

Social care getting support from your council

Wales

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

Together, we are strong enough to stop MS.

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

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

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A word from Carolyne, whose husband has MS

MS is unpredictable. 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.

Tony had first class life-saving treatment in hospital. 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.

Carolyne

Five things to know

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From 2016 social care in Wales has changed

You now can choose to have more control over the care you get

The assessment of what you need is very important. This booklet can help you be ready for it

You may have to pay towards the cost of care and support services

If you care for someone with MS, you have a right to have an assessment of what help you need



About this booklet

This booklet looks at services, help and support you can get in Wales if you have multiple sclerosis (MS). It focuses on 'social care'.

Social care is the name for care and support you can get from your council.

If you don't have MS but look after someone who does, you might benefit from social care too.

If you do have MS, social care can help you live as independent a life as possible.

You might need it more if your MS gets worse. Social care is about giving you what you need so that your well-being is better.

Social care covers lots of services, such as help with:

- getting washed or dressed
- doing laundry or shopping
- getting to work
- enjoying leisure activities

Social care can include equipment or changes to your home that make life easier. It can also cover support for your family carer.

Another part of social care is when you move into residential care instead of living at home.

You might get social care services at home, in a care home or a day centre. Social care doesn't include medical care from the Health Service (NHS).

The Social Services department of your local council should make sure you get the social care services you need when you most need them.

This booklet covers important changes that were made to social care services in Wales in 2016. It's also available in Welsh from our Cardiff office (see page 34).

One last thing. Where you see a word in bold in this booklet, it means you can turn to the back and find it explained.

What type of help might I get?

Councils offer lots of services. If you qualify for this support, your council will give you details of the help they can give you.

What they offer depends on what they found when they looked at what you need during your 'assessment'. What services you can choose depends on what you need and what you'd prefer.

Social care services can cover:

Home care

This is care you get in your home. It 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 (using a '**direct payment'** from your '**personal budget**' – see page 26). A PA may work for only a few hours a week, or several hours each day (or night), helping with things such as:

- **personal care** things like getting in and out of bed, having a wash or shower, getting dressed or using the toilet
- eating or preparing meals
- going to the shops
- help with taking medication
- cleaning, such as vacuuming
- driving you or helping you get around
- 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 then it might not cover things like cleaning, shopping or transport.

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 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 26.

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 which people can go to on certain days of the week.

If you qualify for this service, the local council can arrange for you to visit the centre so you can decide if it's something you want.

Each centre works differently, but most offer a range of leisure activities. Not all councils have day centres.

Respite care

If a friend or member of your family helps you, your council may offer you or them a break for a morning or afternoon each week or longer ('respite care'). They give you the care you need while the person who normally cares for you has a break.

Your council might also provide 'sitting services'. This is when someone comes to keep you company or help with your personal care.

How often this can happen will depend on what you need. It might be once or several times a year.

Our booklet 'Short breaks' has more on this and how the MS Society could help.

We might be able to help with paying for:

- a specialist break that includes respite care at a respite centre or care or nursing home
- paid care workers, specialist accommodation and equipment that all add to the cost of a holiday

Social care has other ways of helping carers. See page 32.

Equipment and changes to your home

If you have a disability your council is responsible for assessing your need for specialist equipment. This could include things like a hoist, grab rails, ramps, wider doors, a bath seat, specialist cutlery, and so on.

If you qualify for help from the council for equipment, you can choose to have it provided by them or buy it yourself with **direct payments.**

Direct payments let you choose something slightly different. For example, you might want a bath seat in the same colour as your bathroom.

If what you want is more expensive than what the council provides, you'll have to pay the extra yourself.

Paying for changes to your home

In Wales, if you own your own home, you can get Disabled Facilities Grants (DFG) of up to £36,000 to help with the costs of adapting it to make it easier for someone with a disability to use. This could include things like a replacing a bath with a levelaccess (walk-in) shower.

The rules around these grants are complicated. You'll need to have an assessment of your money situation.

You may not get the full cost of the adaptations. Waiting lists for Disabled Facilities Grants can be long but this does vary from one area to another.

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 if they're '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 more details.

