

Personal Health Budget Information Guides



Information Guide 1: An introduction to personal health budgets

Who, and what, are these information guides for?

This series of guides aims to provide realistic and useful information about personal health budgets, so that people are better equipped to ask relevant questions and make the choices that are right for them about their health and well-being. The guides are intended for individuals and families who want to know more and who are considering having a personal health budget, and may also be useful for professionals.

People and families interested in having a personal health budget may be considering this option for a whole range of different reasons. A person may have a changing health condition or a change of circumstances. Often people are living with complex health conditions and may want more choice and control in their care and support.

The organisations responsible for local implementation of personal health budgets are Integrated Care Boards. There are currently 42 of these across the country, all with unique histories and different ways of doing things. Each is responsible for responding to the varied needs of their local population.

Peoplehub have created these information guides because our lived experience is that personal health budgets, when done well, can make a huge positive difference in people's lives. We've also found that things go more smoothly when people are well-informed about what is and isn't possible, and aim to work together with their local health team.

This first guide in the series provides some key information about personal health budgets.

It explains what they are, who can have one and how you might start the process of applying for one.

1. What is a personal health budget, and what is it for?

As you can see, a personal health budget is an amount of money to support a person's identified health and well-being needs.

This does not just mean "what you need to make you better," it may also mean "what you need to stay well" and it might include all sorts of things which promote physical and mental health, for example, diet and exercise.

Some aspects of your care will remain with the NHS, as they do for all of us. This will include any primary care (GPs, practice nurses etc.), acute or emergency care needs, as well as the specialist medical

"A personal health budget is an amount of money to support a person's identified health and well-being needs, which is planned and agreed between the person, their representative, or, in the case of children, their families or carers, and the local NHS team. It is not new money, but money that would normally have been spent by the NHS on a person's care, being spent in a more flexible way to meet their identified needs. The use of personal health budgets is one way of providing more personalised care and means tailoring services and support for people to enable them to have choice, control and flexibility over their care. Personal wheelchair budgets are another form of personal health budget."

(NHS England – Guidance on the legal rights to have personal health budgets and personal wheelchair budgets – December 2019)

oversight of your health condition/s from hospital consultants and their teams.

The aim is that personal health budgets enable people to have greater choice, flexibility and control in managing their health and well-being.

The Guidance for Direct Payments in Health reinforces this aim: *"As far as possible, the person, with support from professionals, carers and others, should make the choices about how their needs are met."*

So you should be central to the decision-making process about exactly how your

personal health budget is used, and it has to be linked to meeting your identified health and well-being needs .

Health needs can be relatively broad (e.g. to be able to be well enough to go out and see my family and friends) or quite specific (e.g. to maintain skin integrity by training paid carers to change dressings on a daily basis).

Not everyone wants the same in life so it's crucial that you have the opportunity to discuss with health professionals what matters to you, and to agree together how to best meet your identified health and well-being needs.

The formal personal health budget pilot evaluation in 2012 gathered evidence about what worked well in the very first personal health budget pilots.

“Evidence shows that better outcomes are achieved where:

- *There is clear information about personal health budgets, tailored to people’s needs*
- *There is access to independent advice from brokers, voluntary organisations, direct payment support services and peer networks*
- *People know how much money they have to spend on their care before care planning and are given control of their budget*
- *People are given a high degree of flexibility and choice to spend their budget on services that make sense to them, which may include services not traditionally provided by the NHS*
- *Care plans cover all areas of the person’s life, including their aspirations, wishes and needs and adopt a positive approach to managing risk.”*

(NHS England - Guidance on the legal rights to have personal health budgets and personal wheelchair budgets – December 2019)

This learning provides good evidence about what works well when delivering personal health budgets.

Having clear and easy to understand information is important at all stages of the personal health budget process, but especially so when people are first offered the option as a way of having more choice and control in their own health and well-being.

Although the evidence clearly supports people having access to independent advice, peer networks and other types of support, this does still vary across the country.

Knowing how much money is available before you start to plan is really important. It enables you to make a realistic plan, and to prioritise the things that matter most to you within that plan.

One of the most exciting findings of the research was that personal health budgets achieved better outcomes in places that supported greater flexibility in how the money was spent.

Personal health budgets were shown to work best when the planning process is holistic, encompassing not only a person’s needs but also their hopes and strengths.

