

PERSONAL HEALTH BUDGETS GUIDE

Budget setting for NHS Continuing Healthcare



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Personal health budgets

A personal health budget is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person and their local NHS team. Our vision for personal health budgets is to enable people with long term conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive.

What are the essential parts of a personal health budget?

The person with the personal health budget (or their representative) will:

- Be able to choose the health and wellbeing outcomes they want to achieve, in agreement with a health care professional
- Know how much money they have for their health care and support
- Be enabled to create their own care plan, with support if they want it
- Be able to choose how their budget is held and managed, including the right to ask for a direct payment
- Be able to spend the money in ways and at times that make sense to them, as agreed in their plan

How can a personal health budget be managed?

Personal health budgets can be managed in three ways, or a combination of them:

- Notional budget: the money is held by the NHS
- Third party budget: the money is paid to an organisation that holds the money on the person's behalf
- Direct payment for health care: the money is paid to the person or their representative

The NHS already has the necessary powers to offer personal health budgets, although only approved pilot sites can currently make direct payments for health care.

What are the stages of the personal health budgets process?

- Making contact and getting clear information
- Understanding the person's health and wellbeing needs
- Working out the amount of money available
- Making a care plan
- Organising care and support
- Monitoring and review

1 Introduction

This guide explains how to decide the amount of a personal health budget. It explains how budget setting fits within the principles of personal health budgets for people in receipt of NHS Continuing Healthcare. It should be read together with the Department of Health's national framework and practice guidance for NHS Continuing Healthcare.¹

It is very important to take account of carers' rights when implementing personal health budgets. This guide explains how a personal health budget can be offered in a way that takes account of the whole family's situation, based on legislation and guidance on carers.

The guide includes some examples of how pilot sites have carried out budget setting in practice. Other NHS organisations may find these examples useful, but there is no requirement to use any tool.

Other good practice guidance on personal health budgets is available in the personal health budgets toolkit:
www.personalhealthbudgets.dh.gov.uk/Toolkit

2 Context

What is NHS Continuing Healthcare?

The Department of Health has published a revised national framework setting out a single national system for determining eligibility for NHS Continuing Healthcare, and including detailed practice guidance.¹ The national framework states that:

NHS continuing healthcare means a package of ongoing care that is arranged and funded solely by the NHS where the individual has been found to have a primary health need as set out in this guidance. Such care is provided to an individual aged 18 or over, to meet needs that have arisen as a result of disability, accident or illness. (para 13)

In future, parents of children receiving care through the national framework for children and young people's continuing care² will also have the right to ask for a personal health budget. This fits with the government commitment that, subject to piloting, children with special educational needs and disability will be able to have a personal budget by 2014.³

What is the NHS already required to do?

While personal health budgets are a new development, the approach builds on and is supported by the core values and principles already set out in the national framework:

The actual services provided as part of the package should be seen in the wider context of best practice and service development for each client group. Eligibility for NHS continuing healthcare places no limits on the settings in which the package of support can be offered or on the type of service delivery. (para 13)

The process of assessment and decision-making should be person-centred. This means placing the individual, their perception of their support needs, and their preferred models of support at the heart of the assessment and care-planning process. (para 42)

The national framework requires the NHS to follow the principles of personalisation:

CCGs (clinical commissioning groups) should commission services using models that maximise personalisation and individual control and that reflect the individual's

preferences, as far as possible. It is particularly important that this approach should be taken when an individual who was previously in receipt of an LA (local authority) direct payment begins to receive NHS continuing healthcare; otherwise they may experience a loss of the control they had previously exercised over their care. (para 169)

CCGs and LAs should operate person-centred commissioning and procurement arrangements, so that unnecessary changes of provider or of care package do not take place purely because the responsible commissioner has changed from a CCG to an LA (or vice versa). (para 170)

For people who are eligible for NHS Continuing Healthcare, NHS money can be used to meet a very wide range of outcomes – including health, social care and accommodation needs:

Where an individual has a primary health need and is therefore eligible for NHS Continuing Healthcare, the NHS is responsible for providing all of that individual's assessed needs – including accommodation, if that is part of the overall need. (para 33)

The national framework also explains how the NHS is expected to take account of personal choice and how this should be balanced against costs:

In many circumstances there will be a range of options for packages of support and their settings that will be appropriate for the individual's needs. The starting point for agreeing the package and the setting where NHS continuing healthcare services are to be provided should be the individual's preferences. (para 83.2)

Cost has to be balanced against other factors in the individual case, such as an individual's desire to continue to live in a family environment. (para 83.3)

Many people prefer to continue living at home – and this should be explored even where a person's needs are complex, where there are perceived risks that may need to be managed, or where end-of-life care is needed. It is important to understand carers' views and the situation of the family as a whole.

