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Personal health budgets


Information for people in England living with or affected by motor neurone disease, or Kennedy's disease

We all need to access healthcare from time to time. With MND, the range of possible symptoms means you may need to access a number of healthcare services. This is also likely to be the case if you're living with Kennedy's disease.

In England, the NHS usually arranges healthcare services for people based on their needs. However, with MND or Kennedy's disease, you may be able to get a personal health budget, which gives more choice and control over the healthcare services you access.

This information sheet covers what personal health budgets are and includes the following sections:

- 1: What do the words mean?**
- 2: How does a personal health budget work?**
- 3: Is a personal health budget right for me?**
- 4: How do I get a personal health budget?**
- 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.

This information sheet has been evidenced, user tested and reviewed by experts.


This information only applies to people living in England. Healthcare services may differ across regions. Contact your health and social care team to find out how services work in your local area.

1: What do the words mean?

Words used for different healthcare services can sometimes sound similar. The following explanations may help:

direct payments

One way of managing a personal health budget, where you receive your budget in direct payments to your bank account. You can use this money to choose and pay for services yourself, rather than having them arranged for you.

 You can also receive direct payments to choose your own social care services. For more information, see: Information sheet 10B – *What is social care?*

integrated personal budget

A budget for both your healthcare and social care needs. This is currently only available in some areas of England as it is still being tested. It will roll out to more areas in the future.

NHS Continuing Healthcare (CHC)


This is when all your combined health and social care services are paid for by the NHS, if you require a high level of support for complex medical needs. With MND, you may qualify for CHC, but this is unlikely in the early stages of the disease. Even in the later stages, it can be difficult to get.

If you qualify for CHC and wish to receive care in your own home, you can receive this as a personal health budget.

 To find out more about CHC, see: Information sheet 10D – *NHS Continuing Healthcare*


personal budget (for social care needs)

An amount of money from adult social care services in England to provide you with help for personal care and daily routines.

 For more detail, see: Information sheet 10B – *What is social care?*

personal wheelchair budget (PWB)

A form of personal health budget which allows posture and mobility needs to be included in wider care planning. This can enable you to access more choices of wheelchair. Find out more at: www.england.nhs.uk/personal-health-budgets/personal-wheelchair-budgets/frequently-asked-questions

 For more detail on wheelchairs, see: Information sheet 11C – *Equipment and wheelchairs*

primary care The more day-to-day care available in local areas, provided by professionals you might visit first about a health concern. You generally receive primary care from your GP, chemist, community nurse and dentist. Personal health budgets **cannot** cover primary care needs.

secondary care Provided by professionals with expertise in a particular area. You usually need to be referred to secondary care services by your GP. Secondary care may be provided in a hospital or clinic, or at home. Examples of secondary care include physiotherapy, speech and language therapy, occupational therapy, community nursing care and the equipment needed to support this. Personal health budgets **can** cover secondary care services.

2: How does a personal health budget work?

The NHS in England is split up into around 200 local Clinical Commissioning Groups (CCGs), who plan and pay for healthcare services in their area. To find your local CCG, visit: www.nhs.uk/Service-Search/Clinical-Commissioning-Group/LocationSearch/1

Traditionally, healthcare services are organised by your healthcare team for you, and your local CCG pays for these. However, with a personal health budget, you can have more control over the healthcare services you access, to help manage your condition.

Personal health budgets may work slightly differently in each area, so contact your local NHS team for detailed information, after reading this sheet (for example your care centre or network co-ordinator or your GP).

What is a personal health budget?

A personal health budget is an amount of money to support your health and wellbeing needs.

This budget is planned and agreed between you and your local NHS team. There are different ways the budget can be managed (see later heading *How can the personal health budget be managed?*). In some cases, you may have a budget that covers both your health and social care needs, which is known as an integrated personal budget.

You will have an assessment with a healthcare professional, where together you will determine what your health and wellbeing needs are. See later heading, *How does the assessment work?* for more information.

Personal health budgets are not new money, just a different way of spending NHS funds. Having a personal health budget does **not** mean you will:

- receive more services than you need
- receive more expensive services
- be given special rights to services not available through the NHS.

Who can get a personal health budget?

