

Information Sheet 1: Getting started with a personal health budget

This series of guides aims to provide realistic and useful information about personal health budgets. It is mainly intended for individuals and families who want to know more and who are considering using a personal health budget but will also be useful for professionals. It provides very practical down-to earth advice so that individuals and families are equipped to ask pertinent questions, make the right choices and decisions and ultimately to get what they need to live their life.

Personal health budgets are very new and are not yet widely understood within the NHS. Systems and processes are still being developed and personal health budgets are at various stages of implementation across the country. It is also the case that everywhere in England is different. There are 212 Clinical Commissioning Groups (the organisations responsible for local implementation of personal health budgets) all with unique histories and different ways of doing things. And of course, we are living at a time of unprecedented austerity in public finances and personal health budgets do not bring with them any extra funding. The money for personal health budgets is the same NHS money used differently.

*People and families interested in using personal health budgets are often considering this option at a time of considerable change in their lives. A person may have a new diagnosis, a deteriorating health condition or an accident. It can be difficult to remain patient with a personal health budget approach that is still being developed through local interpretation and decision-making. Our experience is that, done well, the effort is worth it. Peoplehub is an organisation of people **using** personal health budgets and we provide this advice based on our lived experience that personal health budgets can make a huge positive difference **if** all concerned are well-informed, knowledgeable about what is and is not achievable and proceed sensibly and with mutual respect.*

This first guide provides some key information about personal health budgets, explains who can have one and how you might start the process of being considered for one.

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

A personal health budget is an amount of money to support a person's health and wellbeing needs, planned and agreed between the person and their local NHS team. The vision for personal health budgets is to enable people with long-term conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive.

This means that the person with the personal health budget or their representative must:

- Be able to choose the health outcomes they want to achieve.
- Know how much money they have for their health care and support.
- Be enabled to create their own care plan, with support if they want it.
- Be able to choose how their budget is held and managed.
- Be able to spend the money in ways and at times that make sense to them, as agreed in their plan.

A personal health budget is an amount of money to meet 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. The aim is that personal health budgets help people have greater choice, flexibility and control in managing their health and well being.

So you should be central to the decision-making process about exactly what your personal health budget is *for*: this is what is meant above by the term *health outcome*. Health outcomes can be relatively broad (for example, to be able to be well enough to go out and see my family and friends) or quite specific (for example, 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 outcomes.

2. Who can have a personal budget and who decides if I qualify?

Currently, the group of people who have 'the right to have' a personal health budget are those who are eligible for *NHS continuing health care*. This is a very specific group who have been through a *formal assessment process, which has identified a primary health need. This means that your main or primary need for care must relate to your health based on a set of strict criteria.*

Eligibility for NHS continuing healthcare does not depend on:

- *a specific health condition, illness or diagnosis*
- *who provides the care, or*
- *where the care is provided*

If you have a disability or if you've been diagnosed with a long-term illness or condition, this doesn't necessarily mean that you'll be eligible for NHS continuing healthcare.

Instead, a person's eligibility for NHS continuing health care depends on four factors:

- the *nature* of their needs, the impact on the person and the types of care and support required
- the *complexity* of their needs and the skills required to care for them
- the *intensity* (quantity and degree) of their needs and the support required
- the *unpredictability* of changes in their needs and the responses required

NHS Continuing Health Care is a complete package of health and social care that is paid for by the NHS.

All areas of the country have a team of clinical staff who are responsible for using the national guidance to decide precisely who it is that qualifies for NHS Continuing Health Care. Most often continuing health care assessors become involved through the health care system. However, if you want to find out more, it's worth asking for the contact details of the lead person for continuing health care assessments. There is also more on continuing health care in guide 5.

