

Information Sheet 4: Top tips for personal health budgets

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.*

The fourth guide in this series provides some ideas and tips for getting and managing a personal health budget and for working with the health professionals who are supporting you. The tips are fairly general and are best read alongside the earlier information sheets.

The first four tips are useful as you are beginning to think about a personal health budget for the first time.

1. Get informed: information is power

Before you start on your personal health budget journey, it may be helpful to find out:

- *All about personal health budgets: what can they do, who can get them, would they suit you? Read these guides, access websites especially www.peoplehub.org and the NHS Choices personal health budgets pages. If you have time, it's well worth reading Vidhya Alakeson's book.*
- *How your local NHS works including the name and area covered by your local Clinical Commissioning Group (CCG). In particular, find out anything you can about what your local Clinical Commissioning Group has done about personal health budgets. It's helpful to know how many people in your area have a personal health budget and how have they experienced the process? Find out whether your local Clinical Commissioning Group was a pilot area for personal health budgets and whether there is any ongoing project work.*

- *Anything specific that affects you; either about your medical condition or about how the NHS treats people with your condition. Does it seem likely that you will qualify for a personal health budget and if so what specific information might you need to help you? See if you can find out if people with your health condition are being offered personal health budgets in your area.*

2. Get support: talk to others

- *Is there a local peer network of people with personal health budgets? Get contact details and consider approaching them. Before you do, think through at least a bit about what **you** want to know. With any luck, things will emerge in conversation and as you learn more, you should become clearer about what you'd like to ask. For example, what is it that you are most worried about? It might help to write things down before you meet someone for the first time.*
- *If there is no peer network, who else is around who can help? Sometimes there is a local **Centre for Independent Living (CIL)** or similar user led organisation that has expertise in supporting people with personal health budgets. Sometimes there are personal health budget brokers. You may also want to ask your local continuing health care if they could put you in touch with someone who has a personal health budget who'd be happy to talk to you.*

3. Use the research evidence

- *Become familiar with what the relevant research says about your condition and the best ways of managing it and become confident in quoting this. For more on this see Guide 5 in this series.*
- *Become familiar with the relevant research on personal health budgets. There is an excellent summary called "How to get Good Results; key learning from the evaluation" which you will find on the peoplehub website www.peoplehub.org.uk*
- *In particular, make the connection between your intended health outcome and what it is you are proposing to buy with your personal health budget. You need to be clear about how this particular purchase will help? Also, be prepared to talk about the risks involved if you are not able to make the particular purchase.*

4. Making sense of all the information

- *People sometimes feel confused when they have read the national policy on personal health budgets and then experience the local interpretation. Please bear in mind that it is local decision-making that will determine your experience of a personal health budget.*
- *Personal health budgets are grounded in some key principles and practice that is counter-cultural within the National Health Service. Not everyone in the NHS fully understands what a good personal health budget looks like and some people misunderstand what is possible. The best way to get a solid understanding about personal health budgets is to access information from a range of sources.*

5. Staying as healthy as possible and getting what you want from life. What might your health outcomes be?

- *The critical and most life-changing aspect of personal health budgets is often the process of **care and support planning**. This derives from **person-centred planning** and we describe it in detail in guide 2 of this series. Even before you get to this point in the process, it's useful to familiarise yourself with the approach and start thinking about where you want to get to with the help of a personal health budget.*
- *Think in particular about your **health outcomes**, the things that are essential to help you to stay as healthy as you can, done in a way that you feel comfortable with and which you believe a personal health budget might help with. There is a short list of nine key criteria and a few key questions in guide 2 which will help you begin to think in this way and you can find more examples on-line. If you begin to take this approach early in your journey, this will help you decide if a personal health budget is for you; and it may also help in your discussions with health professionals.*

The next couple of tips are useful to consider at the assessment and early planning stages. You will then need to revisit them once you have been allocated your "indicative allocation" and you are at the care and support planning stage.

6. Consider how you want to manage your personal health budget.

- *There are three options: you can take your budget as a direct payment into your bank account and manage it yourself (with help if necessary); you can take it as a notional budget or a virtual budget, which means that the health service will manage it for you; you can identify a so-called 'third party' to manage it - this can be an individual or an organisation; or some combination of these.*
- *Guide 3 explains more about each of these alternatives and gives some additional advice. Some key things to consider, however are:*
 - ~ *How much **personal** control do you want over your budget?*
 - ~ *What **skills and experience** do you have? Are you good with managing money; are you comfortable with IT; and if you are considering employing people do you have experience of managing staff and dealing with HR issues?*
 - ~ ***Who else** is around who might help? What about friends and family in particular? Do you know of third-parties locally that others have used?*

7. Think about how you might use all the resources available to you, not just your personal health budget. Don't simply focus on the money.