Where there is concern that a person may lack mental capacity, it is important to follow the guidance in the national framework (paras 48–53). A person is presumed to have capacity unless it is established that they lack capacity to make the particular decision in question at the time when it needs to be made. Where there is concern that a person may lack capacity in respect of the particular decision, consideration needs to be given first to whether there is any form of help (for example with communication) that would enable them to make the decision.

Carers and NHS Continuing Healthcare

Carers provide a substantial amount of support to many people who are eligible for NHS Continuing Healthcare. The national framework states that:

CCGs and LAs should bear in mind that a carer who provides (or intends to provide) substantial care on a regular basis has a right to have their needs as a carer assessed (Carers and Disabled Children Act 2000, as amended by the Carers (Equal Opportunities) Act 2004). Should the CCG identify a carer in the course of its assessment process, it should inform them of their right to a carer's assessment and advise them to contact their LA or, with their permission, refer them for this purpose. (para 54)

The willingness of family members to supplement support should also be taken into account, although no pressure should be put on them to offer such support. CCGs should not make assumptions about any individual, group or community being available to care for family members. (para 83.3)

The government strategy for carers emphasises the need to consider the whole family:

Personalisation can provide individuals, carers and families with more choice, more control and more flexibility in the way that care and

support are provided. Personalisation and a whole-family approach are complementary – it is important to look at a family's needs as a whole but also to make sure that individual carers' and users' views are sought and cultural expectations are clarified when considering how best to support a family. No assumptions should be made about a carer's ability and willingness to care.⁴

When people are assessed for NHS Continuing Healthcare, it is important that the situation and needs of carers are fully assessed. Carers need to be able to continue working, stay well, be able to meet other family responsibilities, and have a break from caring. Outcomes for carers can be included in the care and support plan, and the level of the personal health budget should take these needs into account.

What outcomes can a personal health budget help to achieve?

Important aspects of good care planning are set out in the national framework for NHS Continuing Healthcare:

The care planning process ... focuses on goal setting and outcomes that people want to achieve, including carers (and) results in an overarching, single care plan that is owned by the person but can be accessed by those

providing direct care/services or other relevant people as agreed by the individual, e.g. their carer(s). The important aspect of this is that the care planning discussion has taken place with an emphasis on goal setting, equal partnership, negotiation and shared decision making. (para 78.2)

Good plans are not narrowly focused only on health needs, but cover a wide range of outcomes. A plan might include goals that concern:

- health
- social care

- financial security
- accommodation
- education
- employment
- family life and parenting.

