



## Planning with your personal health budget

This is the second information sheet in a set and there are others being developed. The first information sheet is about 'knowing the deal' and the third one is about the "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.

This information sheet is about developing a support plan. 'Support plan' is the term we like to use because it emphasises that you are the person making the plan (with 'assistance' if necessary). The NHS prefers the term 'care plan.' In the context of personal health budgets, they mean the same thing.

### Ensuring you are at the centre

A good plan will have you at its centre. Your plan is a tool to help you think creatively about how you want to shape your life by making the best use of your budget and any other resources you may have to help.

The support plan is the '*heart of personal health budgets*'. This way of seeing the world, or 'person-centred thinking' as it is sometimes called, needs to inform the whole process from the moment you first consider a personal health budget to the point when you are reviewing how it has been working for you – and beyond.

***Developing your support plan is an important step towards getting a personal health budget and shaping your life in a way that makes sense to you. It is the point in the process where you sit down and think through what you really want and need in your life and for your health. You can then discuss what this means in very practical terms with other important people in your life and with the health professionals who are advising you. This will help you come to some decisions about how you can use a personal health budget to maintain or improve your health and get a better life.***

## **Have you got the assistance you need to make a plan?**

It is important that you are not on your own when making your plan. The availability of experienced people to help in this way varies from place to place across the country. Because personal budgets started in social care, it is very likely that you will find people and organisations around who are skilled in developing social care support plans, but perhaps not so for health care. The principles of 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.

## **What does your plan look like and what does it contain?**

**What the plan looks like should be entirely up to you but it needs to include some key elements:**

1. It needs to say who you are as a person with your strengths and skills and your personal social context, as well as your health needs. If you are supporting someone who lacks capacity to make their own decisions the plan must show how this decision was reached and identify who will speak on their behalf.
2. Describe what is working and not working from your perspective.
3. Detail what is important to you and what is important for your health
4. Identify and address any risks and how they will be mitigated to an acceptable level; it is important to think about a contingency plan for if things go wrong and a point of contact in health services.
5. Describe the health outcomes you want to achieve and how you hope to achieve them.
6. Describe in broad terms how the money will be held and managed and show how you will use it 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. This will include a named care coordinator.
8. Describe how and when the outcomes, and the money, will be monitored and reviewed. (This will include describing how people will know your plan is going well, and how people would know if things were going wrong.)

You will record these in your own way. Most plans are written documents, often using a simple format that is set out for you (you can get examples from the websites listed below under 'Specific Help with Support Planning'). Some people with social care support plans have used video or computer generated graphics, others have used mainly illustrations. Different types of plan reflect different types of people with different ideas and different needs.

It is reasonable for the NHS to ask for you to work with them to make their own record of the support plan using their own forms and format, and they may need to ask you about some things that you hadn't considered. They need to do this in order to satisfy themselves that the plan is workable and safe and will be a good use of public money.

## **Having an open mind: What's working and not working?**

When you are making a plan you need to *start from where you are*. One way of discovering this is for you to ask the questions, *what is working and what is not working* in various aspects of my life today?

Do this in an open-minded way. Think about your 'health needs' but not *only* about your health needs. Your health needs are part of your life, and a support plan is a picture of you as a whole-person, making decisions and managing your life with help from others. The personal health budget is provided to help you meet your health needs in a way that makes sense both to you and to the NHS.

## **What's important to you and what is important for your health?**

The next stage is to consider what is important *to* you, and also what matters *for your health*. You are the only one who can know what matters to you because you are unique; you have different likes, dislikes and ideas from everyone else. These things need to be part of your plan.

It is also the case that you will probably also have a good idea of what's important *for your health*. Doctors, nurses and other health professionals will add their opinions to help you understand and decide this. For example you may be well aware that you need to keep your blood sugar at a certain level- the doctor or nurse can give specific detail about the correct level for your particular illness, age and context. Health professionals also play a vital part in helping you to explore really difficult issues around loss and adjustment to a different life after accidents or strokes or following a life limiting diagnosis.

## **Helping you Stay Safe and Well**

Personal health budgets help people to get control and make choices in order to live a good life. This always involves taking certain risks. The important thing is to think through how to do this in the most sensible way. This is something that the NHS Commissioners (Primary Care Trust or Clinical Commissioning Group) have a duty to discuss with you: you can expect them to talk with you about how you intend to identify, evaluate and manage risks. When planning for a personal health budget, risk and responsibility should always be openly discussed and shared.