Health professionals, and the NHS as a whole, have historically placed great emphasis on keeping people safe and well – for good reason. Taken to an extreme though, risk aversion can limit people’s ability to live a full life.

Personal health budgets at their heart are about a shift in relationship between people and their health professionals. This includes a deeper understanding of each other’s perspectives about risk, and a sharing of responsibility for those risks. The evidence backs up a positive approach to managing risk.

When personal health budgets were first being developed, people with lived experience worked alongside the NHS to ensure that the learning from social care personal budgets - both positive and negative - was used to inform how personal health budgets were created

and implemented. The evidence from the personal health budget pilot evaluation also showed several clear indicators for good practice which have informed later guidance.

It was important that descriptive measures were jointly agreed that would serve to help

people recognise a true personal health budget. People with lived experience co-created, with the NHS, the key features of a personal health budget below. To be able to be counted as a personal health budget, these six key features need to be in place. (Personal health budget mandatory data collection guidance, NHS England – 2018)

The key features of a personal health budget

“There are six key features of a personal health budget that ensure people experience the best outcomes possible.

A person should:

- *Be central in developing their personalised care and support plan and agree who is involved*
- *Be able to agree the health and wellbeing outcomes (and learning outcomes for children and young people with education, health and care plans) they want to achieve, in dialogue with relevant health, education and social care professionals*
- *Know upfront an indication of how much money they have available for healthcare and support*
- *Have enough money in the budget to meet the health and wellbeing needs and outcomes agreed in the personalised care and support plan*
- *Have the option to manage the money as a direct payment, a notional budget, a third-party budget or a mix of these approaches*
- *Be able to use the money to meet their outcomes in ways and at times that make sense to them, as agreed in their personalised care and support plan.”*

(NHS England – Guidance on the legal rights to have personal health budgets and personal wheelchair budgets – December 2019)

2. What is the difference between a social care personal budget and a personal health budget?

There are 2 statutory bodies for funding care and support within England. One is your Local Authority social care department, and the other is your local NHS commissioning department. Even though we all know that our health and social needs inter-relate, the system is set up in 2 distinct ways.

Broadly, the social care system provides support for some people who need it to help them keep their independence and dignity. It's intended for help with everyday things like washing and dressing,

getting in and out of bed, and keeping your home clean and safe. However, it is not always available to everyone and eligibility is determined by the Care Act (2014). People may be required to make a financial contribution towards the cost of their eligible social care needs. This is not the same for NHS health care, because a core principle of the NHS is that it is free at the point of delivery.

A person's eligibility and determination of their health and/or social care needs is done through a joint assessment between the local authority and the local NHS Continuing Health Care team. Sometimes people can be deemed to have both health and social care needs. In this instance, they may be eligible for a joint funded care package, which may, or may not, be integrated.

For both health and social care budgets,

eligibility for funding and services can change. A person's condition may deteriorate from having an eligible social care need to having an eligible health need, or the other way round. Other people go straight into healthcare. This can be both confusing and distressing particularly when support is working well and may be disrupted.

The National Framework for Continuing Health Care (2018) states, "*Neither the NHS nor a Local Authority should unilaterally withdraw from an existing funding arrangement without a joint reassessment of the individual, and without first consulting one another and the individual about the proposed change of arrangement. It is essential that alternative funding arrangements are agreed and put into effect before any withdrawal of existing funding, in order to ensure continuity of care.*"

There is more information and some helpful short videos about social care from the King's Fund here – <https://www.kingsfund.org.uk/projects/what-is-social-care> and some factsheets about the Care Act, including assessment and eligibility, here – <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets>

3. Who can have a personal health budget?

Currently, the groups of people who have a legal 'right to have' a personal health budget are those who are eligible for:

- NHS Continuing Health Care and children's NHS Continuing Care
- Section 117 after-care under the Mental Health Act
- local NHS wheelchair services

The legal rights have been expanded over recent years.

There is much more information on Continuing Health Care funding in our *NHS Continuing Health Care* information packs.

NHS Continuing Health Care and NHS Continuing Care (since 2014)

This is funding for a very specific group of people who have been through a formal assessment process, which has identified a primary health need. This is not at all as straightforward as it might sound. It is based on an assessment of your overall needs which is carried out using a National Decision Support Tool (see Further Reading for links to the National Frameworks).

