



**peoplehub**  
personal health budgets network

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# NHS Continuing Healthcare Assessment:

**What follows if I am eligible and what choices do I have about a personal health budget?**

INFORMATION PACK THREE OF THREE



# Who has written this and why?

This information is written by people who have been through the NHS Continuing Healthcare assessment process, with input from health professionals and other specialists. We were asked to consider what might improve people's experience of the NHS Continuing Healthcare process for everyone aged 18+.

We thought about what would have helped us most, when we were faced with the assessment, and we wanted to share the answers to three main sets of questions.

## **This pack focuses on the third of these sets of questions, including:**

- If I am eligible for NHS Continuing Healthcare funding, then I have a legal right to have that funding as a personal health budget.
- How can I weigh up how much choice and control I wish to take?

**Pack one focus on the first set of questions:** NHS Continuing Healthcare Assessment: What is it? Including questions regarding eligibility.

**Pack two focus on the second set of questions:** What can I expect and how can I prepare?

We know that sometimes we can all feel there isn't time to read lots of documents but it's important that you know that there are several NHS documents which contain in-depth information about NHS Continuing Healthcare and personal health budgets. We've listed some of those at the end and included other useful sources of help and explanation.

The NHS Continuing Healthcare process is first and foremost an assessment of need. A full consideration of how best to meet those needs should follow, regardless of whether you are eligible for NHS Continuing Healthcare funding or not. However, if you are eligible for NHS Continuing Healthcare then you have a legal right to have that funding as a personal health budget. This opens up a range of choices and the potential for you to have far more control and to tailor your plan to address what matters most to you as well as what matters most for your health and wellbeing.

We deliberately say that there is "potential" for more control because we know that your experience will depend on the way in which personal health budgets are implemented locally. This pack gives you information on the guidelines that should help inform what you are offered.



# What is a personal health budget?

*“A personal health budget is an amount of money to support a person’s identified health and wellbeing needs the application of which is planned and agreed between the individual, their representative, or, in the case of children, their families or carers and the local NHS team. It is not new money, but is money that would normally have been spent by the NHS on a person’s care being spent more flexibly to meet their identified needs”.*

This definition is from “Guidance on Direct Payments for Healthcare: Understanding the Regulations” and there is a link to this at the end. It is a useful set of information and advice to know about. It includes for example what the money can be spent on, how the money can be held and managed, what needs to be in a plan and how the care planning process is meant to work.

Direct payments for healthcare are one of the ways of providing all or part of a personal health budget. However, it’s important to know that there are other ways for you to receive and manage your personal health budget.



# How can a personal health budget be managed?

A personal health budget can be managed in three ways, or a combination of them:

- 1) Notional budget.** No money changes hands. The individual is informed how much money is available and talks to their local NHS team about the different ways to spend that money on meeting their needs. The NHS team will then arrange the agreed care and support.
- 2) Budget held by a 'third party'.** An organisation or trust that is independent of the individual and the NHS, holds the money for the individual and supports them to meet their health and well-being outcomes.
- 3) Direct payment for healthcare.** The individual receives the money directly to buy the care and support that they have decided they need, in agreement with their local NHS team. They have to show what the money has been spent on, but the individual, or their representative, buys and manages the services.

Help and support to choose the right option for you should be available in your locality, but bear in mind that these are all new arrangements and the national picture is still patchy. Some areas are not yet very experienced with personal health budgets and you might be given inaccurate information. So it's very useful to know that although the regulations in the Guidance only apply to direct payments for healthcare, it specifically states that "the information in this guidance will be useful for all types of personal health budgets." The Guidance also makes clear that: "most of the steps, such as care planning, budget setting, and the principles around empowering people to make decisions about their own care, will be the same irrespective of the way the personal health budget is provided."

The best time to make an informed decision about how you would like to have the funding is during the process of writing your care and support plan. This is because, as you become more clear about what you want to achieve, and how much needs to be done, you will be better placed to weigh up how much direct control you want to have.





# What are our experiences of traditional care and of personal health budgets?

When we started to create this information, we shared our own experiences and discussed why we had found personal health budgets made a useful difference in our lives.

