



Knowing the deal

This is the first information sheet in a set. There are others being developed and the next two available are about “planning with your personal health budget and “ways to hold and manage a personal health budget”. We’ve written them from our direct experience and hope you find them useful.

We’ve also found that many of us like to talk with or email other people who’ve got a personal health budget to ask questions. We’ve set up the peoplehub personal health budget forum as a network for people using personal health budgets. You’ll find the forum in our ‘community section.’”

What is a personal health budget and what’s it for?

“A personal health budget is NHS money allocated to someone with an identified health need that enables them to have greater control when planning and meeting their chosen health outcomes. Its purpose is to ensure that people with long-term health conditions and disabilities have the chance to shape their lives by making the decisions about their health and wellbeing that matter most to them.

A personal health budget has **five essential parts**. If any of these are missing, then the person is less likely to be able to make decisions about their health which matter most to them, and the personal health budget is less likely to be effective.

The five essential parts of a personal health budget:

1. The person knows how much money they have, so they can use that information to plan and to budget in an ongoing way.
2. The person chooses the personal health outcomes to be achieved, in agreement with their health professionals.
3. The person is enabled to create their own care plan, with whatever support they may want, to meet care planning process criteria.
4. The person freely chooses the way in which their budget is held and managed.
5. Whichever option is chosen to hold and manage the money, the person must be able to spend it at times and in ways that make sense to them, within the national rules set in place by the Department of Health.

Personal health budgets are a different way of doing things. They give you more choice and control over how your health needs are met by enabling you to use NHS money in new and creative ways. The things you want to buy or the services you choose may differ quite considerably from those traditionally provided by the NHS. For example, you may choose a piece of equipment that could improve your fitness, or membership of a gym. If you need paid support for personal care, then you may want to employ your own personal assistants instead of using a nursing agency.

However, before you can start to plan, it’s really important for you to know what ‘the deal is’. You will need to know what you can and cannot buy, what your responsibilities are and what help is available for you to make the best use of your budget. You may find that the rules differ according to where you live because each Primary Care Trust, (or Clinical Commissioning Group), will have their own local policies. This fact sheet should help you ask the right questions to find out what ‘the deal’ is in your area.

At the present time (2012), personal health budgets are the responsibility of local Primary Care Trusts (PCTs). These responsibilities are being taken over by the new Clinical Commissioning Groups (CCGs) as part of the NHS reforms. These Trusts

and Groups are sometimes known as ‘the commissioners’ because they are the NHS officials responsible for planning and paying for (‘commissioning’) health services.

If you have difficulty getting answers to these questions, you ask your local commissioners.

Useful questions to ask

1. How much and why?

You need to know exactly how much money you have from the NHS in your personal health budget.

You need to be clear when and how the money will be paid to you and the period of time it is to cover. You need to know when this sum will be reviewed and whether there will be inflationary increases. You need to be clear which NHS services you will continue to use in the same way you always have, and which you will choose to include within your personal health budget.

It also helps if you understand how your PCT has arrived at this figure. Personal health budgets are still very new and the NHS is only now beginning to work out a fair and open way of allocating money to people, so at this stage the answer to this question may not be straightforward. But if you can find out why the figure is what it is, then you can challenge it if it seems unfair or if the NHS seeks to reduce it at a later date.

If any of these things are unclear, **ask the commissioners.**

2. What help can I have to manage the money?

Once you know how much money is available to you, then you also need to know what support there is to help you manage the budget. This will enable you to decide how you would prefer the money to be held - that is to say, whether it is paid directly to you (a ‘direct payment’) or is looked after for you by a ‘third party organisation’ or managed by the NHS (a ‘notional budget’). See the next section for more information on these alternatives.

The help and support available will be different in different localities and, because personal health budgets are new, the knowledge and expertise available locally will also vary a lot. The **Resources to Help** section at the end of this information sheet gives some ideas about the sorts of organisation you might find useful.