Section 117 after-care (since 2019)

People are eligible for Section 117 after-care if they have been detained under sections 3, 37, 45A, 47 or 48 of the Mental Health Act 1983. When they leave hospital, Section 117 after-care services traditionally include healthcare, social care and employment services, supported accommodation, and services to meet people's social, cultural and spiritual needs.

NHS Wheelchair services (since 2019)

People who are referred and meet the eligibility criteria of their local NHS wheelchair service, and people who are already registered with the wheelchair service, are eligible for a personal wheelchair budget when they require a new wheelchair or specialist buggy, either through a change in clinical needs or in the condition of the current chair.

Since April 2016, there has also been an expectation that personal health budgets will become available for other groups of people, including people with a learning disability, autism or both.

For information about personal health budgets in each local area, please refer to your local Integrated Care System website. All Integrated Care Systems are required to inform eligible people about their right to a personal health budget.

4. How can a personal health budget be managed?

Help and support to choose the right option for you should be available in your locality, but the national picture is still patchy.

The best time to make the decision about how you would like to manage your own personal health budget is when you have drafted your care and support plan, you're clear about what you want to achieve, and what that will involve.

A personal health budget can be managed in one of three ways, or in a combination of them:

- **Notional Budget**

No money changes hands. The individual is informed how much money is available and talks to their local NHS team about the different ways to spend that money on meeting their needs. The NHS team will then arrange the agreed care and support.

- **Third Party Budget**

A different organisation or trust holds the money for the individual and supports them to meet their health and well-being outcomes.

- **Direct Payment Budget**

The individual receives the money directly to buy the care and support that they have decided they need, in agreement with their local NHS team. They have to show what the money has been spent on, and the individual, or their representative, buys and manages the services.

There is much more detailed information on the different ways to manage a personal health budget in the third guide in this series – *Choosing how to hold a personal health budget*.

5. What can a personal health budget pay for?

The personal health budget pilot evaluation showed that personal health budgets worked best where people had real flexibility over how they could use their budgets.

On an individual level, what a personal health budget can be spent on depends on the health and well-being outcomes that have been agreed and how you want to achieve them.

However, Integrated Care Boards are free to implement their own local decision-making policies. Bear in mind that sometimes NHS staff might be un-used to people using NHS money for things other than traditional services e.g. using a personal health budget for a gym membership.

The Guidance on Direct Payments for Healthcare (2014) very helpfully states *“CCGs should be careful not to exclude unusual requests without examining the proposal on a case by case basis; these may have significant benefits for people’s health and wellbeing.”*

(CCGs – Clinical Commissioning Groups - were replaced by ICSs in 2022 but the Guidance still refers to CCGs.)

It is always important to explain as clearly as you can how your suggestions will enable you to achieve your outcomes, and the risks if this doesn’t happen.

There are particular exclusions for their use where the personal health budget is received as a direct payment and a full list can be found in the NHS Direct Payments Regulations 2014. Importantly, they state that: *“Although these regulations only apply to direct payments, the information in this guidance will be useful for all types of personal health budgets.”*

Personal health budgets cannot be used for anything that is illegal, nor for alcohol, tobacco, gambling or debt repayment.

There are also certain NHS services which will remain as such: principally primary care and emergency care services.

6. How have other people used their personal health budgets?

There are several stories on the peoplehub website that illustrate how people have used their personal health budget to meet their health and well-being outcomes. There are also some case studies on the NHS England website (see Further Reading).

People have frequently chosen to use their personal health budget to take control over choosing who provides their care and support, often through employing their own personal assistants.

People have also used their budgets in creative ways to meet their identified health needs, such as:

- An exercise programme or gym membership to maintain fitness and cardiac health
- Pain relief therapy including hydrotherapy and complementary therapies
- Assistance dogs to help daily living and alert to medical emergencies
- Drum kits to improve and maintain co-ordination and range of movement
- Singing lessons/choirs to improve breathing, lung function and social connection
- Different ways of family carers being supported to have a break from their caring role

The formal research evaluation of personal health budgets in 2012 said:

“The configuration of personal health budgets...appeared to be important. Generally, a more positive effect on outcome indicators was seen where sites choose to be explicit in informing the patients about the budget amount; provided a degree of flexibility as to what services could be purchased; and provided greater choice as to how the budget could be managed. Some negative impacts were found for sites using configurations with less flexibility and choice than other sites.”

(Forder et al., 2012).

