



10B

Direct payments and personalisation

Information for people with or affected by motor neurone disease

With MND, there may come a time when you need help from social care or healthcare services. This can all be managed for you or you can choose services for yourself by accepting direct payments.

This information sheet looks at how budgets are agreed to meet your needs and how you can use direct payments to manage these budgets, if this is what you wish.

The content includes the following sections:

- 1: What do the different terms mean?**
- 2: How does a personal budget work for social care services?**
- 3: How does a personal health budget work for healthcare services?**
- 4: Can I appeal against a decision?**
- 5: How do I find out more?**



This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.



This symbol is used to highlight **quotes** from other people with or affected by MND.



The MND Association has been certified as a producer of reliable health and social care information.

www.england.nhs.uk/tis

If you live in Scotland, contact MND Scotland for advice (see *Useful organisations* in section 5: *How do I find out more?* for contact details). Please be aware that assessment and services may work in different ways across regions.

1: What do the different terms mean?

Terms used for health and social care budgets are similar, which can be confusing. The following explanations may help:

personalisation:	This is the name the Government uses to describe how health and social care are becoming more personal. Your needs and choices should lead what happens, rather than someone else making choices for you. This means putting you at the centre of your own care and support to give you more control over your life, often called 'self-directed support'.
personal budget:	This is an amount of money from adult social care services to provide you with help for personal care and daily routines. You will receive a care assessment to work out what you need and a financial assessment to work out how much you may need to contribute. You can have services arranged for you or manage this yourself using direct payments (see <i>direct payments</i> in this table).
personal health budget:	This is an amount of money from the NHS for extra healthcare services to help you manage a long term condition, such as additional physiotherapy or home nursing care. You can still see your GP and receive emergency treatment, but these are not part of your personal health budget. You will be assessed by the NHS to work out what you need, but not financially assessed, as the NHS pays for your personal health budget.

<p>direct payments:</p>	<p>Once your personal budget or personal health budget is agreed, you can select and buy services for yourself, if you wish (rather than having services arranged for you). If so, you will receive your budget in direct payments to your account. This means you have more control over when you receive care and who provides it, but you take responsibility for arranging and paying for each service. You can get help to manage direct payments (see later heading <i>What happens if I choose direct payments for a personal budget?</i>). You may want to think about whether or not this is the right option for you (see later heading <i>Are direct payments the right choice for me?</i>).</p>
<p>means testing:</p>	<p>This is a term used by adult social care services to describe how you will be financially assessed. Means testing looks at your income and savings to work out how much you need to pay towards social care services and how much your local authority will pay (or health and social care trust if you live in Northern Ireland). Some benefit claims may also be means tested.</p> <p> To find out more about benefits, see Information sheet 10A – <i>Benefits and entitlements</i>.</p> <p>Healthcare is not means tested, as your personal health budget is paid in full by the NHS.</p>
<p>NHS Continuing Healthcare:</p>	<p>This is when all your combined health and social care needs are paid for by the NHS if you require a high level of support for complex medical needs. Sometimes this is managed through a shared package of care with adult social care services. With MND, you may qualify for continuing care, but this would be unlikely in the early stages of the disease. Even in the later stages, it is not guaranteed unless you meet strict guidelines.</p> <p> To find out more about how to claim, see Information sheet 10D – <i>NHS Continuing Healthcare</i>.</p> <p>You do not have to qualify for continuing care to get a personal health budget, but if you do qualify, you have the right to ask for one.</p>
<p>Integrated Personal Commissioning (IPC):</p>	<p>This describes how personal budgets and personal health budgets may be pooled as a single budget in the future. We will revise this information sheet when changes are made.</p>

2. How does a personal budget work for social care?

How do I get a personal budget?

If you live in England or Wales and need help with your daily care at home, contact adult social care services through your local authority. Personal budgets are not available in Northern Ireland, but direct payments are available. These work in a very similar way to personal budgets. To access direct payments in Northern Ireland, or for more information, contact your local health and social care trust.

To start the process of getting a personal budget, ask for a community care assessment. This will usually take place at your home. You will be asked questions to work out the care you need. If you have someone supporting you, they can also ask for a carer's assessment to look at their needs. Both assessments can happen at the same time or separately.

