

In the Self Directed Support chapter (page 8) we mentioned the different ways you can choose to manage your personal budget.

This can be letting your Trust do it, or you being responsible for how the money's spent, or a mix of both.

Specialist organisations can help you plan and organise your care and support. Your keyworker can tell you about these.

You can choose to get your personal budget as a **direct payment** to pay for your care.

Direct payments

These 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 your Trust or care agency provide, such as **personal care**.

Direct payments can also be used for help around the house,

with further education, leisure activities, going shopping or getting out and about.

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 the needs in your care and support plan. You must keep records of how you spend them.

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

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 your Trust.

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

Help managing them

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

The following people can manage your direct payments: you, your carer, partner, someone in your family, a friend or an independent **broker** or **advocate** from a disabled people's organisation.

You can manage some of your direct payments yourself, while someone else manages the rest.

Tips:

- Disability Rights UK (page 37) offer help with direct payments
- the Department of Health has a booklet called A Guide to Receiving Direct Payments. Find it at health-ni.gov.uk/publications/guidance-receiving-direct-payments
- if you hire a personal assistant, the Centre for Independent Living NI (page 36) can give you advice.



I want to complain or appeal

You have a right to appeal if you think your Health and Social Care Trust 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 Trust decides you don't qualify for support but you feel you should
- you feel your Trust 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 your Trust's website. Disability Rights UK (page 37) has a factsheet on how to make an appeal.

Complaints

First take your complaint to whoever gives you the service, to your key worker (if you have one) or to your local health and social care team.

If you're still not happy, your Health and Social Care Trust has a way of dealing with complaints (their 'complaints procedure').

This tells you how to complain, how it's handled and how fast they should reply. Find it on your Trust's website, call them, or get it from your library or key worker.

Complaining doesn't mean your service will stop or be cut back. They welcome comments and complaints. It's important Trusts learn from complaints so that services get better.

If you don't get a reply from your Trust to your complaint, report it to the Office of The Northern Ireland Ombudsman. Find their

details at nipso.org.uk/nipso

Tips:

- get support with your complaint from your local MS Society group (details from the MS Helpline)
- your local Citizens Advice could help – or use an **advocate**
- your local councillor or Member of the Northern Ireland Assembly might take on your complaint

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 Health and Social Care Trust's adult services department.



What help do I need?

Fill this in to help you be ready for your assessment. Find tips on pages 18–21.

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:

1.

	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 or friend who looks after someone with MS without getting paid. Without this help the person with MS couldn't manage.

As a carer you have the right to be assessed by your Health and Social Care Trust. If you qualify for help, a **support plan** is made for you.

This could arrange for you to have a break, get training to give you more skills, receive a carer's cash grant, go to social events, or have complementary therapies.

Your plan could arrange support for the person you care for. That will make your life easier, for example by arranging a **sitting service**.

The assessment should cover:

- your role as a carer and how it affects you
- your physical and mental health and emotional issues
- information about the support you'll get to meet your needs

- caring's impact on your social life, relationships and what you want from life
- whether you need a short break or planned regular breaks from caring
- how often your support plan is reviewed (and at those reviews, whether your plan is meeting your personal goals)
- a plan in case of emergencies

If you and the person you care for 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 didn't qualify for support.

Tips:

- each Trust has a Carer Coordinator. They identify what carers need to carry on being a carer and develop services to meet this
- organisations that support carers are listed on pages 38
- the MS Helpline on **0808 800 8000** has more information for carers



Useful organisations

Advice

Advice NI

Network of advice centres. Search for your nearest centre on their website by county or postcode.

adviceni.net/advice

Centre for Independent Living NI (CILNI)

Provides services to disabled people thinking of or already using direct payments to employ PAs (personal assistants). They offer information, advice and advocacy on independent living and direct payments.