If you qualify for NHS Continuing Healthcare (CHC) and live at home rather than in a nursing home, this will be provided in the form of a personal health budget. This is your right.



For more information on CHC, see:
Information sheet 10D – *NHS Continuing Healthcare*

However, you may also be able to get a personal health budget if you do not qualify for CHC. Personal health budgets are becoming available for more people with long term physical health conditions, including people who are eligible for NHS wheelchair services. Some areas have already started to offer these.

If you are interested in having a personal health budget after reading this information sheet, contact your local CCG to find out about availability. Ask your GP or see *Useful organisations* at the end of this sheet for how to find contact details for your local CCG.

How does the assessment work?

A health or social care professional, usually a nurse assessor, will arrange to come to your home to work out your health and wellbeing needs with you. Remember that you are the expert in how MND affects you and what support would best help you.

The CCG will use the information from the assessment to work out what they can provide you with, and how much it will cost to meet your needs. This will help them decide how much money will be included in your personal health budget.

Once the amount of money has been worked out, you meet with the assessor again to decide what health and wellbeing outcomes you want to achieve, and how you will spend your budget to do this. This information will be written down in a personalised care and support plan. Your plan will include:

- your health and wellbeing needs
- the goals or outcomes you want to achieve
- the amount of money available
- how the money will be spent to meet your needs.

The assessor will then discuss the care and support plan with the CCG for them to agree.



"I found the questions on the assessment form a little insensitive, as they would ask how services would improve my condition or make me better. I'm a positive person, but completing the form is a reminder of having MND at a difficult time."

What can a personal health budget be used for?

You can use a personal health budget for secondary care support, including:

- therapies (for example physiotherapy or hydrotherapy)
- training to help you look after your health needs
- treatment and equipment that meet the goals in your personalised care and support plan.

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



"I used my personal health budget for a one-off payment for adaptations to my push bike. MND means I'm limited to what exercise I can do, but my pushbike is a form of exercise, so we put it in the budget as it is good for me and is another way for me to get out of the house."

A personal health budget **cannot** be used to pay for:

- emergency care
- medication
- the care you get from your GP (known as primary care).

You will never be denied essential treatment for having a personal health budget.

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

- buy cigarettes or alcohol
- gamble
- pay debts
- pay for anything illegal or unlawful.

How can the personal health budget be managed?

Your personal health budget can be managed:

- **with a 'notional budget'** where your healthcare team will tell you how much budget is available, help you find ways to spend the money to meet your needs, and arrange the services for you
- **through a separate organisation, agency or trust (third party)** where another organisation manages the budget and makes any payments for you. They will be responsible for your care and support, and will be the employer of any regular paid carers that support you (known as personal assistants). However, you have full control over decisions, as agreed in your care and support plan. If you choose this option, the money agreed in your personal health budget must cover the cost of using the third party
- **through direct payments to you** where you (or your nominee) are responsible for the budget, and buy and organise your own care and support services, as agreed in your care and support plan.

You can choose a combination of the above methods, if wished.

Can family members or my main unpaid carer manage my personal health budget?

Yes. If you would like more choice over services, but want support with your personal health budget, it may be possible for a family member or trusted friend to manage this for you. This person would be known as your 'nominee'. Ask how this works when planning your budget with your healthcare team. This is not the same as a third party budget, where a professional organisation manages your personal health budget on your behalf.

If you are a family member or unpaid carer supporting someone with MND who is unable to make or communicate decisions, you may be able to manage their personal health budget for them. In this case, you would be the person's 'representative'. Ask the local NHS team for guidance. They can explain the available options and how to keep the person's best interests in mind. Wherever possible, include the person with MND in decisions.

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

No, you cannot add your own money into your personal health budget. Your local NHS team will help ensure your budget contains enough money to meet your agreed health and wellbeing needs.

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

You can spend your own money on extra services outside of those in your care and support plan. For example, to pay privately for more massage or physiotherapy. This would be paid from your own money and separate to your personal health budget.

However, you may be able to top up a personal wheelchair budget, as the rules are slightly different for these.



For details on personal wheelchair budgets, see:
Information sheet 11C – *Equipment and wheelchairs*

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

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

Do I have to have a personal health budget?

No. You do not have to have a personal health budget if you would prefer the NHS to arrange your healthcare for you.