Remember that you are the expert in how MND is affecting you and how you would like to be supported, so ensure you make your views known during the assessment. The more detail you can provide, the better, as this will help you to get the right level of support. To make this easier, try keeping a diary for a week. Write down daily tasks like getting up, showering or dressing. Try to show:

- how long each activity takes you and how tiring this might be
- whether you need help, for example, to stand or do up buttons
- if you find it difficult to do activities you used to enjoy, like going out to buy a newspaper.

Include anything that has been a problem for you, even if it only happens now and then. It is important to consider what you may need in the near future, as well as your current needs.



"The problem with MND is that it is always moving on while you play catch up."

List your questions beforehand to help you ask everything that is important to you. This is also useful if you have speech and communication problems. Take notes or ask someone to help, so you can refer back to the answers. You can also record the discussion to listen to later. Most mobile phones, smartphones and computer tablets can do this.



"You need to be as well informed as possible about how to access services."

You may want to ask the following:

- What will the personal budget cover?
- How much money will be set in the personal budget and how much do I need to contribute to this?

- Can the budget include money to help support quality of life or hobbies?
- Can I get extra money if something unexpected happens and I need more care?
- What services are available to assist with my daily care?
- How do I get emergency care, if my main carer is unable to support me for any reason?
- If I decide to have direct payments, what guidelines do I need to follow and what records do I have to keep?
- Who can help me to manage my direct payments?
- How will you check that I'm spending direct payments correctly?
- Can I change my mind about direct payments and have services arranged instead?

With MND, your needs are likely to change as your symptoms progress. If so, you can ask for a new assessment to review your personal budget.

What happens if a personal budget is agreed?

Following the assessment, you will be told by letter what has been approved in your personal budget. This is worked out by adult social care services and can only include the cost of services agreed at the time of your assessment. The budget uses costs that adult social care services feel are fair. If your financial assessment shows you need to pay towards this, it will be explained in the letter.



"Your financial support needs change as the illness progresses."

Your personal budget will be regularly reviewed and if your needs change, the amounts will be adjusted as a result.

How will I receive my personal budget?

Your personal budget can be provided in different ways:

- by having services arranged and managed for you
- as regular direct payments to you, which you can spend on services of your own choice
- through an account held by your local authority (or health and social care trust in Northern Ireland) which is managed in line with your wishes
- through a third party agency, who will use it to buy services for you in line with your wishes
- a mixture of the above.

You can ask questions about these options at your assessment. Sometimes the local council may feel it is in your best interest to arrange all services directly for you.

What happens if I choose direct payments for a personal budget?

You may want to employ your own care staff to have the same helpers or to buy in services at the times you most need help.



"If I had different help all the time, they wouldn't get used to what I need."

If you want this level of control, you can receive your personal budget through direct payments. You will be required to make a support plan showing which care services you want to use. Once agreed, you will be paid monthly into your bank account, building society, national savings or post office account. You will need to:

- set up a separate account for this, which can only be used to manage your direct payments
- keep records and receipts, involving forms supplied by adult social care services (you will be shown how to do this)
- be prepared for your records to be checked (as adult social care services have to make sure that you spend the money correctly)
- take on the role and responsibility of an employer if you employ a carer as a personal assistant.

Acting as an employer allows you to have the same helper on a regular basis (known as a personal assistant). You will have certain legal responsibilities, particularly in respect of:

- pay
- terms and conditions
- tax and national insurance
- holiday pay
- notice
- statutory sick pay.

In due course you will also be required to set up a and contribute to a pension for anyone you employ who earns more than £10,000 a year, is aged between 22 and the current state retirement age and works in the UK.

You will find more detailed information about your responsibilities as an employer on **www.gov.uk** and it is certainly something that you should discuss along with things like employee insurance at your assessment and consider when making the decision about how you receive your personal budget.

You can get help to manage your direct payments and employer responsibilities. You may wish to think about:

Brokerage schemes: these take over responsibility for your direct payments, in line with your wishes. They can manage tasks for you, such as calculating the pay and tax for a personal assistant. Ask adult social care services if any brokerage schemes are available in your area. The cost is included in your budget and there is no cost to you.