cilbelfast.org

Head & Eastern Area Office

Linden House Beechill Business Park
96 Beechill Road Belfast BT8 7QN

028 9064 8546

Textphone: 028 9064 0598

info@cilni.org

Southern Area Office

Unit 55, Armagh Business Centre

2 Loughgall Road Armagh BT61
7NH

028 3752 2282

southern@cilni.org

Western Area Office

62 Market Street Omagh BT78 1EL

028 8224 8926

western@cilni.org

Northern Area Office

Unit C9, The Business Centre
80–82 Rainey Street, Magherafelt
BT45 5AJ

028 7963 4932

northern@cilni.org

Citizens Advice Northern Ireland

Advice charity with offices across Northern Ireland. They offer advice on things like benefits, debt, consumer, employment and housing.

Find your local office at
citizensadvice.co.uk/pages/get_advice/

Disability Rights UK

Information on benefits and free factsheets are available from its website.

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 Trust's social services

General enquiries: **020 7250 8181**

disabilityrightsuk.org

Housing

Housing Rights Service

Advice on housing issues and law
10–12 High Street Belfast BT1 2BA

028 9024 5640

housingadviceni.org

Northern Ireland Housing Executive (NIHE)

Offers services to people living in socially rented, privately rented and owner occupied accommodation.

03448 920 900

nihe.gov.uk

For details of grants to pay for home adaptations check out:

nihe.gov.uk/index/benefits/home_improvement_grants/grants_available/disabled_facilities_grant.htm

Rights, discrimination and the law

Law Centre NI

124 Donegall Street Belfast BT1

028 9024 4401

admin.belfast@lawcentreni.org

admin.derry@lawcentreni.org.uk

lawcentreni.org

Equality Commission for Northern Ireland

Help with equality issues and human rights.

Equality House 7–9 Shaftesbury Square Belfast BT2 7DP

028 90 500 600

Textphone: 028 9050 0589

information@equalityni.org

equalityni.org

Disability Action

Advice for disabled people, families and carers on benefits, community care and housing. Runs the Centre for Human Rights for People with Disabilities.

disabilityaction.org

Head office Belfast Portside Business Park, 189 Airport Road West, Belfast BT3 9ED

028 9029 7880

Textphone: 028 9029 7882

hq@disabilityaction.org

North West Office 58 Strand Road, Derry, Co. Londonderry BT48 7AJ

028 7136 0811

Textphone: 028 7137 2077

derry@disabilityaction.org

Dungannon office 11 Georges Street, Dungannon BT70 1BP

dungannon@disabilityaction.org

028 8775 2372

Textphone: 028 8775 2372

Carrickfergus office 6 West Street, Carrickfergus BT38 7AR

028 9336 9367

Textphone: 028 9336 9386

carrickfergus@disabilityaction.org

Support for Carers

Carers Northern Ireland

Offers financial and practical advice on benefits, carers employment rights, community care and carers assessments.

028 9043 9843

info@carersni.org

carersuk.org/northernireland

Belfast Carers Centre

Suites 2-5 Merrion Business Centre, 58 Howard Street, Belfast BT1 6PJ

028 9043 7000

info@carerscentre.org

Problems with social care services

Regulation and Quality Improvement Authority

Responsible for the quality of health and social care services.

5 Lanyon Place Belfast BT1 3BT

028 9051 7500

enquiries@rqia.org.uk

Office of the Northern Ireland Ombudsman

Offers help only when you've exhausted an organisation's own complaints procedure

0800 34 34 24

nipso@nipso.org.uk

nipso.org.uk

Money

Independent Living Fund (ILF)

Gives money to severely disabled people in Northern Ireland (and Scotland) who got support from the UK Independent Living Fund before it closed. This pays for care agency staff or personal assistants

0300 200 2022

ilf.scot

Health and Social Care Trusts Northern Ireland

Belfast Health and Social Care Trust (covers Castlereagh)

028 9504 0100

info@belfasttrust.hscni.net

northerntrust.hscni.net

South Eastern Health and Social Care Trust (covers Down, North Down, Newtonards and Lisburn)