However, if you qualify for NHS Continuing Healthcare and receive care at your own home, this will automatically be provided as a personal health budget. You can ask for a notional budget if you want the NHS to arrange your care and support for you (see previous heading *How can the personal health budget be managed?* for more information on notional budgets).

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

Yes. If you feel the personal health budget is not working for you, you can ask your NHS team to:

- review it
- change to a different way of managing the budget
- cancel it and receive your healthcare as you did before.

If you receive NHS Continuing Healthcare at home, you must receive this as a personal health budget. However if you receive this as a notional budget, the NHS manages the money and arranges all care for you (see previous heading *How can the personal health budget be managed?* for more information on notional budgets).

Can I join my personal health budget with a personal budget for social care?

If you have a personal budget for social care services, you may be able to combine this with your personal health budget, if wished. This is called an integrated personal budget. Ask about this when discussing your personalised care and support plan.

3: Is a personal health budget right for me?

If you have NHS Continuing Healthcare (CHC) provided at home, this will be provided as a personal health budget. **This section is aimed at people who do not currently receive CHC.**

Everyone is different, and a personal health budget may not be the right choice for all. Your healthcare team can support you in deciding whether to ask for a personal health budget or not.

A personal health budget may be the right choice for you if:

- you want more choice and control over your healthcare
- you are comfortable going through the assessment process
- you or your nominee are confident in managing the money and paperwork involved (if you choose to accept direct payments).

A personal health budget may not be right for you if:

- your needs are changing rapidly and you or your representative may not be able to manage the arrangements
- you do not want to go through the assessment process
- you are happy for the NHS to arrange your healthcare services for you instead (however this can also be achieved through a notional personal health budget).

How do direct payments work?

If you decide to go ahead with a personal health budget, you can have this as a direct payment so you can choose and pay for the healthcare services you want to access.



“While I had my budget by direct payment, it allowed me freedom and independence.”

Once you have a care and support plan showing the services you want to use, the NHS will transfer the money directly into your bank account, building society, national savings or post office account. This is usually done every month, but you can agree a different timeframe in your plan, if needed.

You will need to:

- set up a separate account, which can only be used to manage your direct payments
- keep records and receipts, involving forms supplied by your NHS team (you will be shown how to do this)
- be prepared for your records to be checked (as the NHS has to make sure that you spend the money correctly)
- take on the role and responsibility of an employer if you want to employ one or more carers to help you on a regular basis (known as personal assistants).

Ask your health and social care team where the closest place is to hand in your records and receipts, so that you can avoid long journeys where possible.



"I had been driving some 14 miles or so away each month to hand in my receipts, only to find out by accident that they had another place where I could have taken them, which is less than 2 miles from my home."

If you have a personal budget for social care needs and manage this by direct payments, you may be able to use the same bank account for your personal health budget direct payments.



For more information, see:
Information sheet 10B – *What is social care?*

Are direct payments the right choice for me?

Direct payments can give you choice and control over the healthcare services you access, but can also require a lot of organisation and paperwork.

Direct payments may be right for you if:

- you or your nominee are confident to manage the money and paperwork involved
- you want more choice over the care services you receive
- you want more choice and control over when you receive care.

Direct payments may not be right for you if:

- your needs are changing rapidly and you may not be able to manage the arrangements
- you are likely to be spending repeated or long periods in hospital
- you are happy to let the NHS or a third party arrange and manage your care
- you do not feel confident about managing records, receipts or employer responsibilities, and don't have a trusted person to take on this responsibility.



"I am happy with the outcome that my budget was purely notional and went directly to the care provider. But then the best carers were chosen. Otherwise, we might have had to be more hands on."

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

If you decide to have direct payments and change your mind, you can choose to have the budget managed for you instead by:

- the NHS (notional)
- a third party
- a mixture of the above.

Contact your local CCG if you change your mind about direct payments. See *Useful organisations* at the end of this sheet for how to find your local CCG, or ask your GP for guidance.

What is a personal assistant?

If you use your personal health budget to pay for people to provide care for you on a regular basis, they will be known as personal assistants (PAs). For example, this may include trained people to provide support with:

- ventilation or tube feeding equipment
- managing secretions (mucus and saliva that can be difficult to clear).

