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Personal health budgets

Information for people with or affected by Motor Neurone Disease (MND) or Kennedy's disease

With MND or Kennedy's disease, you may need a range of healthcare services to help manage your symptoms. In England, you may be able to get a personal health budget for greater choice and control over some of the healthcare services you access. This information sheet explores how these budgets work. The content includes:

- 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 content has been evidenced, user tested and reviewed by experts. See: piftick.org.uk



This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.



This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 5: **How do I find out more?**

Where does this information apply?

Personal health budgets only apply if you are living in England. Services can differ across regions, so ask your healthcare team for guidance in your area. In Wales, Northern Ireland and Scotland, ask your healthcare team for advice on any schemes where you live.

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 then choose and pay for certain services yourself, rather than having them arranged for you.
direct payment managed account	Your direct payment can be managed on your behalf if you wish, by a direct payment support service, solicitor, accountant or other provider. They look after the financial elements in a separate account, but as budget holder, you still sign the direct payment agreement and make decisions about how it's spent.
integrated personal budget	A budget for both your healthcare and social care needs.
integrated care board (ICB)	NHS organisations responsible for the NHS services in the local area, including GP surgeries and hospitals.
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.

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 support and daily routines.
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: england.nhs.uk/personal-health-budgets
primary care	General care provided by healthcare professionals when you first have a health concern. You usually receive primary care from your GP, pharmacist, 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 include physiotherapy, speech and language therapy, occupational therapy, community nursing care and the equipment needed to support this.
urgent and emergency care	Healthcare provided in response to an immediate urgent health need. This is free of charge and is not covered in a personal health budget.

2. How does a personal health budget work?

The NHS in England is split up 42 Integrated Care Boards (ICB's), who plan and pay for healthcare services in their area. To find your local ICB, visit: [nhs.uk/nhs-services/find-your-local-integrated-care-board](https://www.nhs.uk/nhs-services/find-your-local-integrated-care-board)

In most cases healthcare services are organised by your healthcare team for you, and your local ICB pays for these. However, with a personal health budget, you can have more choice and control over the healthcare services you access. This may help you manage your condition in a way that feels more tailored for you.

Personal health budgets may work slightly differently in each area. Contact your local NHS team for more information, such as your GP or MND care co-ordinator if you attend an MND care centre or network.

What is a personal health budget?

A personal health budget uses NHS funding to create an individually agreed personalised care and support plan. This plan offers people greater choice and flexibility over how their assessed health and wellbeing needs are met. This allows you to use the budget where you need it most.

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 in this section:
How can a personal budget be managed?

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.

Having a personal health budget does not mean you will:

- receive more services than you need
- receive more expensive services
- be given access 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.



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 those eligible for NHS wheelchair services.

If you are interested in having a personal health budget after reading this information sheet, contact your local ICB to find out about availability. Ask your GP for contact details of your local ICB.

How does the assessment work?

A health or social care professional 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 ICB 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 health or social care professional 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 health and social care professional will then discuss the care and support plan with the ICB for them to agree.

What can a personal health budget be used for?

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

- therapies such as hydrotherapy
- training to help you look after your health needs
- 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 assessed health and wellbeing needs. You will never be denied NHS treatment because you receive a personal health budget.

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

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



“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.”

You 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?

If you choose to receive your PHB in direct payments, you become responsible for planning, organising, and buying your care (other than primary healthcare through your GP surgery or emergency healthcare, as these are always provided).

The money for your PHB will be transferred into a bank account so you can pay for your care directly.

If you prefer you can choose to have your budget paid to a support service provider who can make payments on your behalf (known as a managed account).

Your personal health budget payment can be managed in three different ways or a combination of these:

1. With a notional budget

This means that once your personalised care and support needs have been assessed, you will be told how much money is available to you, and the NHS team will purchase and manage your care on your behalf.

2. With direct payments

If you receive your PHB in direct payments, either you or your nominee (your chosen representative), will be responsible for planning, organising, and buying your care.

The money is transferred into a bank account so you can pay directly for the healthcare services you choose. If you prefer, you can have your budget paid to a support service provider to make payments on your behalf, which is known as a managed account.

3. Through a separate organisation, agency or trust (third party)

In this case, your PHB is paid directly to a third party that you have chosen. They will manage the PHB and be direct employers of any staff that provide care or services for you. You will need to reach a service agreement with your third party.

You will need to decide who will be responsible for different aspects of the care in the support plan and the managing of the PHB. For example, who is responsible for recruiting staff.

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', sometimes you may see them referred to as 'representative'.

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 nominee.

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 all decisions.

Can I add my own money to 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 those agreed as needed in your personalised 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, the rules are slightly different for personal wheelchair budgets. You may be able to add your own contribution to enhance the wheelchair options available to you.

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.

Ask for a notional budget if you would like the NHS to arrange your care and support for you.



See previous heading in this section:
How can a personal budget be managed?

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.