3. What are the different ways of holding and managing the money?

In some parts of the country the NHS now allows people to have a personal health budget as a **direct payment**. This is money paid *‘instead of services.’* It is paid directly into your bank account, usually on a monthly basis. Direct payments have been available in social care for more than ten years, but they have only recently started in the NHS. We hope that direct payments for healthcare will eventually be available to everyone, irrespective of where you live.

A Personal Health Budget can also be held for you by a **‘third party organisation,’** which might be a legally constituted Trust, or it might be a care agency which might itself be registered with the Care Quality Commission in order to allow it deliver ‘personal care.’

Finally, a personal health budget can be managed for you by the NHS (a **‘notional budget’**).

There are a number of different ways in which all of these different arrangements can operate. This is only a summary and you will need to investigate what is available locally, talk to other personal budget holders and NHS staff and come to a decision on what suits you best.

In any case you need to be clear that a personal health budget means:

That the money is ‘your money’, whether you hold it as a direct payment or another person or organisation holds it on your behalf. You are accountable. (See the next section for more on how you can use it).

That record keeping and monitoring is important but should be kept at a sensible and appropriate level. This is outlined in the Department of Health guidance paper “Direct Payments for Health Care: Information for pilot sites” (July 2010) which states: “The PCT must undertake ongoing monitoring of how the direct payment is being used and the health condition of the person.... Reviews should be light- touch, and should place as few burdens on people, representatives and nominees as possible. PCTs should consider working with local authorities, or other statutory services, to develop joint approaches to reviews, in order to minimise duplication and to reduce the burden on individuals.”

For personal health budgets to work well there needs to be trust in people. This means there needs to be a local acknowledgement that any of us can make mistakes and no-one should be punished for a mistake, only for deliberate fraud or misuse - which we know happens rarely.

If health needs change, the budget can also be changed. The local “deal” should also be clear that, up to an agreed amount, you do not have to seek permission for every-day spending, provided it is in line with your planned outcomes.

For more detail on the options for holding the money see information sheet no 3 “The ways to hold and manage a personal health budget” and ‘*Personal Health Budgets, A Guide to Ways in Which the Money can be Held and Managed,*’ (DH, 2012).

4. What can I spend the money on?

You need to know what you can spend the money on, and what is excluded. There are some national rules. These rules say that you cannot spend it on:

- Emergency or acute NHS services.
- Most ‘primary’ NHS services (GPs, district nursing etc.)
- Gambling, debt-repayment, tobacco, alcohol or anything illegal.

Other than these, you should be able to use the money flexibility to meet your health outcomes. It is possible that PCTs and CGCs may try to apply local restrictions as well. *If so, and if they cause you difficulty, then challenge these rules.* The important thing to remember is that a personal health budget is available to meet your *agreed health outcomes*. The NHS needs to agree that this will work for you, but once they have done so it does not make sense for them to restrict how you use the money. The Department of Health have stated that: “PCTs 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.” (“Direct Payments for Health Care: Information for pilot sites (Department of Health July 2010).

5. Is the time right for you?

The whole point of personal health budgets is that they give you more choice and put you in control of things. This will only work if arrangements are made *at the right time*. The *right time* is rarely at, or shortly after, you have been through a health crisis, or when you are still adjusting to a major change in your life, the diagnosis of a serious long-term condition for example. You should neither be excluded from having a personal health budget nor be pushed into accepting one when you are not ready.

6. Have you got REAL choice?

The NHS has talked about ‘giving patients choice’ for many years now, but this has yet to make enough difference to people’s experiences. Personal health budgets should be different because they start from the person, their needs and wishes and build up from this. Only **you** can say what it feels like in your situation: do you have *real choice*? Talk to others and ask them how things work for them; find out about the full range of health (and other) services that exist in your area; do some research on the internet about what is available elsewhere. If you are not getting what you think you need, either because it is not available locally or because someone deems it not appropriate for you, then get some support, **talk to the commissioners** and put your case. This needs to show how what you want will meet your personal health outcomes.

