

Personal budgets



Multiple sclerosis information

Welcome to this Choices booklet about personal budgets

MS-UK believes we must listen to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices booklet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices booklet has been designed with you in mind. We hope it will answer some of your questions and also provide some first-hand experience from those who have been in your position - people who can truly understand and empathise with your current thoughts and feelings.

Every time you find bold text with quotation marks like this, it is a quote directly from someone affected by multiple sclerosis


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Personal budgets

Support is available from local authorities (your council) for people living with a disability, which could enable you to have more control in your life and maintain your independence and wellbeing. If you could use some extra care and support, this guide will help you understand more about adult social care and the assistance you can gain with a personal budget.

This information applies to England only.



Don't be afraid of asking for help. It means you are being proactive by getting the help you are entitled to and ensuring you are living life to the full



What is adult social care?

Adult social care usually refers to the services and support offered to people in need of practical support due to disability, illness, old age, or caring commitments. Adult social care services consist of support provided by social services professionals, including occupational therapists and social workers, but also includes community-based services and support such as care homes, day centres, home care services, assistive technology and aids and adaptations.

Contact your local occupational therapy service and ask them for tips on how best to do daily tasks and for any equipment that would make daily living easier

I got to see an occupational therapist who got me hand splints made, handles in my bathroom, a shower chair, bed handle stick, crutches and gutter frame

Adult social care services also have a responsibility to safeguard vulnerable adults from harm or abuse and all social care services will have a named person who takes the lead for safeguarding. Local authorities will have overall responsibility.

Using aids they give you doesn't make you disabled – using aids enables you to retain some independence

What is a personal budget?

If you are eligible for financial support from your local authority, you are likely to be offered a personal budget. This is an agreed amount of money to help meet your needs that have been identified in your care and support assessment. It helps disabled people to achieve independent living and allows people to live the life they wish to live.


A personal budget can be received in different ways, but the most popular way is to opt for direct payments.

Direct payments can help you employ a personal assistant (PA) or pay for a care worker from an agency to support you. A PA or carer can help you with lots of different things, like personal/domiciliary care and accessing the community. Direct payments can also be used to pay for other support or services that meet your eligible needs identified in an assessment.


Managing the direct payment

You have choices around how your care and support can be managed. You can request that the local authority arrange all care and support services on your behalf, or you can take a direct payment and arrange and manage the budget and your support yourself. If you choose to take a direct payment you may need to open a dedicated bank account and keep clear and regular records of related finances.

You may be able to use a prepayment card (often local authorities will have this option) which can simplify matters further. It is also possible to use an external agency, such as a local 'centre for independent living' or 'user-led organisation' to look after the money on your behalf.



I use payroll via a support planning service. They deal with all of my personal budget admin, leaving me free from worry about the business side of things. I can relax more about my care and worry less about having to always be alert. I can concentrate on living rather than existing



If you have eligible needs and you choose to take a direct payment you can decide how and where to spend the money to meet your care needs, but the local authority may ask to inspect these accounts on a regular basis to ensure that the money is being spent in the way that they agreed.

The assessment

Your local authority will carry out your initial assessment to see if you are eligible for care and support. An assessment can be a lengthy process and may feel quite daunting, but it is vital for assessing your needs and identifying the level of support that will be made available to you.

Some or all of the assessments may be carried out over the phone, via online forms or face to face. If completing the assessment online or over the phone is too daunting due to your disability, you can request that someone (usually a social worker) come out to see you.


We asked people with MS, who use social care services, for tips around engaging with social services and the assessment process.

Below are 10 of the best.


- Get back-up from the health service people who are involved with you. This is because care assessment practitioners can change frequently
- Take a friend or relative who knows you and how your condition affects you. They can help you explain things and help you to remember later
- Be sure to book your assessment at the time of day when you know that your energy levels are at their highest
- Don't push yourself - if you get tired, tell them, and ask for another appointment
- Gather as much information as possible before the visit from social services - for example, GP details, and your MS nurse's contact details
- Have information about your daily life and routine to hand by making notes in advance. Make a file up with details of your routines, likes, dislikes, contacts and so on, and keep it handy and available
- Tell them everything about your condition and needs
- You need to be blunt about how things are on a bad day and what happens when you have no help. Remember to include the needs met by partners or family
- Ensure you are accompanied by a person of your choice or ask to be represented by an advocate
- Discuss your needs or expectations with your occupational therapist, social worker or care provider to ensure everyone is clear

The assessment is your opportunity to talk about your support needs. It is your time to say what you find difficult now and what you would like to achieve with the right support.