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), this will have been planned by your health and social care professional and provided as a personal health budget.

The rest of this section applies if you do not currently receive CHC.

Your healthcare team can support you in deciding if a personal health budget is right for you 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 (which 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 personalised 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 with your care on a regular basis (these are known as personal assistants).



See information sheet **10B What is social care?**

In most cases, account audits are handled digitally or by post. If you want to do this in person, ask your health and social care team where the closest place is to hand in records and receipts. This helps you 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 also have a personal budget for social care needs, through direct payments, you may be able to use the same bank account for your personal health budget direct payments.

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 and the impact of your symptoms are changing rapidly, and you may not feel 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.

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.



“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.”

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 budget
- a third party
- direct payment managed account
- a mixture of the above.

Contact your local ICB if you change your mind about direct payments.



See section 5: **How do I find out more?** for other organisations. Find your local ICB at: [nhs.uk/nhs-services/find-your-local-integrated-care-board](https://www.nhs.uk/nhs-services/find-your-local-integrated-care-board)
You can also 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 be an employer and have 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 ICB 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?

Anyone receiving NHS Continuing Healthcare can receive this in the form of a personal health budget (if appropriate for care to be provided this way).

If you are not in one of the groups who currently have the legal right to a personal health budget, but want one, ask your local ICB for information on how to apply.

Your GP can advise on how to contact your local ICB, or find details at: **nhs.uk/nhs-services/find-your-local-integrated-care-board**.

If your ICB agrees, you need to be assessed.

What happens if a personal health budget is agreed?

Your ICB needs to agree to your budget, and your personalised care and support plan. Your healthcare team will arrange a time to discuss this, so you can sign the forms.

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.



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

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 personalised support and care 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 budget decision?

Yes, you can appeal any decision made about your healthcare and social care. These are some examples of the areas you can appeal against:

- the final decision response from the ICB to one or more of the 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 for an explanation of the decision.

If you are still unhappy, ask your healthcare team for the best way to approach the NHS complaints procedure in your area.

5. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Find your ICB

To find your Integrated Care Board, see the website below or contact your GP.
Website: [nhs.uk/nhs-services/find-your-local-integrated-care-board](https://www.nhs.uk/nhs-services/find-your-local-integrated-care-board)

Government information

Online government information about benefits and support.

Website: [gov.uk](https://www.gov.uk) (England and Wales)
[nidirect.gov.uk](https://www.nidirect.gov.uk) (Northern Ireland)
[gov.scot](https://www.gov.scot) (Scotland)

MND Scotland

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

Tel: 0141 332 3903
Email: info@mndscotland.org.uk
Website: [mndscotland.org.uk](https://www.mndscotland.org.uk)

NHS UK

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

Website: [nhs.uk](https://www.nhs.uk)

NHS 111

For urgent, but not life-threatening medical help or advice.

Telephone: 111 (England and some areas of Wales)

NHS England personal health budgets

For NHS information on personal health budgets.

Website: [england.nhs.uk/personal-health-budgets](https://www.england.nhs.uk/personal-health-budgets)

PALS

Confidential advice, support and information on health-related matters in England.

Website: [nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service](https://www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service)

Peoplehub

Share experiences and connect with others who have a personal health budget.

Website: [peoplehub.org.uk](https://www.peoplehub.org.uk)

Acknowledgements

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Anita Kromer	Personal Health Budgets Senior Manager, NHS England
Sarah Walker	Senior Manager Personalised Care, Personalised Care Group, NHS England and NHS Improvement
Jennie Walker	Assistant Head of Patient Choice, NHS England

References

References used to support this resource are available on request:

Email: **infofeedback@mindassociation.org**

Or write to:

Information feedback,
Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

Information sheets

- 1A NICE guideline on Motor Neurone Disease
- 6A Physiotherapy
- 6B Complementary therapies
- 10B What is social care?
- 10D NHS Continuing Healthcare

Booklets

- What you should expect from your care
- Types of care
- Personal care
- Living alone with MND or Kennedy's disease
- Caring and MND - quick guide

Large guides

- Living with MND
- Caring and MND - support for you

Search for information by need at: mndassociation.org/careinfofinder

Find information for professionals at: mndassociation.org/professionals

Download our information at: mndassociation.org/publications

Find information in other languages at: mndassociation.org/languages

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: mndassociation.org/mndconnect

Tel: 0808 802 6262

Email: mndconnect@mndassociation.org

Support services

Find out about our support services at: mndassociation.org/our-services

Local and regional support

Find out about our branches and groups at: mndassociation.org/local-support

MND Association Benefits Advice Service

For help to identify claims and how to apply, visit: mndassociation.org/benefitsadvice or call our MND Connect helpline.

Tel: 0808 802 6262

MND Association website and online forum

Website: mndassociation.org

Online forum: forum.mndassociation.org

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 MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on this or any of our information sheets, access our online form at:
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
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at:
infofeedback@mndassociation.org

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