You need to weigh up the risks of any treatments against the possible benefits. It is a good idea to discuss the merits of different treatment options with your doctors and nurses. For other aspects of your plan, you may also want to talk to or seek information from people with similar conditions, voluntary organisations, from the internet, and from friends and family.

Some people will use their budgets to continue to purchase traditional services that they find work well for them, but others will want to do things differently, trying new treatments or ways of having a healthy lifestyle. It will probably not be possible in these circumstances to rely on existing regulations and protocols to help you to stay safe and well and to take sensible risks, so you need to **talk to the commissioners** (Primary Care Trust or Clinical Commissioning Group) about what they suggest.

It may be helpful for you to work with clinicians, commissioners and service providers on how this part of the care plan will be agreed, and recorded. In social care, some local authorities have developed a separate recording sheet specifically to address the issues of risk, where someone is able to record what might go wrong and how they will minimise the likelihood of this happening.

On a sheet like this for personal health budgets there might be a simple checklist of prompts such as:

*Is there anything that the person or their clinician is worried about?*

*Is there anything that has happened in the past that might arise again?*

*Is there a possibility of harm or abuse?*

*Is there adequate support in place if the person wishes to use direct payments to employ their own personal assistant?*

## What is it that you are trying to achieve - the outcomes?

You need to define very clearly and carefully what it is you are trying to achieve. Some outcomes are quite broad ('managing my pain so it is tolerable'); others are very specific ('going down to 2 days/week in my current job and keeping working at that level for at least another year'). The important thing is to make the outcomes concrete so that you can then go on to define what is needed to make them achievable. When thinking about outcomes, it is a really good idea to try and get to see other people's support plans to give you ideas both about what you might aim for in life, and also to help you think through good ways of getting there.

To define an 'outcome' in a way that the NHS is able to support and fund, you need to bring together your ideas (and those of your family and friends) with the expertise and advice of the doctors, nurses and other health professionals who are advising you. You should expect the health professionals to respect your ideas, and if they disagree with you or think you are being unrealistic, to tell you why. Outcomes are *not* services, treatments or therapies, nor are they 'attending a day hospital,' an outpatients department, an osteopath's clinic or anywhere else. Some or all of these things may help you to achieve your outcomes, but they are a *means to an end*, and when setting outcomes we should beware of thinking of these things too early in the process.

## Signing off the plan by the NHS

The NHS will delegate someone to agree ('sign-off') your plan. If all of the above steps have been followed properly, then this shouldn't be a problem. Ideally, the person delegated will be someone who already knows you and has been involved with your care.

***If you have any problems at this stage, talk to the commissioners (the PCT or CGC).***

## Living your life, learning and reviewing

Once your plan is agreed and you have the support and services in place, you are ready to go. You need to try to ensure that you have continuing contact with the health professionals so that they can support you and reassure themselves that things are working for you and to make any changes necessary. You should stay open to the need to make adjustments, especially in the early phases. The NHS should also review your plan regularly: this means talking with you about how things are working and whether there are any changes needed, including changes to the funding available to you. The funding should not be reduced unless your needs change in a way that makes this sensible. It is however, entirely reasonable for the NHS to ask you questions about how you are using the money and to assess whether or not you are working towards achieving the agreed outcomes.

## Resources to Help

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 factsheet. We also give some ideas of the sorts of organisations that may exist in your area and some on-line resources about support planning, which give more background, ideas and provide some formats for plans.

### **National Organisations to help with personal health budgets**

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/>

### **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. Some should know about support planning.

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

### **Specific help with support planning**

Personal health budgets are new and much of the existing information to help write a plan is still aimed largely at social care.

Remember though, that the same principles of person-centredness apply in both social care and health, and many of the tools and techniques described on the websites below are easily adapted. The most important thing is to talk with other people who have made a support plan. In some localities there are individuals or organisations that have set themselves up as 'support planning brokers.' Most will charge, and some may not have had much experience in health care planning so be sure to check.

<http://supportplanning.org/>

<http://www.helensandersonassociates.co.uk/>

<http://www.in-control.org.uk/resources/support-planning.aspx>