If you use your budget in this way, you will have certain legal responsibilities, including:

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

You will also need to set up and pay into a pension for anyone you employ who:

- earns more than £10,000 a year
- is aged between 22 and the current state retirement age
- works in the UK.

Ask your CCG about the support available for you as an employer.

You can choose to have support with managing your direct payments by an organisation who specialise in this, usually called a Direct Payment Support Service. They can help with things like:

- recruiting PAs
- running payroll
- providing HR advice.

4: How do I get a personal health budget?

At the time of print, anyone getting NHS Continuing Healthcare who lives at home has the right to receive this in the form of a personal health budget, if it is appropriate for care to be provided in this way.

If you are not getting NHS Continuing Healthcare (CHC), but you are interested in having a personal health budget, ask your local CCG about availability in your area. In time, more groups of people will have the right to a personal health budget, including people eligible for NHS wheelchair services. This means that if you're living with MND or Kennedy's disease, you are likely to be eligible. However, your local CCG makes this decision, and availability may differ across regions in England.

Your GP can advise on how to contact your local CCG, or you can find details at: **www.nhs.uk/Service-Search/Clinical-Commissioning-Group/LocationSearch/1** If your CCG agrees, you need to be assessed (see *How does the assessment work?* in section 1: *How do personal health budgets work?*).

What happens if a personal health budget is agreed?

Your CCG needs to agree to your budget, and your personalised care and support plan. You will be told in writing if they agree and your healthcare team will arrange a time to discuss this, so you can sign the forms.



"It needs to be a slick smooth process with ample support throughout."

Your healthcare team should also identify a care co-ordinator, who will be your first point of contact if you have any questions. In most cases, this will be a health or social care professional who knows you well. If you choose to have a notional or third party budget, the relevant person can then begin organising your healthcare services for you.

If you choose to have your budget provided in direct payments, you can then begin organising your own healthcare services to meet the needs laid out in your care and support plan.

Your budget will be reviewed after three months to ensure it is still working for you. It will then be reviewed every year, or more often if needed.

Can I appeal against a personal health budgets decision?

Yes. You can make an appeal if you have been refused a personal health budget but are eligible for one, or if you think a decision about it is wrong. There are three areas you can appeal against:

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

To appeal against a personal health budget decision, speak to your healthcare team first. They can ask the CCG to explain their decision. 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).

Find your CCG

To find your local Clinical Commissioning Group, see the website below or contact your GP.

Website: www.nhs.uk/Service-Search/Clinical-Commissioning-Group/LocationSearch/1

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 UK

For health advice and information, 24 hours a day, 365 days a year.

Website: www.nhs.uk

NHS 111

The NHS telephone service for urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111 (England and some areas of Wales)

NHS England personal health budgets

For NHS information on personal health budgets.

Website: www.england.nhs.uk/personal-health-budgets

Patient Advice and Liaisons Service (PALS)

Offers confidential advice, support and information on health-related matters in England, including making complaints. They also provide a point of contact for patients, their families and carers. Find officers from PALS in your local hospital.

Website: www.nhs.uk/chq/Pages/1082.aspx

Peoplehub

Place to share experiences and connect with others who have a personal health budget. Website features stories from people who have a personal health budget, and resources about NHS Continuing Healthcare.

Website: www.peoplehub.org.uk

References

References used to support this information are available on request from:

email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd, Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

Acknowledgements

Thanks to the professionals who helped in the expert review of this information.

Further information

You may also find the following information sheets helpful:

1A – *About the NICE guideline on motor neurone disease*

6A – *Physiotherapy*

6B – *Complementary therapies*

10B – *What is social care?*

10D – *NHS Continuing Healthcare*

You can also refer to our other information resources:

What you should expect from your care – our pocket booklet featuring the main points from the NICE guideline on MND, to help open conversations

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 our helpline MND Connect, who can provide additional information and support.

MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional MND Association staff.

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park,
Northampton NN3 6BJ

MND Association website and online forum

Website: www.mndassociation.org

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

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our online form at:

www.smartsurvey.co.uk/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, Francis Crick House,
6 Summerhouse Rd, Moulton Park Industrial Estate, Moulton Park,
Northampton, NN3 6BJ

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