028 9055 3100

public.relations@setrust.hscni.net

southerntrust.hscni.net

Northern Health and Social Care Trust (covers Moyle, Larne, Antrim, Coleraine, Carrickfergus, Newtownabbey, Ballymoney, Ballymena, Magherafelt and Cookstown)

028 9442 4000

info@northerntrust.hscni.net

northerntrust.hscni.net

Southern Health and Social Care Trust (covers Dungannon, Armagh, Craigavon, Banbridge and Newry and Mourne)

028 3833 4444

corporate.hq@southerntrust.hscni.net

southerntrust.hscni.net

Western Health and Social Care Trust (covers Derry, Omagh, Limavady, Strabane and Fermanagh)

028 7134 5171

info.enquiry@westerntrust.hscni.net

westerntrust.hscni.net

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 gives help ('advocacy') with care and support plans, assessments and making complaints

broker – someone who gives advice, support with care plans, assessments and making complaints

care and support plan (or 'care plan') – you and your Health and Social Care Trust write this if an assessment decides you qualify for help. It puts in writing what services you need. Plans carers have are called '**support plans**'

commode – a chair (often on wheels) with a bowl built into it that you use when you need the toilet

continence/incontinence – when you can/can't control your bladder or bowel and you can/can't hold on when you need the toilet

direct payments – a way of using the money your Health and Social Care Trust gives you to pay for social care. It's paid as an alternative to services you would've got from your Trust. The money goes into a special bank account. You can only spend it on social care services

domiciliary care package – a selection of care services you get in your home from your Health and Social Care Trust

key worker – someone from your Trust who supports you with the care you get and makes sure you're happy with it. They could be a social worker, nurse, occupational therapist or other professional

managed budget – a managed budget lets you stay in control without the responsibility of managing a direct payment. Your Health and Social Care Trust will manage your personal budget payments with whoever provides you with the service you use

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

occupational therapist – someone who 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 Health and Social Care Trust will spend on your social care needs

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

reablement – help to become safer, more independent and confident at home after a hospital stay

Self Directed Support (SDS) – a new way of people getting social care services and support. It gives more

choice and control over how you get support and how you pay for it

short breaks – a break for you and/or a family carer (from half a day each week to longer holidays). Used to be called 'respite'

sitting service – provided by voluntary and private care agencies for local Health and Social Care Trust. The service sends someone to spend time with a person who normally has a family carer. This gives their carer a few hours' break. They can't give medical or personal care

personal assistant or '**PA**' – a person who needs 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 Health and Social Care Trust arranges. Includes help at home with personal care, care homes, day centres, breaks for carers and advice

Further information

Resources

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

To order them email:

shop@mssociety.org.uk or visit
**[mssociety.org.uk/
publications](https://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

A large orange triangle pointing upwards, located in the bottom right corner of the page.

About this resource

With thanks to all the people affected by MS and professionals who contributed to this booklet. Special thanks to Bernie Kelly, Jane McMillan, and especially Geralyn Ainsworth.

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

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

References

A list of references is available on request. Call **0300 500 8084**.

Photography

Photography: Paul Moane

This resource is also available in large print.

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

Contact us



MS Helpline

Freephone 0808 800 8000

(closed on weekends and bank holidays)

helpline@mssociety.org.uk

MS National Centre

0300 500 8084

info@mssociety.org.uk

supportercare@mssociety.org.uk

Online

mssociety.org.uk

facebook.com/MSSociety

twitter.com/mssocietyuk

MS Society Scotland

0131 335 4050

msscotland@mssociety.org.uk

MS Society Northern Ireland

028 9080 2802

nireception@mssociety.org.uk

MS Society Cymru

0300 500 8084

mscymru@mssociety.org.uk

BK35

© MS Society. August 2018

This title will be reviewed within three years of publication.

Multiple Sclerosis Society. Registered charity nos 1139257/SC041990.

Registered as a limited company in England and Wales 07451571.