Residential care

If you need a lot of care, your council may suggest that residential care is best for you.

You'll move out of your home and live somewhere with 24-hour care, or a house or bungalow adapted to your needs.

Sometimes you can have 24hour care available in your home instead if that's practical. If you decide on a care home, you should be offered a choice of homes.

Page 24 looks at paying for a care home, and our booklet 'Residential care and your options' will tell you more.

Information

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

Information should be easy to get hold of and understand. It should be tailored to what you need.

This is all 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.

'Arranged services'

You may read or hear about 'arranged services'. This is when your council sorts out care services for you.

You can't always get the flexibility you want with this. Your Care Manager at the council might have tried to arrange things in the best possible way to fit services in with your life or family. But they can't guarantee services will be delivered in the way you'd want them if you arranged them yourself.

Direct payments let you arrange and pay for services in the way that suits you.

What's changed since 2016?

In April 2016 the Social Services and Well-being (Wales) Act came into force.

It's a new law to improve the wellbeing of people who need care and support. It also covers carers who need support.

'Well-being' means when people:

- are healthy
- feel good about their life
- are safe and protected
- can learn new things

For adults it also means they have control over their life and can work. For children it means they grow up happily and are looked after.

The new law changes how people's needs are assessed and how services are delivered. You now have more say in the care and support you get.

The law also makes you more aware of help you can get in the community, so that you'll need less formal, planned support. This means:

- you'll be asked what matters to you
- you'll have a strong voice when you decide what you need. That way you can enjoy your well-being
- if you need support to make your voice heard, someone can speak on your behalf
- the assessment looks at what you can do, on your own and with help from friends and family
- after the assessment, if you need care and support, it'll be arranged for you
- laws to keep you safe are stronger

It also means:

- there are more services to help you when you need it. That way problems don't get worse
- if you're in education or training, you'll get support to stay in it until you're 25
- it'll be easy for you to get information and advice
- if you're a carer, you'll have a right to be assessed for support, just like the person you care for



Do I qualify for social care?

Your council must find out what care and support you need and what help you qualify for. To do this they'll give you an 'assessment'.

Assessments should now be simpler. Just one person can now do it for you on behalf of different organisations.

What should I do first?

Contact your council's Social Services department or its contact centre. Tell them you want to be assessed for social care.

You'll find their details on your council's website, at a local library, doctors' surgery or in the phone book.

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 32. They might send you a form to fill in and send back or ask questions over the phone.

If they then decide you might qualify for help you should get a visit later from someone who'll do the full assessment.

The council might want to do it over the phone but doing it face to face is better (see 'Doing the assessment' on page 17).

The council might tell you that you don't qualify for an assessment. You can appeal against this decision (see page 29)

Can my assessment be in Welsh?

If you'd rather be assessed in Welsh, ask for this. The law says your council must make this happen. This shouldn't slow down how soon you get your assessment.



My assessment

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

You can have someone with you at your assessment. This could be your family carer or a friend or an **advocate** (see page 18).

During your assessment you'll be asked 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?
- everyday things you can do without help
- things 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 could be going out, seeing friends or getting some 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 wellbeing could be at risk

There'll be questions about ten things in particular:

- Eating well how does your MS affect how you can prepare meals and get drinks?
- 2. Moving around your home can you do this safely, including getting into your home?
- 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 public transport or leisure facilities?

10. Looking after others – do you have difficulties caring for people who rely on you, such as a child?

Need help with two or more of these? Then your council must support you.

They can give you information about local support. They can offer you gadgets to help you do things (like open jars or tins) or make changes to your home (like putting in hand-rails).

Your assessment might show that you need more help at home to get washed or dressed.

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.

That's a good reason for a partner, friend, family member or advocate to be with you for help and support.

Need help understanding or filling in the assessment? Noone you feel you can ask? Then the council should provide you with an **advocate.** See the next page for details 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. They might have assessed other people with MS but with needs that were very different to yours.

So 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 have your assessment. They can support you from start to finish. They'll help you understand what's happening and to say what your needs are. Your council or a disability organisation can find you an advocate.

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

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

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 29). 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.