Care service agencies: these provide agency carers to assist you and usually accept employer responsibility (always check this before hiring an agency carer). This is useful, but you may get different helpers each time.

A trusted person: if they are happy to assist, you can ask a trusted person to manage your direct payments for you such as your partner, main carer, relative or friend.

Are direct payments the right choice for me?

Direct payments may be right for you if:

- you are confident to manage the money and paperwork involved
- you want more choice about the care services you receive
- you want to choose the times when you receive care.



"It works very well for me. I have a very good care manager who helps me a lot, who has known me for years now."

Direct payments may not be right for you if:

- your needs are changing rapidly and you may not be able to manage the arrangements for this
- you are likely to be spending frequent or long periods in hospital
- you are happy to let your local authority arrange and manage your care
- you do not feel confident about managing records, receipts or employer responsibilities.

Ask about the amount of work involved for direct payments either at your assessment or when you receive confirmation about your personal budget. This may help you decide whether direct payments are right for you.



"We have a problem recruiting as we are in a rural area...with social services carers we knew we would always have cover."

If you decide to have direct payments, you can change your mind and have services arranged for you instead. Contact your local adult social care services if this is the case.

How can I use my personal budget?

Your personal budget can only be spent on services agreed for you, which might include:

- personal care, for example, help with bathing and dressing
- up to four weeks respite care in any one year (which is a service to support you, but also gives your main carer a break)
- complementary therapies
- help to pay for a hobby or social activities to support your well-being, such as going to the cinema.

In the same way, if your carer has been granted a personal budget from their Carer's Assessment, their direct payments can only be spent on services agreed to help them, which could include:

- help with housework or gardening
- a training course
- a leisure course or gym membership.

Direct payments cannot be spent on:

- cigarettes or alcohol
- help, care or equipment that should be provided by social services or the NHS
- everyday costs which your own money or other benefits should pay for, like food, transport or rent
- care in a care home (unless this is for respite care)
- employing a family member who lives in the same household as your professional carer (there may be exceptions when this is allowed, depending on the guidelines set by your local authority, or health and social care trust).

Can I add my own money to top up a personal budget?

Following the financial assessment, you may be asked to contribute towards your personal budget. You can add further money as a top up if you wish. However, if you feel your budget is not enough to pay for the care you need, ask to be reassessed.

You also have the right to appeal if you disagree with the amount (see the later heading *Can I appeal against a decision?*).

3: How does a personal health budget work for healthcare needs?

How do I get a personal health budget for healthcare?

A personal health budget works in the same way as a personal budget, except that it covers healthcare needs rather than social care needs. In some cases it may cover both.

You can already ask for a personal health budget to be considered and will have the right to one from October 2014, if you qualify for NHS Continuing Healthcare. Personal health budgets are not currently available in Northern Ireland.

From April 2015, you should be offered the choice regardless of whether you qualify for continuing care, as personal health budgets will start to become available for any long term physical or mental health condition. Many areas have already begun this process.

A personalised health budget allows you to choose the services you want and have more control over when they happen. You do not have to have a personal health budget if you prefer to have the NHS make all arrangements for you.

If you would like a personal health budget, you will need to be assessed. Contact your local health team that coordinates personal health budgets in your area – ask your GP for advice. Remember that you are the expert in how MND is affecting you and how you would like to be supported, so ensure you make your views known during the assessment.

The assessment helps you work out your health and wellbeing goals in the form of a personalised care plan. You will also have guidance on how you can use your budget to keep healthy and safe.

What happens if a personal health budget is agreed?

Once your personalised care plan has been agreed by the NHS, a personal health budget will be provided. You will be informed in writing and an arrangement will be made by your healthcare team for you to discuss and sign the forms.

How does a personal health budget work?

A personal health budget provides you with as much control over your healthcare as you wish to help you manage your condition. This does not mean you will receive more services than you need or more expensive services, or be given special rights to services not available through NHS arrangements.

Your personal health budget can be managed in three different ways:

- with a 'notional budget', where no money changes hands, but your local NHS team tell you how much budget is available in your agreed personalised care plan, help you identify ways to spend the money to meet your needs and arrange the care and support for you
- through a different organisation, agency or trust, where they hold the budget for you, manage this and make any payments on your behalf – but you would still have full control over decisions as agreed in your personalised care plan
- through direct payments to you, where you or your representative are responsible for the budget and buy your own care and support services, as agreed in your personalised care plan.

