

Information Sheet 2: What is care and support planning?

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 second guide is about the critical process of care and support planning. The care and support plan is the heart of the personal health budget process; get this right and your personal health budget has a much greater chance of doing what you want and need it to do.

1. What is a care and support plan and how does it fit with the process of getting a personal health budget?

Your care and support plan starts by setting out who you are and what matters to you. It then defines what it is you want and need from your personal health budget; who is to be involved in helping you get what you want and need; and how this will come together for you. The care and support plan is a pivotal step in the personal health budget process. It follows on from finding out you can have a personal health budget and being told how much money you might be allocated. You should therefore be going into the care and support planning process with two important pieces of information to help you: agreement about your “eligible health needs”; and an “indicative allocation” i.e. a figure which tells you roughly how much the National Health Service is able to allocate to meet those needs. If you are hazy about either of these things you need to ask for clarification.

2. Terminology: why “care and support”?

Unfortunately, the words used in this area are confusing and sometimes people use them interchangeably or in different ways. Broadly speaking, the “old” approach to planning the assistance someone received was termed a “care plan”: “care” sometimes being seen as something that is provided “for” a person, rather than “with” them. Care plans used to focus solely on medication, therapy and health centred tasks. In social care in the last fifteen years or so, the term “care plan” was largely replaced by “support plan” in order to make it clear that thinking had moved on. Now both the NHS and social care services are using the term “care and support plan” which suggests a recognition that both doing “for” and doing “with” are important. The new Care Act in fact distinguishes a “care and support plan” which is for an “eligible adult” from a “support plan” which is the parallel approach for a family carer.

3. Who is responsible for the care and support plan? Who can help prepare it?

It is very important that you are the *owner* of your own care and support plan. This means that you need to feel comfortable with the way it is written, including its format, the language that is used *and* with its content. If you aren’t happy with these things then you may start to have reservations in due course and it won’t work for you as it should. If this is happening – for example you feel pressured into including something you are not comfortable with – then you should say so.

You do need to bear in mind, however, that your local clinical commissioning group, who are responsible for allocating personal health budgets also have important responsibilities and they cannot agree a plan, which doesn’t enable them to fulfil them. Ultimately they need to satisfy themselves that your plan is sensible, cost-effective and that it will help you to stay safe and well. So this means that there will be certain things they are likely to ask you to include in the plan, and they may have legitimate questions or concerns about some of the things you want to include. Almost certainly they will have a form or a template that needs to be completed. This may give you some ideas, but don’t let it constrain you; try to think ‘outside the box’. You may need to discuss and negotiate. Even if the health professionals working with you are happy, the plan is not agreed until it is “signed off” by the clinical commissioning group.

Care and support plans should not be overly complicated or difficult to prepare. They need to centre on a short list of “health outcomes” – the things you need to meet your health and wellbeing needs, brought to fruition in the ways you wish. These outcomes should be realistic and achievable; they should be agreed with the health professionals who are supporting you.

There are now lots of resources and tools available to help people make their plan and there will almost certainly be other people around in your locality that can advise and assist. Your health professional should be able to direct you. For help with care and support planning see <http://www.helensandersonassociates.co.uk/>

Many people involve family and friends in helping them think about and produce their plan, some include a social worker or community nurse. Some people benefit from the help of *personal health budget brokers*, who have particular experience in planning; but you shouldn’t be made to feel you have to use any particular agency or organisation or individual. Often the best assistance is from

people who have also made a plan for themselves or for a family member. In any case, remember that this is *your* plan and you should feel comfortable with it.

