

## Information Sheet 3: Managing 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 third guide is about the options for **managing** a personal health budget. For someone who is eligible for a personal health budget, the decision about “management options” is an important one. Everyone is different and everyone’s circumstances are different. Our skills, opinions and the way we organise our lives can differ enormously which is why there are different management options. This enables people to choose which aspects of their care and support they wish to manage and how.

The support available from the local NHS and the local community is also different depending on where you live. So the decision about the best support arrangement must be a personal one.

This is an updated and expanded version of the earlier peoplehub information sheet, *the ways to hold and manage a personal health budget*.

### **1. What are the different options that are available to you to manage a personal health budget for yourself or for a family member?**

There are three:

- (i) *A health care direct payment*

NHS (England) says that a direct payment is

“an amount of money...which is paid directly to individuals (or their representative) to allow them to purchase the health care they need.... With a direct payment, money identified for the personal health budget is transferred to the person, who then purchases the services and support they want in line with the agreed care plan.... Direct payments for health care must be paid into a separate bank account used solely for that purpose.”

Direct payments have been available for people eligible for *adult social care* funding for more than ten years now, but health care direct payments are new. They are legally defined payments (defined by Act of Parliament and official regulations), which describe them as “*payments in lieu of services.*” What this means is that it is illegal to use a direct payment for any purpose that has not been agreed and is not “in lieu of services.”

(ii) *A third party arrangement*

A third party arrangement is where an amount of money is paid to an organisation that holds it on the person’s behalf. That organisation is legally independent of both the person and of the NHS. The organisation is referred to as a third party because the budget is held neither by the NHS commissioner nor the family. A third party organisation could be an independent user trust (a limited company providing a service to budget holders), or an existing voluntary organisation, a user-led organisation or community interest company. There is more about these options in section 3 below.

(iii) *A notional budget*

Under this option, the money continues to be held by the NHS. The NHS provides the personal health budget holder with a full and clear understanding of the amount of money allocated to them. Also they fully consult with and involve the person. In fact the person should have the same degree of input to the care and support planning process and to decisions about how the money in the personal health budget is used as for either of the other two options. The big difference is that it is the NHS itself which then arranges and pays for the agreed support and services, including any employment of staff where this is part of the plan. It does this by using its usual contracting processes with providers.

*It is your decision about which of the three you opt for; or whether you choose a mix of two or more,*

*The next part of the guide tells you a little more about each of these management options.*

## **2. What is a health care direct payment and how do you decide if it is for you?**

If you have a health care direct payment, the money is transferred to you and you can then use it to buy the goods and services you have chosen to meet your health outcomes. If you are supporting a family member who doesn’t have capacity to consent to hold the money him or herself or who is unable to actually manage the money him or herself, then it 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.

It does not follow from this that if you opt for a direct payment you are on your own, without support to manage the money. Depending on your personal circumstances and what is available locally you may be able to access support from family or friends who have skills and time to help; or

from a paid broker (increasingly brokers are appearing across the country, some working primarily with social care personal budget holders); or from a Direct Payments support service. (Direct Payments Support Services come in a variety of shapes and sizes, from groups of people with experience of using Direct Payments banding together to form a “user-led organisation” through to local branches or offices of national or regional organisations or companies. Once again, these services have mainly worked with social care personal budget holders to date, but some are now extending their work to support personal health budget holders).

In part, this decision will probably depend on precisely what it is you envisage your personal health being used for and how you would like your support delivered. In thinking about this, some of the questions you may need to ask yourself and discuss with others are as follows:

- Am I expecting to spend my budget on one or two large transactions (say on pieces of equipment) or as smaller transactions over a period of time?
- If the latter, do I know how to easily record the transactions in a way that others can understand and if necessary scrutinize?
- Do I need (someone) to employ staff to support or care for me?
- If so, can I easily access the expertise I need to do this? If I am employing them myself, how will I find out about payroll, insurance, tax, recruitment practice, health and safety and a variety of other things.
- Have I got someone I can trust to turn to if managing a direct payment gets too much for me? (You can of course always go back to the NHS and switch to a different option, but you may not want to do this, so it’s useful to have a back-up.
- Ultimately, is this option likely to add to my feeling that I am *in charge* of my life and my health – or is it more likely to seem like an added burden?

You need to decide whether a direct payment is for you. Undoubtedly, a direct payment brings with it greater responsibilities, including certain legal responsibilities, than the other options. But some people prefer them, saying that they also bring a greater *sense of choice and control*, because the control is direct. For some people the fact that their entire personal health budget is directly available to them, rather than seeing a fee going to a third party, is an important consideration. There are many people across the country who have experience of using social care direct payments, and if you are one of those people then this may give you confidence to go forward with a health care direct payment.

It may also be that you consider a *mixed management option*, where you take a direct payment for some aspects of care but not others.

### **3. Third party arrangements; are these for you?**

This is when an organization holds and manages a personal health budget on your behalf. The organisation is independent of the NHS; they are also independent of you, the person eligible for the personal health budget. For this reason, it is known as a “third party arrangement.”