More tips:

- write down what support you need. Use a diary or the table on pages 30–31
- 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
- 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
- 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 at your assessment



My care and support plan

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

You should be given a copy of your plan that you can understand and refer to. This plan puts in writing:

- what your assessment decided 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 the council won't meet

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

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



Paying for care

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

If you have to pay towards your care, how much depends on your personal and financial situation. To work this out you'll probably have an assessment of your money situation. This will take into account:

- your income, for example, a pension or money you get from renting out a property (but it won't include wages you earn from a job)
- 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).

Because you live in Wales you'll have to pay for the full cost of your care if your 'capital' or 'assets' (pensions, savings or investments) are worth more than £24,000*. If you own a home, this won't be taken into account (unless you're paying for a care home).

The most anyone can be charged in Wales at the moment for home care and other non-residential social care services is £70 a week (correct as of June 2017).

* This was the limit in June 2017 but it's likely to go up in the future.

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 a residential care home, they must first 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 Wales you pay for all the cost of your care home if the value of your assets is over £30,000*. 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

*This was the limit in June 2017 but it's likely to go up in the future. 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 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

You can manage it three ways:

- ask your local council to manage your budget 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 (I**SF) You can also use a mix of all three.

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'). These assistants 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 them

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

Direct payments can seem more difficult than they are. Each council in Wales has staff working on direct payments who can help you. There are organisations across Wales who offer information, training and support. The Disability Rights UK Personal Budgets Helpline offers help with this, too (see page 36).

Your carer, partner, a family member or friend can manage direct payments for you. Or ask your council's social care services department about local **brokers** or **advocates**. Or manage some of your direct payments yourself while someone else manages the rest.

You can use direct payments and keep some **arranged services**. Direct payments might work for part of a care package, but for other parts it might feel right to stick with arranged services. Flexibility is an important part of this option.



I want to complain or appeal

You might not be happy with how much help your council is prepared to offer you, or how the service is being provided.

Appeals

You can appeal if:

- you're told you don't qualify for services but you feel your needs are high enough to qualify
- you feel the council didn't look at all of your needs when they made their decision
- you qualify for services but you don't feel your council is offering you enough help

You can get information about appeals from the council, through your local library or on some council websites. The Disability Rights UK Personal Budgets helpline gives advice on appeals as well (see page 36)

Complaints

If you have a complaint about a service, talk first to your social worker if you have one or local social services team. If this doesn't work, ask to see your council's complaints procedure. It might be on their website. Or ask your social worker or get a copy from the library.

Don't be afraid to complain. It's your right. It's how things are made better. Making a complaint doesn't mean your service will stop or be cut back.

If speaking to your social worker doesn't improve things, a complaint is the proper way to go. You might get support locally from Citizens Advice, your councillor, MP or an **advocate**.

You can also contact the '**My MS, My Rights, My Choices**' project. This service gives free independent advocacy support for people across Wales with MS and their carers who wish to complain. Details are on page 34.

If still unhappy, complain to the Public Services Ombudsman for Wales. Details are on page 36.

What help do I need?

Fill this in to get you thinking about what support you need. It'll help you be ready for your assessment. Find tips on pages 18–20.

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

Are you a family member or friend who provides care to someone? The law says you also have a right to be assessed by your council to see what support you need.

By law, if you ask for an assessment, you should get one. It can happen when the person you look after is assessed to see what **social care** services they need. Or you can be assessed separately. That might work better if there are things you'd rather not say in front of the person you care for.

At the assessment you should be asked if you can give them the care they need, and, if you can, whether you want to carry on doing this.

If you don't, this should be taken into account. If you qualify for help, services should be put in place. For example, if you don't want to help with their **personal care**, outside help could be arranged. Your assessment looks at whether caring for someone is affecting your health or wellbeing. Does it make it harder for you to stay in work, have a social life, get to medical appointments or enjoy leisure activities?

Your assessment should cover:

- your role as a carer and how it's affecting you
- your health, including physical, mental and emotional issues
- your feelings and choices about being a carer
- work, study, training and leisure
- relationships, social activities and your goals
- housing
- planning for emergencies

Pages 34–35 have details of where in Wales carers can get support. A factsheet on carer's assessments is on the Carers Wales website.