4. What should a care and support plan include and how should it be structured?

There are a number of steps:

- i) The first step is to work towards developing your personal *health outcomes*. This task is best tackled by asking some questions based on the nine criteria for a good support plan which are listed by the NHS in the document, *Implementing Effective Care Planning*.
 - i. *Show who the person is, with their strengths and skills, and their personal social context, as well as their health and wellbeing needs. If the person lacks capacity to make their own decisions the plan must show how any decision was reached and identify who will speak on the person's behalf.*
 - ii. *Describe what is working and not working from their perspective.*
 - iii. *Detail what is important to the person and what is important for their health and wellbeing.*
 - iv. *Identify and address any risks and how they will be mitigated to an acceptable level, including a contingency plan for if things go wrong, and a point of contact in health services.*
 - v. *State the health and wellbeing outcomes and how it is proposed that those outcomes will be achieved.*
 - vi. *Describe in broad terms how the money will be held and managed and show how it will be used to achieve the outcomes.*
 - vii. *Have an action plan that details who will do what, and when, to ensure that the plan is carried out.*
 - viii. *Include the name of the person's care coordinator. State how, and when, the outcomes and the money, will be monitored and reviewed. (This will include describing how people will know the plan is going well, and how people would know if things were going wrong.)*

The exact questions to be asked will vary depending on circumstances, but they need to cover all of the above criteria. The sorts of issues you may need to think about include:

- What do I enjoy doing that I want to continue doing, or do more of?
- What do I not like doing?
- What are my strengths and abilities? What can I draw on?
- Who do I know who can help?
- What do I want to achieve in the next part of my life? What is stopping me?
- What health issues do I have? How can I best begin to address these?
- What is working well in my life and what is working less well? What needs to happen to change the things that are working less well?

Think about the best way to describe who you are, what you like and what your needs are. This will enable you to develop a list of the things you might do to maintain the level of your health, in a way which works for you. Your health professional will have a form or a template which will probably

include these or similar questions. You might find the form useful -both at this stage and as you go on- to agree exactly *how* you will achieve these things (see below). Don't let the form limit your thinking though: see this as an opportunity to reflect on the whole of your life – something that can be very therapeutic if done well and much more than “filling in a form.”

- ii) You then need to consider how you might make these outcomes come about in your particular circumstances. Who can help? Who in terms of your family, friends and broader network – but also who in terms of health professionals? If there are costs involved, this is where the personal health budget may come in, and part of the process is to find out how much particular services charge. You may also need to buy items of equipment, and you may need a contract to maintain or update these: you might need specialist advice about where to go for such items, but it is surprising how much is now available on-line, and this approach can enable you to shop around. Set out as clearly as you can the item, the cost and how often the cost will recur.
- iii) Next you decide how you wish to hold and manage your personal health budget (direct payment, notional or virtual, third-party or some combination). This is an important decision which we cover more in guide 3. It is usually only at this point that you get a sense of the size and complexity of the task and the role you see yourself playing. As part of this decision you need to think about who else is around to help: is there a partner, relative or friend who is able to help manage a direct payment; is there a local “third party” organisation which can help; am I concerned that a virtual budget will reduce my sense of being in control?
- iv) There are then a series of issues which you will need to think about at this stage: the two major ones, staying safe and review are discussed below.

Do not rush this process. In particular do not rush to solutions, and especially do not be too quick to start thinking of particular services too early: it may be “obvious” that you will need on-going care or therapy – but make sure these decisions are not constrained and that they have their rationale in who you are and how you see your future. Effective use of a personal health budget is about so much more than “services.”

5. *What format should I use?*

Many people will want to use a standard template or form, but others may prefer a blank page or even a video-camera or digital recorder. You need to have in mind what health professionals are telling you about what they need from the process, but at the end of the day it is your plan for your life - and it should be for the health professionals to draw the information they need from your plan or prompt you if it isn't there.

6. *How will a care support plan help keep me safe?*

Personalised support is all about helping and encouraging people to live a full and engaged life. This might mean spending more time out and about in college, libraries, community centres, shops, church, temple or mosque or any variety of other places. It might mean less time in “special” environments, day hospitals, day centres or care homes. It might mean more support from “non-professionals” whose training is different and who aren't always formally accredited. Training is of the greatest importance, but the evidence suggests that the best training, training which keeps

people safe and well, is training which is geared to the very specific needs and circumstances of the individual, that is “person-centred” in other words.