There are a number of variations on this approach:

- (i) An arrangement where you enter into a formal contractual arrangement with an independent organization to manage part or your entire personal health budget. The

contract requires that the organisation delivers all, or some, of the health outcomes, which have been agreed. Today, we find that there are organisations operating in this field that have been established specifically for the purpose of assisting people with personal health budgets or social care personal budgets in exactly this way. Some of them will be local organisations, some regional, and some national. Sometimes the organisation may have a wider remit, such as campaigning on behalf of people with health conditions or disabilities. These organisations are often “user-led” and therefore draw on the direct experience of the people most directly affected. It is important if you are considering this option to find out about the organisation. If possible, talk to other people they have supported in this way, and think about which elements of your care and support plan you wish them to help with.

- (ii) A third party arrangement where the personal health budget is managed by a provider organisation. The organisation takes on the same role as that described above. A “provider organisation” is usually a specialist agency of some kind, which employs nursing or care staff and has expertise in particular conditions or in general nursing or care. If they provide nursing or personal care they will have to be registered with the Care Quality Commission and you will be able to find out more about them at <http://www.cqc.org.uk/> Some provider organisations are “voluntary” or “not for profit”; others are private companies.
- (iii) An individual service fund. This is an approach that has been introduced in some parts of the country for people who use personal budgets for *social care*. Here we are thinking about the same approach for personal *health* budgets. Under this approach, the NHS places all or part of your personal health budget with a named provider who then provides you with the care and support agreed in your plan. Critically, they also agree with the provider precisely how the organisation will make use of the money they are paid to deliver your health outcomes. Your money is “protected” within the provider’s wider budget, and success is judged on the basis of how things turn out for you, not for anyone else.
- (iv) An arrangement with a provider organisation as part of an existing contract with the NHS. A local arrangement might be in place with a number of organisations. Once again, these may be from the voluntary/charitable sector or from the private sector. This option may be of particular relevance where you want something very specific as part of your plan, such as help in the home to help you get up in the morning or go to bed at night or to do other clearly defined tasks. The local NHS will have its own local contractual arrangements with certain organisations and is able to pay in this way. As in the last option, success is judged on the basis of how things turn out for you; but the difference is that the money is not protected within the provider’s wider budget in the same way.
- (v) An independent user trust (or “independent living trust”). A trust of this sort is a group of people, usually friends and family who come together to form a legal entity, which has the sole aim of managing your money for the stated purposes (your agreed health outcomes) on your behalf. Trusts are particularly helpful if you or your family member have difficulties making decisions and/or have been judged to lack capacity in this regard.

It is important to note that some organisations charge a management fee for their service. This is not the case for all organisations or in all localities: practice varies. Nor is the local NHS approach to fees the same everywhere. In some places, the commissioners to the relevant organisations may pay the fee centrally, which means that it is effectively a flat rate for everyone. Elsewhere people who

use third party organisations are asked to pay an hourly rate or a percentage of their personal health budget. You need to find out what happens in your locality.

As personal health budgets become more readily available and more widely used, we should expect there to be more third party options available wherever you live. Of course, the downside of this may be that it is more difficult to decide which approach is best for you. So here are a few tips:

- Don't rush to a decision. It is important to think this through, in a way that is informed by both your personal circumstances and by what is available in your locality.
- Get advice and talk to other people about their experience and views, BUT make your own decision. When peoplehub spoke with families who had *experienced* third party organisations supporting them, many of them highlighted the importance of *peer support* in gaining the confidence they needed to move things forward.
- Families also spoke about the importance of the process of developing trust with the third party organisation - in circumstances where they had sometime lost trust in "the system." One family member described this as being 'like a courtship' as they got to know the organisation and both sides tested the other out. You can read more about what families thought about third party organisations in the document on the NHS (England) website referenced at the end of this guide.
- Bear in mind that different organisations can offer to do different things for you (accounts, manage staff, arrange rotas etc.), but they may also have *different attitudes or approaches*. The attitude to *risk* is a particularly important issue. It is helpful to find out whether an organisation is generally risk-averse or whether they see risk as a positive aspect of everyday life to be embraced and dealt with? Does their approach suit you, or might you be better served by another organisation whose view of life better matches yours?
- Another thing to try and establish when assessing a third party organisation is to what degree they will co-ordinate services for you. Very often people holding personal health budgets have complex lives, and make use of many different health specialisms. It is relatively rare that a GP has the key role in co-ordinating arrangements for people who are eligible for personal health budgets (partly because their needs are often very specialist and co-ordination can be very time consuming), and very often the default is for the family to take on this role. Is this what you want? Or are you looking for a third party organisation to relieve you of this – or to do so in part? You need to think about this and to ask appropriate questions.
- It need not be a final decision: just because you pick one type of arrangement or a given provider, the NHS should make it clear to you that you have the scope to change your mind if things don't work out. However, with careful research, planning and consultation and a measure of luck you may get it right first time.

#### **What makes a good third party arrangement?**

*At a 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.

#### **4. A notional budget: is this for you?**

With this arrangement the money continues to be held by the NHS, but you are given a clear understanding of the sum allocated and how it is to be used to meet your agreed health outcomes. You should always be fully consulted and involved at all stages of the process, with the same degree of input into the care and support planning process as for the two other options.