Your local NHS team will help review and update your care plan after three months and then once every year. You can request further reviews if your needs change.

What happens if I choose direct payments for a personal health budget?

Direct payments for personal health budgets work in a similar way to those for personal budgets.

You need a separate bank account for the direct payments and this account must only be used for services agreed in your personalised care plan. You also need to keep receipts and records of what you spend (see also, *What happens if I choose direct payments for a personal budget?*).

If you would like more choice over services, but want support with direct payments, it may be possible for someone else to manage these for you. Ask how this works when planning your budget with your local NHS team.

If you are a family or unpaid carer, and supporting someone with MND who is unable to make decisions, ask their NHS team for guidance. They can explain the available options and how to keep the person's best interests in mind. Wherever possible, ask the person what they would like to happen.

How can I use my personal health budget?

You can use a personal health budget for support including:

- personal care and healthcare
- training to help you look after your health needs
- treatment and equipment which meet the goals of your care or support plan.

The money can be spent creatively to meet your needs, as long as it is agreed in your care plan. This could include additional respite for your carer or equipment such as a tablet computer. It will depend on what would help you meet your individual needs.

You cannot use the money from a personal health budget to:

- employ a family member who lives in the same household to be your carer (ask your local NHS trust for advice if you feel your situation is exceptional)
- buy cigarettes or alcohol
- gamble
- pay debts
- pay for anything illegal.

You will not be denied essential treatment because you have a personal health budget.

Can I add my own money to top up a personal health budget?

No, personal health budgets cannot be topped up in the same way as a personal budget. You cannot spend your own money on the care identified in your care or support plan, but your local NHS team will help ensure your personal health budget meets your agreed health and wellbeing needs.

It is unlikely you will spend more than planned, but contact your local NHS team if this happens. If your needs change, your budget will be reviewed.

However, you can spend your own money on extra services, beyond what is felt to be necessary in your care plan. For example, to pay for more massage or physiotherapy than your doctor has recommended. This would be separate to your personal health budget. Essential NHS treatment will always be available, regardless of whether you have a personal health budget or not.

What happens if I need to stay in hospital or a hospice?

Arrangements for possible hospital or hospice stays will be discussed and included in your care plan, to include planned and unplanned visits.

Can I change my mind about having a personal health budget?

If you feel the personal health budget is not working for you, you can ask your NHS team to cancel it and receive your healthcare as you did before.

Can I join my personal budget and personal health budget together?

You may be able to combine your budgets, if wished. Ask about this when your personal health budget is being planned.

4: Can I appeal against a decision?

You can make an appeal if you have been refused a personal budget or personal health budget. You can also appeal if you think a decision about either budget is wrong. There are three areas you can appeal against:

- the final decision response from adult social care services to one or more questions in the assessment
- the provisional total amount of money agreed to meet your needs
- the way the money for each care need has been calculated and what you have been told you can use this for.

For appeals against decisions for personal budgets, contact your social worker from adult social care services. Let them know why you want to appeal with clear details to support your case. You can do this in writing, by email or by phone. If you are still unhappy following their response to your appeal, you can make a complaint to the Local Government Ombudsman (see *Useful organisations* in section 5: *How do I find out more?* for contact details).

For appeals against decisions for personal health budgets, speak to your healthcare team first, who should be able to get an explanation from your local NHS. If you are still unhappy, ask your healthcare team about the NHS complaints procedure.

5: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information.

Contact details are correct at time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

Advicenow

Online information on rights and legal issues.

Website: www.advicenow.org.uk

AGE UK

Information on how to access benefits, health care and social care in later life.

Address: Tavis House, 1-6 Tavistock Square, London WC1H 9NA

Telephone: 0800 169 6565 (advice line)

Email: contact@ageuk.org.uk (England)
enquiries@agecymru.org.uk (Wales)
info@ageni.org (Northern Ireland)

Website: [**www.ageuk.org.uk**](http://www.ageuk.org.uk)

Citizens Advice Bureau (CAB)

Free, confidential advice to help resolve legal, money and other problems. Search for local branches on the website.