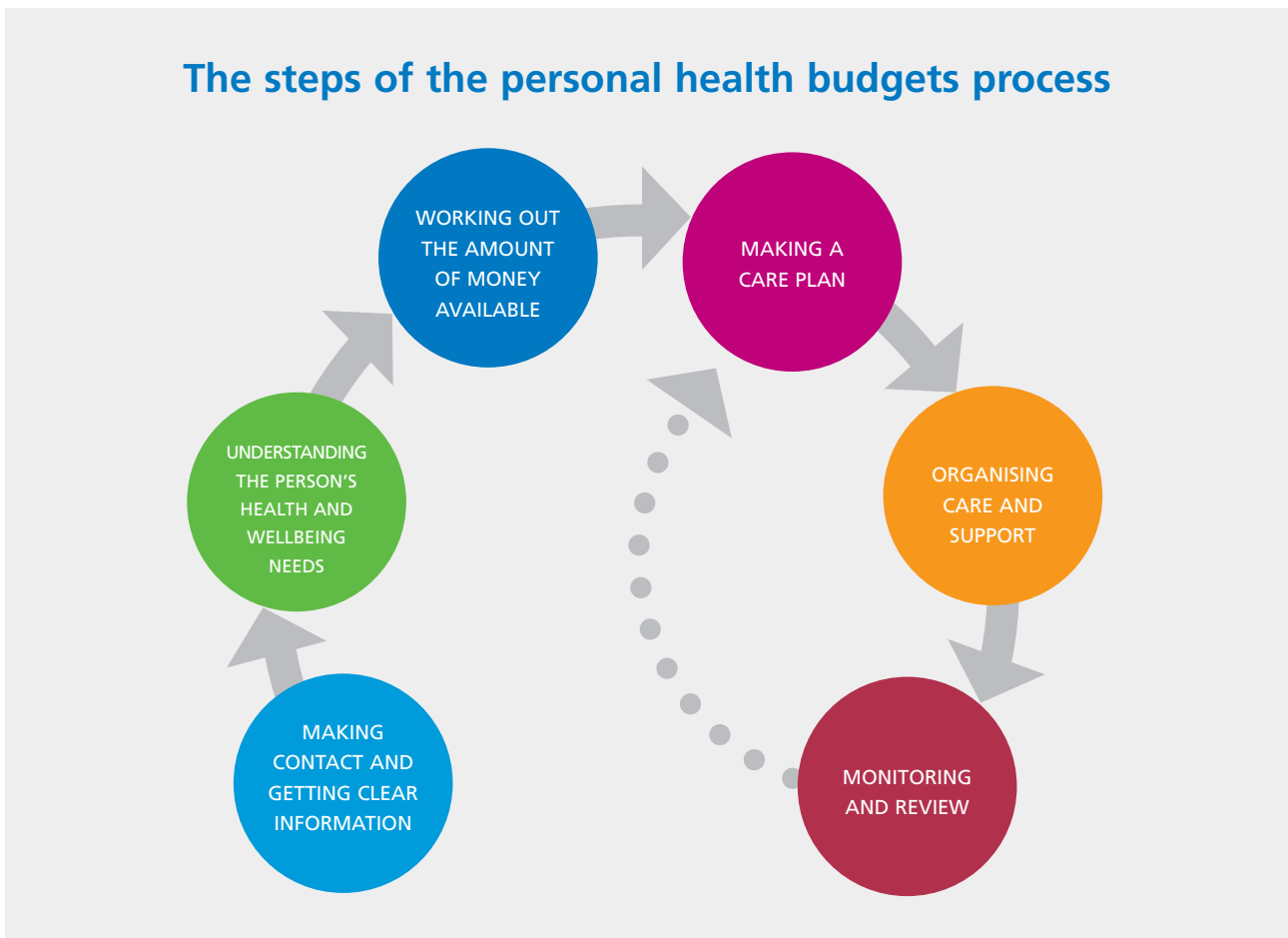
This also means the budget should include enough money to cover everything needed to deliver the outcomes – and this might include staff training and management costs. There may be some outcomes that can be met legitimately from other funding streams, but these should still be included in the care plan.

3 Budget setting

What is budget setting?

Budget setting is one part of the new system that needs to be in place to operate personal health budgets. The diagram

below shows the steps in the process. For people eligible for NHS Continuing Healthcare, budget setting takes place after a decision about eligibility has been reached.



Indicative budget

An indicative personal health budget is an amount of money identified at an early stage in the process to inform care and support planning. It is a prediction – a best guess – of the cost of care and support sufficient to meet the person’s assessed health needs and achieve the outcomes in the care and support plan.

The indicative budget is a guide – it should not be used as a limit, a fixed allocation or an entitlement. Under current guidance, the NHS must meet the assessed needs if a person qualifies for NHS Continuing Healthcare.

The indicative budget does not need to be exact, and in practice it is difficult to design a tool to predict the costs of support for a person accurately. This is because support costs are not simply related to personal needs – costs will differ depending on the setting, the nature of the support arrangement and the amount of support available from carers. As a guide, a tool for calculating indicative budgets is good enough for the purpose if it achieves predictions that are within 20 percent of the final cost for 80 percent of people.

Final budget

The final personal health budget is an amount of money calculated following care and support planning by estimating the costs of the care and support arrangements included in the plan. This is likely to be a more accurate guide to the actual costs of support. The final budget – rather than the indicative budget – is the point at which an approval process is needed.

It should be understood that indicative budgets are only an estimate. For most people the final budget will be higher or lower than the indicative budget, and for some who have special circumstances there may be large variance from the indicative budget.

Why calculate an indicative budget?

One of the essential components of a personal health budget is that the person and their family must know how much money they have in their budget at the start, so they can use that information to plan. The evaluation of the personal health budgets pilot programme found that:

... there was an impact on quality of life when personal health budgets were being implemented following the basic principles underlying the initiative: that is, budget holders know the resource amount before support planning; there is some degree of flexibility in what services can be purchased; and there is choice in deployment options as to how the budget holder would like the resource to be managed.

Potential budget holders should be given better information about the indicative level of the budget, especially before starting care/support planning.⁵

In addition, indicative budgets are a useful aid to decision making. For example, a policy could be set to delegate decision making to a manager or practitioner when the final budget is within an acceptable range (eg 20 percent) of the indicative budget. This could avoid all decisions having to be made by a panel.