7. Have you got the assistance you need to make a plan?

Support planning (or care planning) is at the heart of the personal health budgets process. A separate Factsheet covers the main issues involved in support planning (Information Sheet 2, “*Developing a Great Plan*”). It is important that as part of ‘knowing the deal’ you are clear about what has to be included in the plan and how to get the assistance you might need to make a plan. Once

more, the local capacity to provide this assistance varies enormously. Because personal budgets started in social care, it is very likely that you will find people and organisations around who are experienced in developing social care support plans, but perhaps not so for health care. The principles of self directed support, person-centred thinking and planning are common to both however.

Support plans are not difficult, technical documents, and the best assistance is often from people who have developed their own plan already, or perhaps who have helped a family member to do so. You might be able to find such 'peers' to help you plan by asking NHS staff if they know of anyone or approaching a support group, a user-led organisation or centre for independent living. Such organisations may provide you with other ideas and resources to help you make your own support plan or to find out about local support planning 'brokers.'

It may also be that some NHS staff themselves are in a position to help you plan. The best health professional to do this is someone you feel comfortable with and who understands the purpose of a personal health budget. What's most important is that you are allowed to take the lead. You should have ample opportunity to think things through and to work out what's important to you rather than simply being given the health professional's clinical or professional solutions. Care planning works best if you keep an open mind, listen to all informed opinions and remember that you are the person at the heart of the process.

8. How does the plan get agreed?

Different places will have their own local ways of authorising that plans are OK and that money can therefore be paid and the plans put into action. The PCT or CCG has the decision making power to agree your plan. People Hub are working to keep these decision making processes as simple as possible and as close to the person as possible. We're asking that PCTs/CCGs avoid the use of panels, and delegate this decision making to the local health team who know you best. We think people should be present at all decision making.

9. What if a plan is not agreed?

If a plan is not agreed then there is an expectation that the PCT/CCG explains clearly why it has not agreed, and what it would like to be different or amended so that the plan can be authorised.

10. What can I do if I don't like what is decided or how things have been done?

Each local NHS organisation should have a clear complaints procedure, which should be readily available to you. *Things are arranged differently in different localities across the country, but here are some national resources that may help you with the issues discussed in this information sheet. We also give some ideas of the sorts of organisations that may exist in your area.*

i) National Organisations

The People Hub, the network for people using personal health budgets:

<http://www.peoplehub.org.uk/forum/>

The official Department of Health site, where you can get information about personal health budgets and find more contacts:

<http://www.personalhealthbudgets.dh.gov.uk/>

The Patients' Association, a national association that campaigns for the right for patients to be involved in all aspects of decision making regarding their health care:

<http://www.patients-association.org.uk/>

Disability Rights UK, an umbrella organisation, led by disabled people, with specialist expertise in assisting people who wish to take control of their lives through 'independent living.' :

<http://www.disabilityrightsuk.org/>

Carers' UK, the 'national voice of carers' (families); and the Carers' Trust, which co-ordinates local carers' centres:

<http://www.carersuk.org/>

<http://www.carers.org/>

ii) Local organisations

General advice services include Citizen's Advice Bureaux. You may also find advice services for particular groups within the community, such as young people or people from a particular ethnic or cultural community.

Most localities will also have a '*carer's centre*' (for family carers) and many will have a centre for independent living (CIL), run by and for disabled people. There should also be 'user led organisations,' and 'self-advocacy groups' which offer condition-specific advice and support. Some of these organisations specialise in providing advice and support for people with personal budgets (in social care), and/or with personal health budgets.

Local NHS organisations should be able to offer specific advice about personal health budgets, though it's important to remember that this is still very new to the NHS. Try your local GP surgery, Primary Care Trust (PCT) or Clinical Commissioning Group (CCG).