

Personal Health Budget Information Guides



Information Guide 2: Care and support planning for personal health budgets

Who, and what, are these information guides for?

This series of guides aims to provide realistic and useful information about personal health budgets, so that people are better equipped to ask relevant questions and make the choices that are right for them about their health and well-being. The guides are intended for individuals and families who want to know more and who are considering having a personal health budget, and may also be useful for professionals.

People and families interested in having a personal health budget may be considering this option for a whole range of different reasons. A person may have a changing health condition or a change of circumstances. Often people are living with complex health conditions and may want more choice and control in their care and support.

The organisations responsible for local implementation of personal health budgets are Clinical Commissioning Groups. There are currently 135 of these across the country, all with unique histories and different ways of doing things. Each is responsible for responding to the varied needs of their local population.

Peoplehub have created these information guides because our lived experience is that personal health budgets, when done well, can make a huge positive difference in people's lives. We've also found that things go more smoothly when people are well-informed about what is and isn't possible, and aim to work together with their local health team.

This second guide in the series is about the critical process of care and support planning.

It explains what a care and support plan is, what you need to know to be able to write your plan, and the essential elements that should be included.

1. What is personalised care and support planning and what is it for?

“Personalised care and support planning is a series of facilitated conversations in which the person, or those who know them well, actively participates to explore the management of their health and well-being within the context of their whole life and family situation... It is an essential tool to integrate the person’s experience of all the services they access so they have one joined-up plan that covers their health and wellbeing needs.”

(<https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning>)

The care and support plan is at the heart of the personal health budget process. A well thought out plan has a much greater chance of being agreed, and enabling you to achieve what you want to with your personal health budget.

“Personalised care and support planning aims to ensure a better or different conversation between a person and their health and social care practitioner to create a more equal relationship. The overall aim is to identify what is most important to the person for them to achieve a good life and ensure that the support they receive is designed and coordinated around their desired outcomes... and results in a personalised care and support plan (or an education, health and care (EHC) plan for children and young people).”

(Integrated Personal Commissioning – Personalised Care and Support Planning – 2017 – NHS England)

The process recognises the person’s skills and strengths, as well as their experiences and the things that matter the most to them. It looks at how to sustain the things that are working well, and addresses the things that aren’t working in the person’s life. It identifies health and well-being outcomes, and actions to achieve them.

People’s experiences of the care and support planning process can vary widely. This approach to planning, which focuses on people’s strengths and abilities rather than just needs, and has people themselves central to decision making, is still a relatively new way of doing things in the NHS. Traditionally, the health system has assessed needs and prescribed solutions. This is why it’s important for you to know what good looks like and how the process is intended to work.

The steps of the personal health budget process



Personalised care and support planning is a pivotal step in the personal health budget process.

This diagram shows how the process is meant to work – it doesn't always work like this in practice! We describe each of the steps and explain what they mean in Guide 1 – An introduction to personal health budgets.

It's really important to know roughly how much money is available before you start to plan. This enables you to make a realistic plan, and to prioritise the things that matter most to you within that plan. We feel it is important that people are able to choose how they want the money to be held and managed after they have drafted their care and support plan. This is because drafting the plan will enable you to fully understand what you want to achieve with your budget, what that will involve, and the degree of control that you want over it.

2. What's different about this plan?

The aim of a good personalised care and support plan is that it should be one plan that acts as an overview for all other health and social care plans that someone may have. People with complex health needs often have several different plans related to different aspects of their health condition. These are often written by, and held by, relevant specialist health professionals.

This single over-arching plan need not contain all of the detail of the other plans but should contain the most important information as described in Section 5 of this guide. It should link to any more detailed plans and signpost to any relevant assessments. The idea is to have

one plan which can be read and authorised by the NHS, rather than having a vast plan where the important information can get lost in the detail.

This plan is your plan, to be written by you, with whatever support you need to do that, and held by you. The plan has to be agreed with your health professionals.

Your plan is an opportunity to begin to think about your health and well-being, not only from a perspective of your health needs, but, importantly, in terms of who you are and what matters to you. When we start our plan from this different place, it helps to shift the way we are seen by health and care staff. It enables us to move towards being a more active partner in managing our health.

It's important to recognise yourself as a valued contributor with skills and knowledge rather than only a set of needs to be met. Think about the best way to describe who you are, what you like and what your needs are.

Some of the over-arching questions to kick-off your thinking could include, for example:

- 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 health issues do I have? How can I best begin to address these?
- What do I want to achieve in the next part of my life? What is stopping me?
- 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?

Your health professional may have a form or a template which might include these or similar questions. You might find the form useful to agree exactly how you will achieve these things. **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.”

3. Who is responsible for your plan, and who can help you prepare it?

It is very important that you are the owner of your own care and support plan. For people who can't make their own decisions, a family member or someone who knows them well can act on their behalf.

This means that you need to feel comfortable with the way it's written, including its format, the language that is used and with its content. If you aren't happy with these things then it may not work as effectively as it should. If this is happening –for example if 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 also has important responsibilities. Ultimately they need to satisfy themselves that your plan is sensible, cost-effective and that it will help you to stay safe and well. 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. 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.

There may be support available to you, to help you write your plan, depending on what's available in your local area. 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 may have particular experience in planning;

but you shouldn't be made to feel you have to use any particular agency, 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.

