



The ways to hold and manage a personal health budget

This is the third information sheet in a set and there are others being developed. The first two are - "Knowing the deal" and "Planning with your 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.

The ways to hold and manage a personal health budget fall into three broad categories:

- A direct payment
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- A third party arrangement
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- A notional budget
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Before you start to develop your care plan, it's a good idea to consider how your budget might be held, as the option you choose may impact on both the amount of money you need and the planning process.

You may start out thinking that one option is the better than another, but as you develop your plan or even when you've had your personal health budget for a while, you may find your ideas change.

Choosing how to manage a personal health budget can affect the amount of flexibility, choice and control that you have and how close you are to the decision-making. The option you choose, should not only help you achieve your chosen health outcomes but should also give you the level of control you want in an on-going way.

Some personal health budgets involve managing very large sums of money particularly if you (or the person you are supporting) is in receipt of fully-funded NHS continuing health care. People have compared managing a large personal health budget to running a small business. Whilst you may feel confident to do this, you may also feel you need additional support.

Here are some important things to consider when you're exploring all the options:

Do you live in a personal health budget pilot area with direct payment powers?

You'll need to check whether you live in an area that has direct payments powers. [Click here to see the most up-to-date list \(link\)](#). If you don't live in an area with direct payment powers, you'll need to consider one of the other options.

How much control do you want? What decisions do you want to make and how much responsibility are you comfortable with taking?

You need to think this through because the answer to these questions is fundamental to getting things right. The important thing is that you are able to have the right level of control to achieve your outcomes and are able to make the decisions that matter most to you. Most people assume that this can only be achieved with a direct payment. However, you may find that there are other ways to achieve this e.g. a really good third party arrangement.

"I don't live in a pilot area and was irritated by the idea of a third party as I was used to social care direct payments. However, I found that a third party takes away a lot of the hassle with recruitment, employment contracts and can also support you in meeting with the local primary care trust. It can really help cut down the work load and also provides me with a good sounding board when it comes to the big decisions."

How do you want to employ your staff?

Employing staff can represent a large element of a personal health budget particularly for people in receipt of NHS continuing health care. This can involve:

- Employing a large staff team
- Advertising and recruitment
- Employment law
- Pay roll management
- Team building
- Job specifications, job descriptions and contracts.
- CRB checks
- Training

You may feel comfortable doing this yourself using a direct payment or you may feel you need extra help. You can have help to manage your direct payment or you can use a third party arrangement. The big difference is that if you use a third party arrangement, they can legally employ the staff on your behalf. This can be helpful when dealing with employment issues, disputes and redundancies.

"I wish I had thought more clearly about team roles when I first started... things would be so much easier if we had a team leader from the beginning. I don't want to upset the PA's now by choosing one over the other.. a bit of advice wouldn't have gone amiss."

What about clinical governance?

You'll often hear health care professionals talk about "clinical governance". Put simply, this means helping a person stay safe and well. This is an important aspect of managing a personal health budgets and one where there are some clear differences between health and social care. It can involve:

- Training
- Delegated nursing tasks and ensuring people are competent to do them
- Risk enablement
- Common-sense policies and procedures.
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How you choose to receive the money (as a direct payment, using a third party or as a notional budget) is closely linked to how you want to manage other aspects of the personal health budget. You (or someone close to you) may want to take responsibility for managing some or all of the aspects above or you may want to delegate these tasks e.g. to a broker, a third party organization or by appointing an experienced team leader to help you.

What about training?

Training is really important so that the staff you employ are competent to carry out what can sometimes be very complex nursing tasks. They need to have the right skills but they also need to feel confident both personally and professionally. It is equally important for the health professionals involved with you, to feel confident your staff are providing a high quality and skilled service. Some people are happy to take the lead on training whilst others appreciate some more experienced input.

"I have found that developing a training programme for my personal assistants has really helped them work in a professional way. Somehow they now seem more responsible and actually more empowered. I have found that some of the training can be done by e-learning but other aspects have to be more interactive. It's a combination of professional courses and hands-on experience which can involve quite a lot of extra work to get things up and running"

Do you need an arrangement that is organized locally?

Some people have found it really useful to connect with a local organisation that has strong community links and knows the area really well. Others have found that using a national organization gives them more autonomy.

" Having someone independent alongside you in meetings with your PCT can be a great help. They're not part of the local politics. It can also help if they have a good knowledge of the national agenda".

Do you need support and advocacy?