- *It is important not to focus **too much** on the money. For many people the real joy of having a personal health budget comes with the discovery that there are many other resources available to you which in the past you may have ignored or thought irrelevant. The care and support planning process encourages you to think about your own skills and experience; those of others in your life who love or care about you; and about the resources on offer in*

your local community, particularly “mainstream services” like college, leisure or fitness centre, shops, community centre, library and church, temple or mosque.

- *However it is important to think about the money too, especially if you need specialist support to manage your health condition. You will need to work out what exactly this specialist support might be, where you can access it and how much it costs. All of this information should be readily available from the sources mentioned above, but if it isn't, go back to your trusted health professional and ask their advice.*
- *In due course you will need a financial plan as part of your care and support plan. This will show how much you are spending on particular health outcomes and precisely what goods and services you are buying to make this happen. This does not have to be a sophisticated or very detailed plan - but the NHS managers who are paying you will need to satisfy themselves that what you propose gives good value for public money. You need to clarify with them ahead of time how much freedom and flexibility you have in what you spend. It's important to ask, “ what am I free to change without consulting them”, “in what circumstances might they want to ask more questions or request evidence of what you have spent”. A good financial plan is built on trust and transparency, but you need to be clear about the limits of this.*

Finally some general tips that may help you all the way through the process.

8. Connect with other people who use personal health budgets locally. Build your personal network.

- *The best way to make the most of your personal health budget is by seeing what others have done with theirs and how they have overcome problem. You can get ideas, inspiration and support, you can solve problems together and you can begin to see that no matter how tough life is, someone else has often been there too.*
- *There is a growing number of personal budget and personal health budget holders across the country, By taking the initiative and seeking out others and connecting with them you are not only helping yourself, but you are also helping to build a movement that helps everyone.*

9. Keep things under review: what is working and what is not working, what might I do to change the things that aren't working? Are you achieving your health outcomes?

- *It is really important that you and the health professionals who support you keep things under review, especially in the early days and weeks of your personal health budget - but in the longer term too. You cannot possibly anticipate everything that might happen. Things may be simpler than you thought or more difficult; your health condition may change; one of your supporters may move away; a third party arrangement may not work out.*
- *The critical question is: which aspects of my plan are working, which are not, and what can be done about the ones that are not? Remember this arrangement is about you achieving the health outcomes that were initially agreed. Of course, these outcomes can change. If they do, it is important to think about why and to involve the health professionals in formulating the new ones. In many ways a good review process should be a continuing*

conversation about your plan, a conversation between you and the health professionals supporting you.

- *The health professionals will have their own reporting and review arrangements, which may demand additional information. Hopefully their process will be a helpful one. In any event, if you feel you need a review, or if things change in any way, you should not be afraid to ask for a meeting. It is in everybody's interests to keep up to date and to make sure your personal health budget is working for you.*

10. Also make sure the management arrangements are working for you. How might you change them if you have to?

- *As part of the review discussion, make sure you think about your choice in managing the personal health budget (direct payment/notional or third party) and whether your arrangement is working for you. If someone else is managing the budget for you and that is not working well, this does not automatically mean the only remaining option is a direct payment. It may be possible to find a different health professional or a different third party to help.*

11. Do your best to understand how the system works – and turn this understanding to your advantage

- *Local Clinical Commissioning Groups are required to deliver personal health budgets with a fairly limited amount of national guidance, law or statutory regulation. At this stage in the implementation of personal health budgets, it means that you can be surprisingly influential in helping to shape local policy and practice, particularly if you are well informed, familiar with the research and are willing to be flexible and to work collaboratively. Try to make sure you know what the rules are, be clear about what you want and why you want it and stick to your guns.*
- *But don't waste your limited energy on battles that aren't worth fighting. Today's NHS does not meet every "health need" and some things people are expected to live with. As we have already stated, personal health budgets do not bring extra resources with them and although they can make things much better for individuals by bringing increased choice and control, this does not mean they are the panacea for all our health issues.*

12. If you run into problems consider your options. Don't despair.

- *This is really important. All through this set of guides we have been stressing the need to make connections, especially with others who are using a personal health budget. If you run into difficulty this is where others can help with support and advice. Other people will almost certainly have had similar experiences, either in your local area or elsewhere: so connect, ask questions and keep going.*