We also explored what were some of the difficult things about having a personal health budget and we have tried to share both in this pack. **The following tables outline some thoughts about possible benefits and challenges of traditionally provided care and personal health budgets.**

<b>POSSIBLE BENEFITS</b> Traditionally provided support:	<b>POSSIBLE CHALLENGES</b> Traditionally provided support:
<ul style="list-style-type: none"> <li>• Good for transition period</li> <li>• Larger pool of staff</li> <li>• Keep current support</li> <li>• Staff already trained by agency</li> <li>• Speed issue for fast track care</li> <li>• It is known</li> <li>• Not having to think about it or make decisions</li> <li>• Not taking responsibility</li> <li>• Someone else does it for you</li> <li>• Don't have to be an employer</li> <li>• Don't have to do staff rota</li> <li>• Little responsibility (training)</li> <li>• Allows you to moan about services and people without having to take responsibility</li> <li>• Speed in setting it up</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of consistency of care and staffing</li> <li>• Being left on a Friday</li> <li>• Monday to Friday Agency</li> <li>• Non personal service</li> <li>• High turnover of staff</li> <li>• Poor rota and structure of support</li> <li>• Lack of training and poor training</li> <li>• High cost poor quality</li> <li>• Low paid staff</li> <li>• Low staff morale</li> <li>• No flexibility or choice of staff</li> <li>• Families left without support</li> <li>• Not involved in recruitment</li> <li>• Bad match</li> <li>• High turnover</li> <li>• Staff undervalued</li> <li>• Geographical restrictions (staff can't go outside boundary so no holiday)</li> <li>• Providers' profit first, staff second, patient not on list</li> <li>• Staff inappropriate</li> <li>• Inconsistent staff, poor time keeping</li> <li>• Detachment from being involved (family excluded and the individual)</li> <li>• No CHOICE</li> </ul>



<b>POSSIBLE BENEFITS</b> <b>Personal health budgets:</b>	<b>POSSIBLE CHALLENGES</b> <b>Personal health budgets:</b>
<ul style="list-style-type: none"> <li>• We are in control</li> <li>• Bespoke training</li> <li>• Flexible care and adaptability</li> <li>• Stay out late</li> <li>• No “middle man”</li> <li>• Flexible use of money</li> <li>• Well paid staff gives continuity</li> <li>• Bring in your own independent support</li> <li>• In control of staff rota</li> <li>• Building your own team</li> <li>• Can build trust</li> <li>• High standard of care</li> <li>• Person centred</li> <li>• Quality of life</li> <li>• Extends life</li> <li>• Consistency</li> <li>• Reduced hospitalization</li> <li>• Shorter hospital stays – just treated then home</li> <li>• Choice of staff</li> <li>• Better trained staff</li> <li>• Better pay and contracts for staff</li> <li>• Healthy quality of life</li> <li>• Flexible meeting of outcomes</li> <li>• PAs have more security</li> <li>• Happier staff, families and individuals</li> <li>• Better support and quality of life for the money</li> <li>• Keeping staff and cost effective</li> <li>• Rewarding when challenges overcome!</li> </ul>	<ul style="list-style-type: none"> <li>• Set up/ implementation</li> <li>• Lack of support</li> <li>• Staff conflict and conflict management</li> <li>• Being an employer (if you choose to be one)</li> <li>• Lack of third party organisations to be an employer for you</li> <li>• Lack of information on the options</li> <li>• New to health</li> <li>• Lack of clarity of the “deal” and how to be creative</li> <li>• Challenge of taking on the responsibility and making decisions</li> <li>• Overwhelming</li> <li>• Resistance from CCGs</li> <li>• Lack of support when not done well</li> <li>• Delay of reviews</li> <li>• Issues with staff</li> <li>• Understanding what exactly the system is looking for (outcomes!)</li> <li>• Needing help with care plans</li> <li>• HMRC don’t answer their phones – (if you need help to) register as employer</li> <li>• Admin/ payroll/ HR/supervision</li> <li>• Breakages</li> </ul>





# Personal preferences – how do I weigh up what matters most to me?

The positives and negatives which we've illustrated as possible will all be weighed differently depending on what sort of a person you are, what life experiences you've had and what is happening currently.

Everyone can have a personal health budget when we remember that a personal health budget means knowing how much money you can have; being involved in making a plan to the extent that you want to; and choosing how you want the money to be held and managed.

## Some things to consider:

- How much involvement do you want?
- How much control are you interested in having?
- Would you be interested in being an employer or need someone else to do that on your behalf?

- In terms of what's happening at the moment with your support – what is working and what is not working for you?
- What things do you find frustrating or stressful currently?
- What things make no sense to you about current arrangements?
- Is what you currently have in place working for you in terms of recruitment, retention, training and competence, people who match your personality and interests, how care is provided and when care is provided...?