Every individual, whether a person with a support need or a family carer, is entitled to an assessment of need if they requested it from their local adult social care department (1).



Occupational therapy assessment of my home was very useful, both to initiate immediate minor adaptations, and start the process of planning major adaptations for the future



The assessment will cover your physical, mental and emotional needs and the assessor from social services must consider the following areas

- Your needs and how they impact on your care
- The things that matter to you, for instance, you may need help with personal care or help to get to your local MS therapy centre
- Your choices and goals, for example, if you wish to take up a new activity, see people that matter to you or have preferences for the way you are cared for
- The types of services, information, advice and resources, which will prevent or delay further care and support needs from arising and therefore helping you stay well for longer

The Care Act 2014 brought in national rules for assessing who is eligible for care and support. It is local authorities who decide whether or not your needs can be considered as having what the law calls 'eligible needs'.

You can, of course, have anyone of your choosing accompany you during the assessment, whether that is a partner, family member or friend. However, if you have substantial difficulty in communicating your wishes, understanding your rights, or retaining information and there is no other appropriate person to support you, social services must provide you with an independent advocate to support you during (and after) the assessment process.

The local authority will also carry out a financial assessment to determine how much care they can fund and how much money you will have to contribute towards care services.

If you are not eligible for adult social care funding, you can still access care and support services, but you will need to pay for them from your own resources. This is often referred to as 'self-funding'.

Community equipment and minor adaptations needed as a result of your assessment may be free, but unlike NHS care, adult social care support is a chargeable service. Your local council have the right to request a contribution from you depending on your personal financial circumstances.

In simple terms, if you have £23,250 or over in savings, you will pay the full costs of your care package. Once your savings are below £23,250 you will pay a contribution towards your care until your savings are below £14,250, at which point adult social care would pay for all your care costs (values are correct as of August 2021) (2).

In addition to your savings, the financial assessment looks at any income and assets that you have. It also includes any joint savings

or finances in joint accounts, however, only ‘half’ would be assessed. Your local authority is likely to openly publish their care and support charging policy and if requested will supply you with a copy.

The local authority will carry out an individualised financial assessment after their workers have completed a full needs assessment (if you have eligible needs).

You have a right to see and gain a copy of your assessment once it is completed. Read it carefully and make sure that it covers all aspects of your life and support needs. An assessment should be reviewed regularly (usually yearly), and you can go back to adult social care at any time if things change in your life and your needs increase.

You, or one of your family members, may decide to make contact with the local authority to find out more about what support is available. If you already have a social worker, then you should speak to them first. If you are not known to adult social care you will need to contact their team and go through an initial assessment.

What help you might get as a result of the assessment

The local authority has a duty to provide people with information and advice. Many local authority areas have developed new websites that contain a raft of information about care, support and living with long-term conditions. The type of information that is available should cover how to access care services, how to obtain financial advice and how to raise issues if you have worries that someone is at risk of harm or neglect. Even if someone is not eligible for support from the local authority they should get personalised information and advice (in writing) after an assessment.

If you have eligible needs and are offered a direct payment or a package of care and support, the type of help you may get can be

Employing a personal assistant

This is where you would write a personalised job description (written around your assessed needs) and employ a care worker directly yourself. You would be actively involved in the management of the worker, and you would be their employer.

Using a care and support agency

You may choose to use a professional care provider based in your community to provide you with the care you need either in your own home or to help you access the community.

To use and pay for services at an MS therapy centre

Attending an MS therapy centre may help you maintain ability, may help to prevent or delay progression, and can provide opportunities to mix with other people with MS which could have both peer support and social benefits. This could also provide a family carer with a short break from their caring role, which would be a valid way of using your direct payment.

To pay for transport costs

If transport is an issue for you (and you can evidence public transport is not accessible or too challenging) social services may agree for you to use some of your direct payment on transport costs. This could enable you to engage in activities such as attending a day service or other community services.

Replacement care or respite services

If you have a family carer and you are reliant on them for substantial care and support, it may be that they need a regular short break or even a residential respite break. Your assessment will identify these needs and your direct payment could be used to pay for these kinds of services.