7. What are the steps in getting a personal health budget?

a. Make contact

Speak to someone who can tell you more and provide you with more information. This might be through your Integrated Care System, someone in your local Continuing Healthcare team or a voluntary organisation.

b. Eligibility and assessment

The next step is to find out if you are eligible for a personal health budget through an assessment of your health and well-being

needs. The person who does this assessment with you, and how it's carried out will vary depending on local systems. However, there is a nationally agreed Continuing Healthcare assessment process.

c. Get an indicative budget

If it is agreed that you can have a personal health budget, then the organisation responsible for delivering personal health budgets will need to work out how much money they believe will meet your needs.

This sum is sometimes referred to as an indicative budget: it is a rough sum to help you plan realistically, and it might change (up or down) later in the process when it becomes clearer exactly what you need, what is reasonable and how much money is required to meet your needs.

d. Make a care and support plan

This plan is at the heart of the process: it starts with a clear description of who you are and what matters most to you. It then details your health needs and how best to meet them in a way which is personal to you and your family. Care and support plans should be simple, use every-day language and have clear actions and timescales that are assigned to named people. The best plans are those where someone has had the space and time to genuinely reflect on how to tailor their care and support to effectively meet their health and well-being outcomes.

Health professionals will need to contribute to the plan but you might find it helpful to speak to others, particularly those who already have experience of using personal health budgets or someone from a peer network or "user-led" organisation.

It is essential that you and your family feel that the plan is personal to you. You must be confident that it is what you want and that it will work for you. This is by no means the same as saying that you are entitled to public money for any and every wish. NHS managers have to agree that the plan is sound, sensible and affordable but nor should you feel you should downplay your needs. The second guide in this series explores care and support planning in much more depth.

e. Choose how you want to manage the budget

You should have all three options for managing the budget explained to you. We feel it is important that people are able to make this choice after they have drafted their care and support plan. This is because drafting the plan will enable you to fully understand what you want to achieve with your budget and the degree of control that

you want over it. There is more detailed information in the third guide in this series.

f. Have the plan agreed

Every personal health budget plan has to be agreed by the people responsible for the funding. Each local health system will have their own process for agreeing and authorising personal health budget plans. It's useful to find out how your local system makes these decisions so that you know the timescales and what needs to be included in the plan.

g. Put the plan into action

How you do this depends on the nature of your health outcomes and how those outcomes could be met. People who have opted for a direct payment to employ a support team, will need to consider staff recruitment. This process shouldn't feel too onerous because there should be help and

advice available to you. There is an excellent personal assistant toolkit guide which is available directly from Skills for Care (see Further Reading). If you have chosen a third party organisation to manage your budget, you will now be working with them on the most important next steps.

h. Monitoring and review

This is a key aspect of the personal health budget process. A good review asks: what is working and what is not working and what, if anything, needs to change. Personal health budget holders often have a fluctuating or deteriorating health condition so reviews are important to address any significant changes in your health and well-being or other circumstances. As well as having a scheduled review agreed in the plan, there should be an option for budget holders to ask for a review at any time.

FURTHER READING

This is the first guide in a series of information guides about personal health budgets.

The other guides are:

- 2 – Care and support planning for personal health budgets
- 3 – Choosing how to hold a personal health budget
- 4 – Top tips for personal health budgets

Available from www.peoplehub.org.uk



Guidance on the legal rights to have personal health budgets and personal wheelchair budgets (updated 2022) NHS England

<https://www.england.nhs.uk/publication/guidance-on-the-legal-rights-to-have-personal-health-budgets-and-personal-wheelchair-budgets/>

Guidance on Direct Payments for Healthcare: Understanding the Regulations (updated 2022) NHS England

<https://www.england.nhs.uk/publication/guidance-on-direct-payments-for-healthcare-understanding-the-regulations/>

Evaluation of the Personal Health Budget Pilot Programme (2012) Forder et al.

https://www.phbe.org.uk/index_phbe.html

Peoplehub Continuing Healthcare information packs – with links to further useful information and resources

<https://www.peoplehub.org.uk/personal-health-budgets/#resources>

National framework for NHS Continuing Healthcare

<https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

National Framework for Children and Young People's Continuing Care

<https://www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework>

NHS England Personal Health Budget Case Studies

<https://www.england.nhs.uk/personalisedcare/evidence-and-case-studies/>

<https://www.england.nhs.uk/personalisedcare/comprehensive-model/case-studies/>