You could feel "I'm exhausted I don't want to have to be involved – I'm too tired". But the experience of those of us who have had a personal health budget is that once we've got it set up, we are far less tired because we can relax knowing we can trust the great plan we have put in place.



Many people with NHS Continuing Healthcare in the national peer network use a third party, which can give the choice and control you want without having to be an employer. People can think that having a personal health budget means having to take it as a direct payment and be an employer.

They think it is all or nothing. When done well, it doesn't mean this. With a personal health budget you can still use an agency to employ staff you choose, on your behalf, if you use a good third party organisation.

This table gives a quick glance summary of what the different options offer:

	NOTIONAL BUDGET	GOOD THIRD PARTY BUDGET	DIRECT PAYMENT BUDGET
Knowing how much money I have to plan with	✓	✓	✓
Creating my plan	✓	✓	✓
Being fully involved in staff job descriptions and person specifications	✗	✓	✓
Being involved in recruitment	✗	✓	✓
Staff timetabling	✗	✓	✓
Being involved in Staff training and competence	✗	✓	✓
Being an employer	✗	✗	✓





## What makes a good third party arrangement?

While many people can readily see what a “notional” budget and a “direct payment” are, there has been some confusion about how people understand the “budget held by a third party”.

This is partly because in social care that term has sometimes been used to describe direct payment support services, which are altogether different. We know that the terms can be perplexing and so Peoplehub’s website has summary information sheets on personal health budgets, including Information Sheet Three “Managing a personal health budget” which explains the ways to hold and manage the money. [They are available to download here.](#)

At a national personal health budget 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 and recruit the personal assistants they want, with assistance if needed, and be fully involved in planning, delivering or commissioning any training required by their Personal Assistants.
- 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, (which in practice may need to be in discussion with the NHS); 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. "When calculating the budget, CCGs should ensure that they recognise the additional 'hidden' costs. For example, if someone is employing an assistant, they must ensure that there is sufficient funding available to cover the additional necessary costs of employment such as tax, National Insurance, training and development, pension contributions, any necessary insurance such as public liability, emergency cover and so on." ("Guidance on direct payments for healthcare – understanding the regulations").

The peoplehub website also gives lots of people's individual stories sharing how personal health budgets have worked for them.

*"Previously the vital question of how the individual would like to live their life was never asked. There was little planning around the individual and often the debate would be around generic symptom management, and too often on the professional assumption that any other way would be too risky or too onerous."*

*"Personal health budgets allow people to move from a world where others know best, to one where their input is valued above all others but not in isolation from others."*

*"It is a way to allow the individual to be at the heart of the planning process, identifying with key health professionals the things that really matter to them and which allow them to lead a safe and fulfilling life"*

- Personal health budgets peer network member, 2012





Useful  
information  
about about  
personal  
health  
budgets  
and NHS  
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[NHS England Personal Health Budgets.](#)

[NHS England personal health budget resources.](#)

[Guidance on Direct Payments for Healthcare: Understanding the Regulations.](#)

[PeopleHub.](#)

[Royal College of General Practitioners personal health budgets guide for GPs.](#)

[Beacon](#) – A national organisation which offers free independent expert advice and information totally focussed on NHS Continuing Healthcare. tel: 0345 548 0300.

[Decision Support Tool for NHS Continuing Healthcare](#) – This is the tool which will be used to do the assessment. It has the “domains” or types of need which will be assessed.

[NHS England Operating Model for NHS Continuing Healthcare](#) – This is all about HOW the process should be done. It has statements at the end about what anyone should expect from the process “I statements”.

[NHS Continuing Healthcare and NHS funded Nursing Care Public Information leaflet.](#)

[The National Framework for NHS Continuing Healthcare and NHS funded Nursing Care](#) – Sets out the full principles and processes.

[NHS Continuing Healthcare Checklist](#) – This is the quick initial checklist used to decide whether you can be referred for a full assessment.

[You can find links to all of the Continuing Healthcare assessment documents and National Framework guidelines here.](#)

[NHS Greenwich CCG](#) – NHS Greenwich CCG has created an animated graphics film to help explain the framework better. The film is about 30 minutes long, and there are 2 versions. The “continuous play” version is the whole film. The “playlist version” is the same film divided into sections, and you can move between the sections by using the menu control. The film uses pictures, audio and text, and there is no spoken information that is not also shown in text.

[The Care Act 2014](#) (came into effect in April 2015).

[The Care Act 2014 easy to read version.](#)

[Carers UK have summarised the Care Act information available.](#)