4 What issues need to be taken into account?

A focus on outcomes

Personal health budgets offer a chance to move towards an outcome-focused way of working. This enables people taking up personal health budgets to have flexibility in how to achieve an agreed set of health and wellbeing goals. This has several implications.

- The outcomes agreed in the care and support plan can be broader than the specific health needs identified in an assessment, and may be worded differently.
- The purpose of the budget is to enable the person to achieve a set of outcomes – it is not a budget provided to buy a specified number of hours of support as there may be better – and perhaps cheaper – ways to achieve these outcomes.
- Even if the budget is based on the cost of conventional services, this should not constrain how the budget is used. For example, a budget setting tool should not be used to specify the number of hours of support in the care plan, or hourly rates of pay.
- The budget may be used to buy goods and services not previously provided by the NHS.

Deciding what costs to include

Some people may have additional needs for mainstream NHS or council services that are not included in their personal health budget. The national framework makes clear that these entitlements continue:

Those in receipt of NHS continuing healthcare continue to be entitled to access the full range of primary, community, secondary and other health services. (para 173)

For example, a person may continue to be provided with equipment from a joint equipment store, or a disabled facilities grant to pay for adaptations, in addition to their personal health budget. As well as the personal health budget, carers may have an entitlement to carers' services from the local council, which can include carers' direct payments.

Taking into account the needs of carers

People who receive no support from family carers or other informal carers may need a higher level of formal paid support. For this reason, it may be necessary to make an adjustment to the indicative budget to take into account the amount of support provided by carers.

When making an adjustment, it is important to consider several factors.

- The adjustment will need to take into account the situation for the whole family, the impact on carers, and any information from a carer's assessment.
- The impact of caring on family life, and carers' rights to a normal life, should be considered carefully. It should never be assumed that carers are able or willing to continue.
- If an adjustment is made, the indicative budget may also need to include extra money to enable the carer to meet their own needs, identified in an assessment – this can be used, for example, to arrange short breaks, but once again it is important to allow flexibility in the way money is used.

Skills and knowledge

Budget setting is part of the personal health budget process and is not a back-office task.

It is important for NHS staff, including finance and contract managers as well as frontline professionals, to develop an understanding of the change in approach required by personalisation.

This might include training on the principles of personalisation, personal health budgets, and care and support planning.

It is good practice for people who have experience as a personal budget holder, including family members, to take part in, or even lead, training.

Staff directly involved in budget setting work and decisions also need a good understanding of the person's and family's situation. This will avoid decisions on a person's budget being taken based on incomplete information.

5 Practice examples

The following examples demonstrate how pilot sites have carried out budget setting in practice. Other NHS organisations may find these examples useful, but there is no requirement to use any particular tool. Other approaches may be more suitable, for example for people who are receiving support and services from both the NHS and social services.

NHS Manchester budget setting tool

NHS Manchester has developed a budget setting tool based on the decision support tool for NHS Continuing Healthcare. As part of the personal health budgets pilot programme, the tool has been tested with around 60 people in six pilot sites.

The tool works by estimating the costs of providing a conventional home care package that could be expected to meet the needs identified using the decision support tool.

The tool uses as inputs the levels from the decision support tool, and the hourly rates for home care being paid locally. This is used to estimate the cost of providing support using a conventional home care package. An adjustment is also made for support provided by carers, and the tool also allows an amount to be added to reflect carers' needs.

The tool has been tested in Oxfordshire, Somerset, Hull and Nottingham. This work has shown that the costs of care and support vary substantially between English regions and also between city and rural areas. This is particularly the case for services such as home care which are provided by independent organisations.

A budget setting tool will need to be flexible enough to take into account local costs. While costs may also vary within localities, it is usually not essential to take this into account for setting indicative budgets.

Appendix 1 NHS Manchester budget setting tool – Template

Appendix 2 NHS Manchester budget setting tool – Instructions

Appendix 3 NHS Manchester budget setting tool – Issues to consider

NHS Oxfordshire – calculating budgets bottom-up

NHS Oxfordshire has developed an indicative budget setting model based on developing an initial outline of the care and support arrangement needed to meet the needs of the person and their family. The elements of the package are then costed using a spreadsheet to come to an indicative budget. The final budget is agreed once the care and support plan has been developed more fully.

Unlike the NHS Manchester tool, this approach does not rely on the decision support tool. In a similar way to the NHS Manchester tool, it provides a rough indicative budget to inform support planning.

Appendix 4 NHS Oxfordshire indicative budget setting model

Appendix 5 NHS Oxfordshire indicative budget form

6 References

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