With a notional budget, the NHS arranges and pays for your support and services. Where relevant, this includes, taking care of the employment of care and support staff through its usual provider and contracting processes. A health professional should discuss with you *which providers* you prefer and should take your views into account. It may be the case that the list of experienced and qualified providers who can help you in your locality is a short one, (this will depend on a variety of things including the nature of your condition and the outcomes you are looking to achieve and the local approach to procurement and contacting). In any event, this is something worth finding out about and if the choices are very limited you may need to ask yourself if you are happy with this.

Generally speaking, it is probably harder to take novel or imaginative approaches to meeting needs if you are using a notional budget, since you will have a reduced capacity to source and obtain things in your own unique way. It may also be less easy to have a *sense* of control in making and implementing important decisions, whatever the reality.

So for some people a notional budget is simply not *different enough* from what they have been used to, and they tell us that it fails to open things up in the way that they wish. For others, however, a notional budget does deliver a much greater degree of choice and control, but brings

none or very few of the additional burdens that they perceive are associated with the other options.

*The last part of the guide suggests a few other things you may wish to think about when making these decisions.*

### **5. What else do you need to bear in mind when thinking about these options?**

What then are the broad things you may wish to consider when making the important decision about the best “management option” for you? We can list some of these things as follows:

(i) *Your health outcomes and the steps needed to achieve these as set out in your care and support plan.* This is important to consider because *what* it is you are aiming for may influence *how* you decide you can best achieve it. For example, it may make certain day-to-day purchases and life more straightforward if you have money in *your* bank account.

(ii) *The nature and level of care and support you require.* Let’s consider a scenario where you or your family member has a high level of need that requires, for example, 24-hour care every day of the week. You decide that the way to achieve this is by employing a team of personal assistants or health care assistants. In a situation like this, you will almost certainly require on-going involvement from *someone* with significant knowledge of employment law, recruitment practices, payroll processes, and staff management. They may also need an awareness of how to use specialist equipment or perform specialist procedures. In discussion with health professionals, you may think that this is best done either through a third party arrangement or by using a notional budget, rather than a direct payment. On the other hand, if you (or a family member) have experience of employing staff or there is an excellent support service available locally, it may still be OK to use a direct payment.

(iii) *The nature of services/equipment required and the options for purchasing them.* Nowadays, many services and items of equipment can be readily sourced and purchased by ordinary members of the public (and sometimes more cheaply than by your local NHS). This may encourage you to be proactive in finding what you need. However, it’s worth bearing in mind that there may be issues about specialist contracts, about equipment support and maintenance and about health and safety considerations - all of which adds a layer of complexity to any purchases. You may therefore decide that these are best dealt with by someone else and perhaps someone with specialist knowledge.

(iv) *The degree of flexibility in the services and support you are looking for.* It is important to say that it does not (or should not) follow that just because you are managing your support through a direct payment you will automatically have more “flexibility” – but it is probably equally fair to say that it is usually easier to change things quickly or do things spontaneously with a direct payment than with other arrangements. Something else to bear in mind.

(v) *How much direct control of the money and budgetary management you want.* By definition, a direct payment brings more direct control than other arrangements. How important is this to *you*?

(vi) *Which aspects of the care and support plan you want to take full responsibility for.* 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 oversight of your health condition from hospital consultants and their teams. The question is: are there other aspects of your care which best sits with others to oversee and manage, whilst you take full responsibility via a direct payment for the remainder? This is something to think about and discuss. Depending on what you decide, it may lead you to choose a mixed management option.

(vii) *Are there specific elements of your care plan that you want help with?* There are some quite specialist areas that it is important to get right and which may warrant management by specialist professionals. Examples include employment law, staff recruitment and training, payroll, accounting practices and perhaps moving and handling/health and safety issues. Again this needs careful thought and discussion.

## **6. Final considerations**

The decisions you take about the *management* of your personal health budget will be critical in determining whether it is successful for you or not. Depending on your circumstances these decisions can be quite difficult and complicated; or they may be straightforward and obvious. As we have already said, these decisions are not irrevocable, but they are significant and it is well worth putting time and effort into getting them right.

Something that is sometimes said when thinking about personalisation: *we are all the same* (we all want a decent life), *but we are all different* (we have different personal histories, experiences, hopes and dreams - as well as different health issues). So the decisions you make about the management of your personal health budget and the way you reach those decisions has to be personal to you.

### **Further reading**

NHS (England)(2012) Personal Budgets Guide, Third Party Budgets, the families' perspective, available at

[http://www.personalhealthbudgets.england.nhs.uk/library/Resources/Personalhealthbudgets/Toolkit/HowPHBwork/ManagingPHBs/Phb\\_guide\\_Third\\_party\\_organisations\\_-\\_the\\_families\\_perspective.pdf](http://www.personalhealthbudgets.england.nhs.uk/library/Resources/Personalhealthbudgets/Toolkit/HowPHBwork/ManagingPHBs/Phb_guide_Third_party_organisations_-_the_families_perspective.pdf)