The government has now decided to give patients more direct control. They expect clinical commissioning groups to lead a major expansion in 2015/16 in the offer and delivery of personal health budgets to people, where evidence indicates they would benefit. By 2016, the government expects that personal health budgets or integrated personal budgets across health and social care should be an option for people with learning difficulties. Clinical Commissioning Groups are expected to engage widely and fully with their local communities and patients, including with their local Healthwatch, and include clear goals on expanding personal health budgets within their published local Joint Health and Wellbeing Strategy.

In July 2014 Simon Stevens, the Chief Executive of the NHS made an announcement about a new programme to be known as Integrated Personal Commissioning which will bring together health and social care personal budgets. His announcement is summarised in the box below.

The Integrated Personal Commissioning (IPC) programme

The programme will for the first time blend comprehensive health and social care funding for individuals, and allow them to direct how it is used.

Four groups of high-need individuals in eight demonstrator sites are included in the first wave from April 2015. These are:

- people with long term conditions, including frail elderly people at risk of care home admission
- children with complex needs
- people with learning disabilities, and
- people with severe and enduring mental health problems.

The demonstrator sites named by NHS England and the Local Government Association are in Barnsley, Cheshire, Luton, Stockton on Tees, Tower Hamlets, Hampshire, Portsmouth, and South West.

The important message is that although the group of people who have ‘the right to have’ a personal health budget remains restricted, the rules which govern this are changing rapidly, so it’s worth keeping a watchful eye.

How can a personal health budget be managed?

- *A personal health budget can be managed in three ways, or a combination of them:*
 1. ***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.*
 2. ***Budget held by a third party.*** *A different organisation or trust holds the money for the individual and supports them to meet their health and well-being outcomes.*
 3. ***Direct payment for healthcare.*** *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, but the individual, or their representative, buys and manages the services.

Help and support to choose the right option for you should be available in your locality, but bear in mind that these are all new arrangements and the national picture is still patchy. The best time to make this decision is when you have written your care and support plan and you're clear about what you want to achieve.

Finding the right 'third party' to help may also be tricky. There is much more about third party arrangements in guide 3. Also see *Third Party Budgets: the Families' Perspective* (Department of Health, 2012) which gives more detail about the practical arrangements and which sets out in particular the things that matter most to families. Follow this link - http://www.peoplehub.org.uk/Personal_health1.pdf

3. What can a personal health budget pay for?

Personal health budgets are not appropriate for all types of healthcare. 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 National Health Service (Direct Payments) Regulations 2013. Although the regulations refer specifically to direct payments, for consistency and good practice the exclusions should be applied to 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.

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, Clinical Commissioning Groups are free to implement their local decision-making policies. Bear in mind that sometimes NHS staff may not know much about personal health budgets and they 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. If you find yourself in dispute, it is important find out if there is a transparent local policy and what it says. It is always helpful 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.

4. Examples of how people have used their personal health budget

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. These include

- Care staff, who may do a range of things including delegated health care tasks and personal care
- A healthy eating programme
- An exercise programme
- Tele-health equipment
- Gym membership
- Acupuncture and other complementary therapies
- Pain relief therapy

- Physiotherapy
- Counselling
- Specialist daily living equipment
- Help with transport costs to get around the community
- Short breaks

There is now a considerable body of evidence to back the efficacy of enabling the flexible use of NHS resources. 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).

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

- a. Make contact with someone who can tell you more. This might be your continuing health care team or local voluntary organisation like Age Concern.
- b. Discuss your health with a trusted health professional to establish whether your health and well-being needs could potentially be met through the use of a personal health budget and whether this is on offer to you.
- c. 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 allocation*: 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 you defining your *health outcomes* (above) and working out how best to meet them in a way which is personal to you and your family in your particular circumstances. 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. Once implemented, plans should be reviewed appropriately to establish how well the plan is working. 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. There are some tools available to help you make your own plan (see for example <http://www.helensandersonassociates.co.uk/>).

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 be persuaded to downplay your needs. Criteria for a good plan are listed in the box below.