We asked people with MS who use care and support services to share their experiences of using a direct payment and social care services.

This is what people had to say...



I have a direct payment budget to enable me to get out and about for six hours a week. One day I visit a local café for food and a chat, and the other day I use my carer to support me at a local MS group



My PA helps me by cooking, going shopping and doing housework. This has meant I have the energy to do voluntary work, study and spend time with my friends. My life is fulfilling and not a struggle to survive



We were able to hire a nanny/housekeeper. It was the best decision, it allowed me to get well but still be a big part of our children's lives. Luckily, we all got on well with the person we chose. It was like having a friendly aunt look after us



I ended up employing someone already known to me. They help me look after my son, getting him to and from school. My PA helps me keep on top of the house and shopping

Here are some top tips they shared with us...



Be organised. I set up spreadsheets for the timesheets, expenses and make lists of jobs for the PA. You need to think ahead



If you employ your own PA you can set out your own hours of care and not rely on agencies



Try and get regular carers - it helps the difficult delivery of personal care services



Don't give up if at first you can't find a suitable carer, keep contacting agencies or if you already use an agency, explain to them that the carer isn't on your wavelength and ask if they have another carer they could introduce to you

Planning your support

If you have been awarded a personal budget and chosen to take it as a direct payment, the next step would be to make a support plan showing how you will spend your money to meet your needs. A social worker or a professional working on behalf of the local authority will usually give you a choice about how you can write your support plan. Your social worker may write the support plan with you, you can write a support plan yourself, or in some areas, you can be referred to an independent service, who will work with you to write a support plan that suits your needs and wishes.

The plan would then need to be submitted to the local authority for agreement that this is the best use of funds and the best way to meet your needs. Your support plan should include information about you and your disability. You should include information about who you are as a person, your goals for the future and how the support plan will help you achieve these goals.

The support plan should include the barriers you face because of your disability, the difficulties you face on a regular basis and how the direct payment will help you overcome these barriers. Planning in this way helps the local authority understand what is important to you and also how you will keep yourself safe from abuse or neglect.

The support plan should have information about your personal support network, including family carers, friends and unpaid people that support you in life.

Your plan should list how you would spend your money and how your needs would be met as a result of the support gained. Your plan should budget for the year ahead including any contingency costs that need to be considered. Your plan should also show how you will manage the money.

We asked the MS community to share tips that help them manage and plan for their support. Here are some of the suggestions they shared...



I used an advocacy service for advice regards employment law



I get payroll support from a charity, meaning I don't transfer money. I just complete timesheets. Also, I ask expert advice about things like sick pay policy, bank holiday pay, and so on



I suggest using a payroll company. The paperwork is very daunting. Keep everything! You will be regularly audited



I use an organisation to run my personal budget and the employment of my PA. It enables me to keep control of my personal budget. They offer me a support planning service, payroll service, and employment contracts, employment law advice, and they also take care of my insurance requirements



Once the support plan is in place, monitor its delivery - are they coming on time, are the staff skilled/trained sufficiently to meet your needs and that you are paying exactly for the services delivered? Whoever's money it is, it is your responsibility to ensure it is spent correctly

Care and support planning resources

National Voices is a coalition of health and social care charities that are committed to people being in control of their own health and care. They have written a guide to care and support planning that you may find useful. The focus is on creating a person-centred plan tailored to you and your own desired outcomes. The guide contains links to short videos and other useful pieces of information (3).

A further free resource is 'Create my Support Plan' which has been developed by the West of England Centre for Inclusive Living (WECIL), a user-led charitable organisation based in Bristol and funded by the Department of Health (4).

Purple is an organisation that works with disabled people in a variety of ways including services that support people that use direct payments. One of their services is providing help with support planning. If you are having a social care review and need to start creating a support plan, or perhaps you need one amending, your adult social care key worker can refer to Purple for support (5).

Example personal budget support plan

Please see MS-UK's example of a personal budget support

plan available to download in a Word document version from www.ms-uk.org/choiceslife.

This plan is based on a real person with MS and shows how their social care support is used. All identifying aspects have been removed and some minor aspects of the plan have been changed to protect anonymity. To draw up the support plan, we used Purple's support planning template which is available on their website (6).

Case study

Here is a simple case study of a person with fluctuating needs, taken from the care and support statutory guidance issued by the UK Government.