It remains the duty of clinical professionals and NHS managers to assure themselves that the care arrangements that they agree to, are able to keep people safe: they have a duty of care. Part of the function of the care and support plan and the care and support plan approval process is to ensure that risks are set out, thought through and mitigated. This is something you need to consider and to discuss with the health professionals supporting you as you plan.

7. *How are care and support plans agreed?*

We have already said that care plans need to be “signed-off” (agreed) by the local NHS. As one of the key texts on personal health budgets (Alakeson, 2014) makes clear there are very few national rules for administering personal health budgets and this means that each locality now *should* have its own local personal health budget framework, setting out exactly who is responsible for what, including the question of the criteria against which care and support plans are signed off, and who is responsible. If your health professional is unclear or you are unable to trace your local framework, then you are best advised to contact your clinical commissioning group or local Healthwatch and ask their advice. It is important when writing your plan that you know what the rules of the game are, and therefore how to frame what you prepare in a way which gives it the best chance of being agreed. Someone may come back to you to ask questions or suggest changes; if this happens don’t worry, be open to what they suggest and give it some thought.

8. *How should my care and support plan be reviewed?*

It is of the greatest importance that your care and support plan and all that flows from it stays on track. It would be very difficult to anticipate every contingency and everything that might go wrong (or indeed well!) ahead of time. The best reviews are an “on-going conversation,” with your needs and wishes as the central point of concern.

Each care and support plan should identify a named care coordinator from the NHS. You should feel comfortable to ask them for a review at any time if you feel it is necessary.

9. *Is a care and support plan a “person-centred plan”?*

“Person-centred planning” is a phrase you may often hear when people are talking about personal health budgets and how they are set up and managed. We often talk about the importance of “person-centred-ness” as opposed to the old “service-centred” approaches. Person centred thinking asks questions about your life: what is and is not working, what might it take for you to have a good day, who is the best person to provide you with support, what have you tried and what have you learned?

The way we have been describing care and support plans in this guide does indeed suggest that they should be person-centred: it is your plan and it should be structured around your hopes and wishes and the way you wish to live your life. Person-centred planning has its origins in North America, where it was used initially with people with intellectual impairments. It arrived in the UK in the 1990s and was highly influential in the same sector. It became particularly important and powerful

when the planning process was linked to the offer of “resources with which to plan” in the form of a social care personal budget in the mid-2000s; it is this same impetus which drives care planning in personal health budgets.

Care and support plans and person-centred plans are not identical. Health professionals’ forms and templates sometimes require information that would not normally be part of a person-centred plan. However: a good care and support plan is always person-centred, in that it starts from the person, it asks questions which seek to understand and build upon their individuality and it has the ultimate aim of defining what it takes for this particular person to make the most of what is available to them, including the resources in their personal health budget.

10. What else do I need to know about care and support plans?

When people using a personal health budget today were surveyed about their experience of care and support planning, they highlighted *stories of how other people had used their budget* as the most important feature. It is often instructive and inspiring to read how others have approached similar challenges to the ones you face. This is particularly so in a new area like personal health budgets, where imagination and ideas are at a premium and where people often tend to be blinded to “the possible,” by what has sometimes been an overly paternalistic care system designed for a previous generation.

See the peoplehub website for a range of personal stories of this kind. www.peoplehub.org.uk.

In the same survey, people went on to talk more broadly about the support they needed to manage a personal health budget. They spoke about the importance of support *throughout the process*, not just when they were at the stage of making their plan and setting things up.

Many of the things that you are asked to share in the course of these processes are very intimate and personal: it does seem imperative that services are sensitive and responsive to this fact. So it is important to have it in mind from day one that you are on a journey into territory that in some respects is still uncharted. Not all local NHS professionals you meet will be aware of the principles and purpose of a personal health budget and you may need to be both patient and assertive in getting exactly what you require to succeed.

Further reading

Alakeson, Vidhya (2014), *Delivering Personal Health Budgets, A Guide to Policy and Practice*, Bristol, Policy Press

Department of Health (2012), *Implementing Effective Care Planning*, available at <http://www.peoplehub.org.uk/effectivecareplan.pdf>