Telephone: 08444 111 444 (for England,
or contact your local CAB branch)
0844 477 2020 (for Wales)

Website: [**www.citizensadvice.org.uk**](http://www.citizensadvice.org.uk) (main site)
[**www.adviceguide.org.uk**](http://www.adviceguide.org.uk) (helpsite)

Department of Health

Government policy, guidance and publications for our health services.

Address: Customer Service Centre, The Department of Health, Richmond House,
79 Whitehall, London SW1A 2NL

Telephone: 0207 210 4850

Email: through the website contact page

Website: [**www.dh.gov.uk**](http://www.dh.gov.uk)

DIAL UK

Disability Information and Advice Line services (DIALs) run by and for people with disabilities.

Address: DIAL UK (Scope), St Catherine's, Tickhill Road, Doncaster,
South Yorkshire DN4 8QN

Telephone: 0808 800 3333 (helpline)

Email: helpline@scope.org.uk

Website: [**www.scope.org.uk/support/disabled-people/local-advice**](http://www.scope.org.uk/support/disabled-people/local-advice)

Disability Law Service

Assistance on disability law.

Address: Disability Law Service 39-45 Cavell Street, London, E1 2BP

Telephone: 020 7791 9800

Email: advice@dls.org.uk

Website: [**www.dls.org.uk**](http://www.dls.org.uk)

GOV.UK

Online government information about benefits and support.

Email: different contacts are given on the website for various subjects

Website: [**www.gov.uk**](http://www.gov.uk) (England and Wales)
[**www.nidirect.gov.uk**](http://www.nidirect.gov.uk) (Northern Ireland)

In Control

A national charity to improve self-directed support and personalisation.

Address: In Control, Carillon House, Chapel Lane, Wythall, West Midlands B47 6JX
Telephone: 01564 821 650
Email: admin@in-control.org.uk
Website: www.in-control.org.uk

Health in Wales

Online help about NHS services and health boards in Wales (see also NHS Direct Wales).

Email: through the website contact page
Website: www.wales.nhs.uk

Local Government Ombudsman

A body who look at complaints about councils and some other authorities and organisations, including adult social care providers (such as care homes and home care providers). They provide a free service and investigate complaints in a fair and independent way.

Address: The Local Government Ombudsman, PO Box 4771, Coventry CV4 0EH
Telephone: 0300 061 0614
Email: through the online complaint form on the website
Website: www.lgo.org.uk

MND Scotland

Care, information and research funding for people affected by MND in Scotland.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA
Telephone: 0141 332 3903
Email: info@mndscotland.org.uk
Website: www.mndscotland.org.uk

NHS Choices

The main online reference for the NHS.

Address: Customer Service Centre, The Department of Health, Richmond House, 79 Whitehall, London SW1A 2NL
Telephone: 0207 210 4850
Email: through the website contact page
Website: www.nhs.uk

NHS 111

24 hour NHS helpline for urgent but not life-threatening medical problems.

Telephone: 111 (England)

NHS Direct Wales

Health advice and information service for Wales.

Telephone: 0845 4647
Website: www.nhsdirect.wales.nhs.uk

NHS Northern Ireland

Online information about NHS services in Northern Ireland.

Email: through the website contact page

Website: **www.hscni.net**

NI Direct

Government information about health and social care in Northern Ireland.

Email: through the website contact page

Website: **www.nidirect.gov.uk**

References

References used to support this information are available on request from:
email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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Further information

We have related information sheets you may find helpful:

10A – *Benefits and entitlements*

10C – *Disabled Facilities Grants*

10D – *NHS Continuing Healthcare*

10E – *Work and MND*

You can also refer to our main guides:

Living with motor neurone disease – our guide to MND and how to manage its impact, including guidance about your finances

Caring and MND: support for you – comprehensive information for family carers, who are supporting someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

You can download most of our publications from our website at: www.mndassociation.org/publications or order in print from the MND Connect team, who can provide additional information and support:



MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, PO Box 246, Northampton NN1 2PR

MND Association website and online forum

Website: www.mndassociation.org

Online forum: <http://forum.mndassociation.org> or through the website

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them. If you would like to provide feedback on any of our information sheets, you can access an online form at: www.surveymonkey.com/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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