Miss S has multiple sclerosis and requires a frame or wheelchair for mobility. Miss S experiences high levels of fatigue, but for the majority of the time she feels able to cope with daily life with a small amount of care and support. However, during relapses she has been unable to sit up, walk or transfer, has lost the use of an arm or lost her vision completely. This can last for a few weeks and happens two or three times a year, requiring 24-hour support for all daily activities.

In the past, Miss S was hospitalised during relapses as she was unable to cope at home. However, for the past three years, she has received a care and support package that includes direct payments, which allows her to save up one month's worth of 24-hour care for when she needs it, and this is detailed in the care and support plan.

Miss S can now instantly access the extra support she needs without reassessment and has the reassurance that she will be able to put plans in place to cope with any fluctuating needs. She has not been hospitalised since (7).

Further information

Assessments for adults needing support

<https://carersuk.stagingbox.co.uk/help-and-advice/practical-support/getting-care-and-support/needs-assessment>

Assessments for unpaid family carers

<https://carersuk.stagingbox.co.uk/help-and-advice/practical-support/getting-care-and-support/carers-assessment>

Create my Support Plan

www.createmysupportplan.co.uk

Gov.uk – applying for a needs assessment

www.gov.uk/apply-needs-assessment-social-services

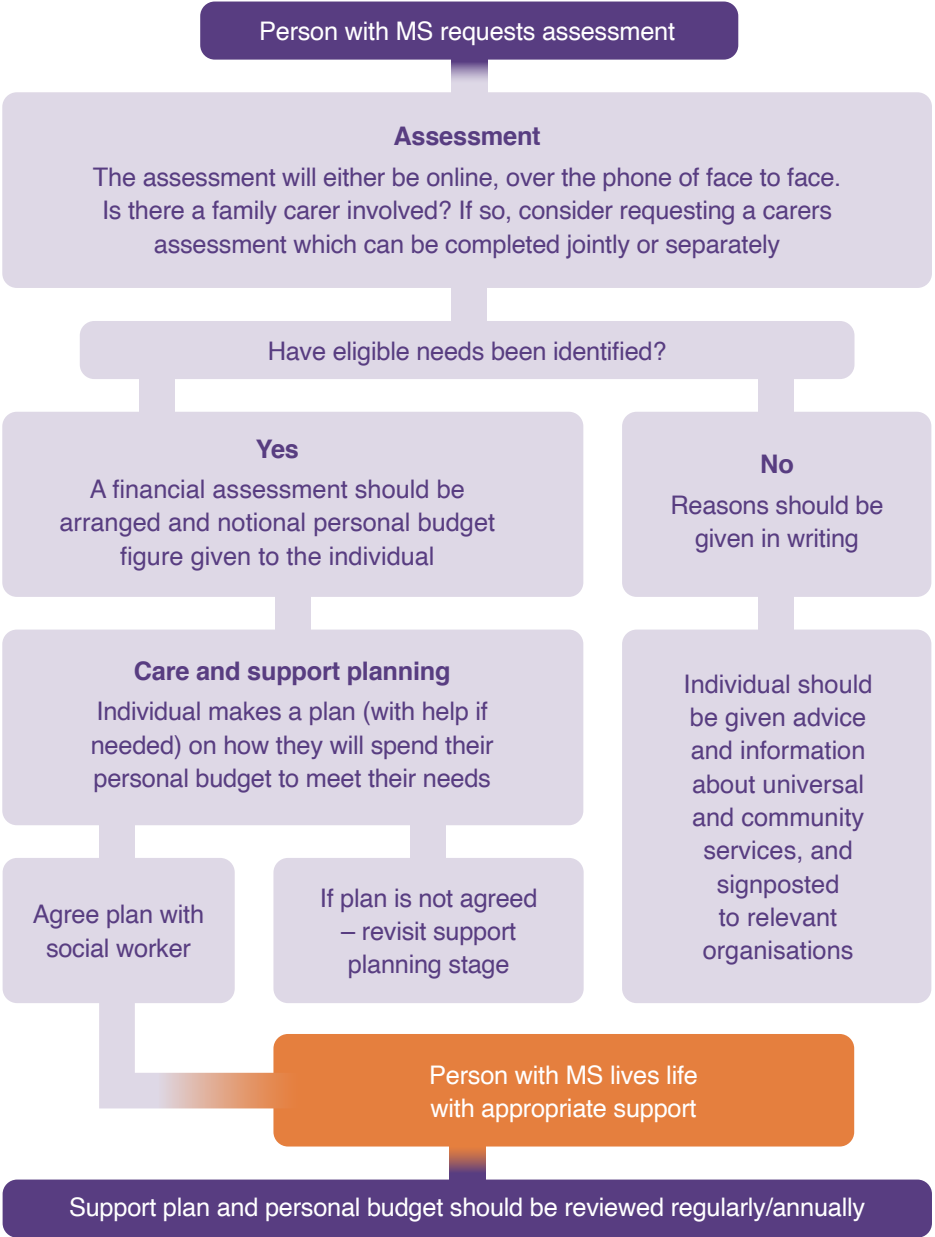
National Voices

www.nationalvoices.org.uk/publications/our-publications/care-and-support-planning-guide

Purple

<https://wearepurple.org.uk/direct-payment-support/managing-your-personal-budget/support-planning/>