Experience has shown that having the right support in the early stages can make a long-term difference to the success of your personal health budget. What support is available will depend on where you live. It may come from an advocacy service, a voluntary organization, a third party agency or a direct payments service. Whichever option you choose, it's crucial that the people providing support and advocacy really understand the purpose of a personal health budget and the context in which they are being developed. Whilst there are many similarities between social care personal budgets and personal health budgets, there are also significant differences. The differences really come to light when dealing with complex health issues.

We know from personal experience that living with a long-term health condition and complex health needs bring lots of uncertainty. Life can be very unpredictable with lots of peaks and troughs so it's worth thinking about what support you might need when the going gets tough.

Do you need help with budgeting and accounts?

Personal health budgets involve administration and financial management, which can feel daunting at the beginning. It can involve setting up a bank account, pay roll, insurance and financial returns. It's helpful to find out what is available.

So what are your options?

The ways to have a personal health budget fall into three main categories. Within each, there are further sub-categories. This section may raise further questions for you, in which case you may find it useful to post them on the forum. Members of the forum have a wealth of information to share from their own direct experience and local knowledge.

Health care direct payments

You may have moved to an NHS funded personal health budget from a social care personal budget in which case you will probably be familiar with direct payments. If you've already had a social care direct payment, you will need to check whether your Primary Care Trust or Clinical Commissioning Group has the necessary powers to give you a health care direct payment.

If you have a health care direct payment, the money is transferred to you and you buy the goods and services you have chosen. If you are supporting someone who doesn't have capacity to consent, the money can be paid to you as a representative. As the budget holder (or representative), you will be directly responsible and accountable for how the money is spent. If you employ staff, you will be their legal employer.

However, there are several ways you can be supported:

1. By family and friends who have resources and skills they can offer you.
2. By a paid broker.
3. By a direct payment service.

A good local support service for direct payments can make all the difference in making direct payments successful for people.

Direct payment support services can be provided by the local council, user led organisations, voluntary or independent organisations. A support service can provide people with help and support in managing many different tasks.

Third Party Arrangements

This is when an organization that is independent of both the NHS and the budget holder or their representative holds the money on the person's behalf.

Some personal health budget holders have chosen to use a third party arrangement because they live outside a pilot area. However, they soon find that using a good third party organisation, can give them a helpful level of security and support as well as the degree of autonomy and control they need.

There are a variety of ways in which third party arrangements can be established.

These include:

A third party arrangement for a personal health budget through an independent organization

A third party arrangement where the personal health budget is managed by a support provider

An individual service fund – An individual service fund is when the NHS directly places all or part of someone's personal health budget with a provider chosen by the person, solely for their benefit.

Flexibly managing non-recurring payments through a third party arrangement

A third party arrangement for a personal health budget through an independent user trust

A third party arrangement for a personal health budget through a personal care company

Arrangements can be made with voluntary and private organisations, such as domiciliary care agencies, charities and other newer forms of non-profit making enterprise such as community interest companies. The local NHS will have its own rules as to which organisations it is able to pay money to.

What makes a good third party arrangement?

At a recent national peer network meeting, budget holders considered what makes a good third party arrangement. These are some of their thoughts:

The budget should be held in a dedicated bank account in the person's name.

Budget holders or their representatives should be free to identify, recruit, and train the personal assistants they want, with assistance if needed. They must also be free to identify key roles and allocate responsibilities e.g. to a team leader.

The budget holder or their representative should be able to set rates of pay and have a direct input into the employment contract.

The third party and the budget holder (or their representative) should have clearly defined roles and should be comfortable in their role.

It is important that the third party should be fully aware of the individual health context, have an in-depth understanding of personal health budgets and their national context.

A third party should provide a good fit with the family, facilitating effective communication and empathetic support.

It is advisable to have a clearly defined contract that is agreed in advance of starting a third party arrangement. This should cover all areas of responsibility so that everyone is clear about roles and responsibilities or 'who does what'. The contract should also identify areas that may incur additional costs e.g. training, criminal record bureau checks, accounting systems.

Management charges for third party arrangements

Some organizations charge a management fee for their service. Whether or not this applies and how much the fee will be, can depend on what is happening in your local area. Your PCT or CCG may have a contract with an organization to provide support to people with a personal health budget. This service may incur a small charge or no cost at all.

However, you may be commissioning the service yourself (or for the person you are supporting). Some organisations charge an hourly rate whilst others charge a percentage of your personal health budget. This is typically between 4 – 7 %. It is important that this arrangement represents good value for money and supports quality decision-making and outcomes.

Notional Budgets

This represents a more traditional arrangement. The services and care will continue to be provided by the NHS but the notional budget allows the budget holder to know how much money is available and to influence the planning process.

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).