Useful organisations

Support MS Society Cymru

For details of support we provide in Wales to people with MS and their families, friends and carers visit mssociety.org.uk/near-me/ national-offices/ms-societycymru

MS Society Cymru Temple Court, Cathedral Road Cardiff CF11 9HA Wales 0300 500 8084 mscymru@mssociety.org.uk

'My Ms, My Rights, My Choices' project

Big Lottery funded project providing information, advice and advocacy services across Wales for people with MS and their carers.

Contact Adele Gilmour, Information, Advice and Advocacy Manager Wales

Adele.Gilmour@mssociety.org.uk 0208 438 0715 Mob: 0786 469 1394

Care and Social Services Inspectorate Wales (CSSIW)

They inspect and regulate adult care, child care and social services for people in Wales.

Welsh Government office Rhydycar Business Park Merthyr Tydfil CF48 1UZ 0300 7900 126 cssiw.org.uk

Carers Trust and local Crossroads organisations

Support for carers and those they care for. For details of local Crossroads respite care services in Wales call:

0292 009 0087 wales@carers.org carers.org

Carers Wales

Can provide unpaid carers (family or friends) with information leaflets and telephone support from a national helpline run by qualified, trained staff.

Carers Line 0808 808 7777 Find their factsheet on carer's assessments at:

www.carersuk.org/help-andadvice/practical-support/ getting-care-and-support/carersassessment

carerswales.org

Citizens Advice

Local offices of Citizens Advice are in the phone book and on their website. They also run an online advice guide. Choose the section of their site for Wales.

adviceguide.org.uk

03454 04 05 06 (English) 03454 04 05 05 (Welsh)

Disability Living Foundation

Free, impartial advice about all types of specialist equipment. Helpline **0300 999 0004 dlf.org.uk livingmadeeasy.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

Details on: dls.org.uk/free-advice/ online-advice/community-carelaw/

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

Telephone/textphone **020 7791 9800**

msadvice@dls.org.uk 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)

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

Disability Wales

Has information for people using direct payments and on direct payments support schemes in Wales.

029 20887325

info@disabilitywales.org www.disabilitywales.org

Public Services Ombudsman for Wales

Independent body with legal powers to look into complaints about public services (including social care) and independent care providers.

03007900203

ask@ombudsman-wales.org.uk www.ombudsman-wales.org.uk

New words explained

adaptations – changes in your home, from structural alterations to gadgets and changes to furniture and fittings

advocate – independent person who helps with care and support plans, assessments and making complaints

arranged services – when your council sorts out care services for you

assessment – a 'care and support assessment' is a conversation with someone from your council to find out how they can help you. Carers can have an assessment of what they need, too

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') – if an assessment decides you qualify for help, your council writes this with you. It puts in writing what services you need. 'Support plans' are the plans that carers have

direct payments – a way of paying for social care using money your council gives you. It goes into a special bank account. You can only spend it on social care services Individual Service Fund (ISF) – when your council gives your personal budget to an organisation that provides services. You tell them the services you need. ISFs give you control over services without the responsibility of direct payments

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

personal assistant or 'PA' – a person you hire with a **direct payment** to help with things like **personal care**

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

personal care – help with getting up, washing or getting 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 your council arranges. It covers advice, day centres, help at home with **personal care**, breaks for carers and care homes

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, in particular Simon Jones, Western Bay Social Services and Well-Being Act Implementation Lead, Swansea. 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: Simon Rawles (cover, p6, 13, 14, 23 and 33) and Amit Lennon (p20, 24 and 28).

This resource is also available in large print.

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

Contact us

MS Helpline

Freephone 0808 800 8000 (closed on weekends and bank holidays) helpline@mssociety.org.uk

MS National Centre

0300 500 8084 info@mssociety.org.uk supportercare@mssociety.org.uk

Online

mssociety.org.uk facebook.com/MSSociety twitter.com/mssocietyuk

MS Society Scotland

0131 335 4050 msscotland@mssociety.org.uk

MS Society Northern Ireland

028 9080 2802 nireception@mssociety.org.uk

MS Society Cymru

0300 500 8084 mscymru@mssociety.org.uk

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