Care Act (2014) assessment and personal budget flowchart



About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people's rights to make informed decisions for themselves.

The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.



New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

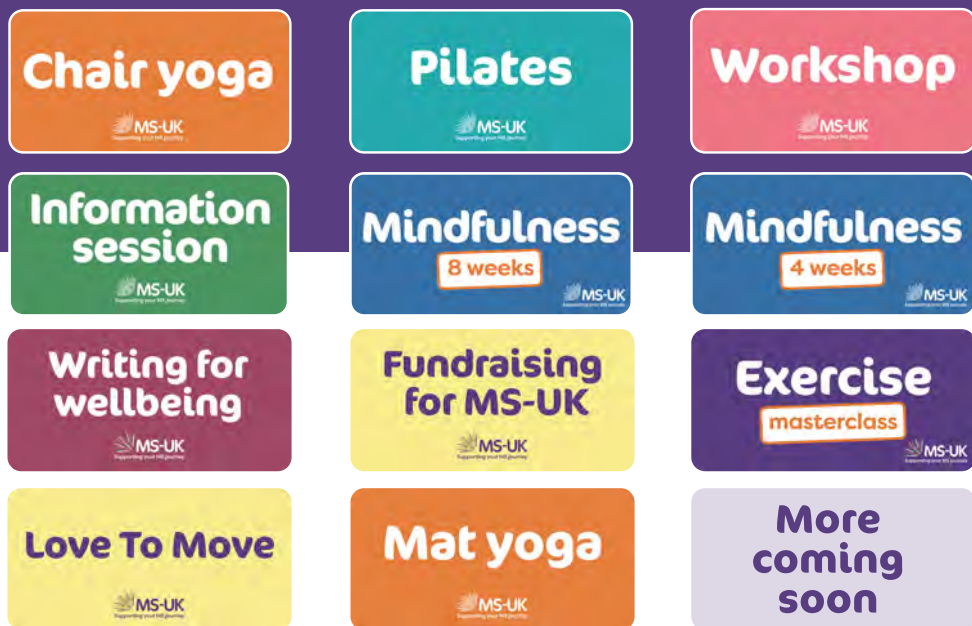
Available in print, audio version, large print and digitally.

About MS-UK

Peer Support Service

Our Peer Support Service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more www.ms-uk.org/peer-support-service or email peersupport@ms-uk.org.





Online activities

MS-UK offers a variety of online activities to stay active and connected for those affected by MS and manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. Visit our website to explore and find out more.

E-learning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created accredited Learning courses that can help you do this. Visit <https://ms-uk.org/excellence-ms/> to find out more.

Sources

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Last reviewed October 2021

Check out MS-UK's online activities

Live a happier and healthier life with MS



- ✓ Accessible online exercise classes
- ✓ Chair yoga classes
- ✓ Mindfulness courses

- ✓ Interactive workshops
- ✓ Information sessions
- ✓ Peer Support Service

Don't miss out – sign up for our new online activities today!

Visit www.ms-uk.org or contact us at register@ms-uk.org

 **MS-UK**
Supporting your MS journey

Registered charity number 1033731

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Registered Company Name

Multiple Sclerosis-UK Limited, trading as MS-UK

Company Number 2842023

Registered Charity Number 1033731

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