CRITERIA FOR A GOOD PLAN
1) Show who the person is, with their strengths and skills, and their personal social context, as well as their health and wellbeing needs. If the person lacks capacity to make their own decisions, the plan must show how any decision was reached and identify who will speak on the person's behalf.
2) Describe what is <i>working and not working</i> from their perspective.
3) Detail what is important <i>to</i> the person and what is important <i>for</i> their health and wellbeing.
4) Identify and address any risks and how they will be mitigated to an acceptable level, including a contingency plan for if things go wrong, and a point of contact in health services.
5) State the health and wellbeing outcomes to be achieved and how it is proposed that those outcomes will be achieved.
6) Describe in broad terms how the money will be held and managed and show how it will be used to achieve the outcomes.
7) Have an action plan that details who will do what and when to ensure that the plan is carried out.
8) Include the name of the person's care coordinator.
9) State how and when the outcomes, and the money, will be monitored and reviewed. (This will include describing how people will know the plan is going well, and how people would know if things were going wrong.)

- e. Local arrangements will vary as to how your plan is agreed and who makes that decision. Once the plan is agreed, it's time to 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 at <http://www.employingpersonalassistants.co.uk>. 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.
- f. Monitoring and review is a key aspect of the personal health budget process. A good review asks: what is working and what is not working and what 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.

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

Your local council social care department provides social care personal budgets, which is separate from the National Health Service. Some people need practical or emotional care or support to lead an active life and do the everyday things that most of us take for granted. The social care system provides this support for those who need it to help them keep their independence and dignity. However, they are not available to everyone and eligibility is determined by local Fair Access to Care criteria. In many areas, people's assessed needs have to be deemed 'substantial' or 'critical' to receive funding. Even then, people may be required to make a financial contribution because social care services are means tested.

Sometimes people have both health and social care needs. In this instance, they may be eligible for both a health and social care budget, 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 improve or deteriorate and they may move from having an eligible social care need to having an eligible health need, or vice versa. Others 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 (2012) states, "Neither the NHS nor an LA 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.

7. In summary, what are the key features of a personal health budget?

The personal health budget delivery team has worked closely with and listened carefully to the National Personal Health Budget Peer Network. What did people using personal health budgets say the process would look like if it were working well? They said.....

- I know where to go for clear and accessible information and feel well-informed and supported
- I know how much money is available and how it was calculated, and have enough to meet all my health and wellbeing needs
- I have a budget that includes all my health and wellbeing needs, except for those met through primary care and emergency care services
- I have a plan that covers all my health and wellbeing needs, except for those met through primary care and emergency care services, and which takes account of my family situation
- I can choose between all three options for managing my budget, including a direct payment
- I have control over organising my care and support in the ways and at the times that make sense to me
- I am an equal partner in all decision-making and my expertise is recognised and valued
- I have a plan, which takes account of risks in a positive way and enables me to lead as full a life as possible.
- I find the process clear and transparent, and it is easy to get my plan agreed and problems resolved

- I am supported to review my plan, to see what's working and not working, and to make any changes needed

The list above will help you recognise how well personal health budgets are being implemented in your local area.

Further reading

Department of Health (2012), *Third party budgets: the families' perspective*, available at:

<http://www.personalhealthbudgets.england.nhs.uk/library/Resources/Personalhealthbudgets/>

Department of Health (2012), *Evaluation of the Personal Health Budgets Pilot Programme*: Julien Forder, Karen Jones, Caroline Glendinning, James Caiels, Elizabeth Welch, Kate Baxter, Jacqueline Davidson, Karen Windle, Annie Irvine, Dominic King and Paul Dolan, available at

<https://www.phbe.org.uk/index-phbe.php>

If you want to know more about how the NHS now works, there is a helpful guide called *Understanding the New NHS* at <http://www.england.nhs.uk/wp-content/uploads/2014/06/simple-nhs-guide.pdf> . The guide is aimed at people working in the service, but it provides information that may be useful for everybody.