“The care plan is an agreement between the CCG and the person receiving direct payments, and includes responsibilities on both sides. It is therefore vital that people are supported throughout the care planning process. This will help ensure that they are able to make informed decisions in their best interests, and that they do not find the process overly burdensome or overwhelming. This support could take many forms -it may be from their healthcare professional, but some people may prefer an independent person to guide them through the process and liaise with the relevant parties. As with each aspect of personal health budgets, the best approach is to enable choice and not assume that the same option suits everyone.”

(Guidance on Direct Payments for Healthcare: Understanding the Regulations – 2014 - NHS England)

4. What do you need to know to be able to write your plan?

Before you can begin to write your plan, there are some essential pieces of information to know:

- Am I eligible for a personal health budget?

There are certain groups of people who have a 'legal right' to have a personal health budget. Each Clinical Commissioning Group should have a local offer beyond those legally entitled. See Guide 1 – An introduction to personal health budgets for more information on eligibility.

- What are my assessed eligible health needs?

All assessments should have been carried out before you write your plan, so that you are clear about which health needs the NHS recognises it has a responsibility to meet.

- Roughly how much will my personal health budget be?

This will be your indicative budget, which will be developed in relation to what the NHS agrees to be your eligible health and wellbeing needs.

- What needs to be included in the plan?

See section 5 of this guide for essential content that should be included.

- What are the options for managing a personal health budget?

There are 3 main options for holding a personal health budget. Guide 3 – Choosing

how to hold a personal health budget explains each of these.

- What I can spend my personal health budget on?

On an individual level, what a personal health budget can be spent on depends on the health and well-being outcomes that have been agreed and how you want to achieve them. However, Clinical Commissioning Groups are free to implement their own local decision-making policies. There are examples of how people have used their personal health budget creatively in Guide 1 – An introduction to personal health budgets.

- How my plan will be agreed and signed off by the NHS?

This will vary from place to place, and it's important to find out what your local decision-making process is.

If you are unclear about any of this information, it's important to find the answers.

5. What needs to be included in your plan?

There is no nationally recognised template for a good personalised care and support plan. A lot has been written about the care-planning conversation and the process of developing a plan, but there has been concern that somehow having a template might mean that a plan is not personalised. Peoplehub takes a different view.

We believe that setting out all the essential elements of what should be in a plan is helpful. The personalisation comes from the way in which the conversation is held and the plan is developed. It's about the process, not

the form. If everyone knows what should be in the plan then misunderstandings can be avoided and the plan can be more readily agreed.

Essential Content

The elements that should be included in your plan can be broadly summarised into the following section headings. We'll explain each of these in a little more detail. The language that you use, and the layout of your plan, should make sense to you.

- About
- Contact details & decision making
- Details of health condition/s
- Needs and outcomes
- Action plan
- Training of PAs and delegated healthcare tasks
- Contingency planning and risk management
- Budget details
- Reviews
- Sign off

About

This introduces who you are and describes you as a person. It can include –

- what people appreciate about you - the things you're good at and that other people value about you
- how you got to where you are today – any information you want to include about your life, background, culture and community
- what matters to you – the things that are important to you, people, hobbies, passions and interests
- how best to support you – specific information that would be useful for other people to know

Contact details and decision making

This should include –

- your own personal contact details, what you like to be called, your first language, any communication needs, and communication preferences.

- Contacts for your next of kin, closest relatives and family carers.
- Professional contacts including any advocate, care co-ordinator and support planning facilitator along with named health professionals and specialist organisations.

It's important to consider to what extent you are able and want to make decisions, and who might help you, and/or act on your behalf. You may want to include –

- Representative contact details
- How and by whom the decisions in your plan are made
- Any advance directives and where they are held

Details of health condition/s

This is where to describe in summary your health condition/s and how they affect you. You may want to include how long you've had each condition, whether they interact and whether they change

over time. It will be important to include details of any medication that you take, any allergies and drug reactions, and current on-going treatments.

Needs and Outcomes

Your eligible assessed healthcare needs are the best place to start for this. For each need, it is important to link an outcome or goal which shows how things will be different.

You can describe the things that work well for you, that you wish to retain, and those that don't work well, that you wish to change or remove. It is helpful to first look at what is important to you, what best support looks like to you, and then consider what is working and what is not working in those areas, from your own perspective and from that of other people. We go into more detail about what an outcome is and how to develop them later in this guide.

Action Plan

No plan is any good only as a piece of paper – it needs to be put into action! This is where you plan how your outcomes will be met. It is about how, and who, will make it happen. Look at each of your outcomes and decide what needs to be done to achieve them. What could be done to achieve each outcome? Who can help? Who in terms of your family, friends and broader network – but also who in terms of health professionals?

Take time with 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 basis in who you are and how you see your future. Effective use of a personal health budget is about so much more than “services.”

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 things cost- like employing personal assistants. 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 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.

Training of Personal Assistants and delegated healthcare tasks

If you are going to be employing PAs with your personal health budget, it's important to think about their training and competence. Many personal health budget holders have said that the most important thing in recruiting staff is that

they have the right values and attitudes, as the skills can be trained.

There is often mandatory training that every PA is expected to do. If your PAs will be doing any clinical or healthcare tasks, they will need specialist training and assessment of competence.

“Delegation of specific healthcare tasks should be considered within the care planning process... The care plan should make clear the task that is to be delegated, the limits of the delegation and how risks will be managed.... For tasks that can be delegated, the action plan needs to identify how the associated training will be provided and who will be responsible for assessment of competence, ongoing support to the PA, and clinical review of the person’s needs.”

(Delegation of healthcare tasks to personal assistants within personal health budgets and Integrated Personal Commissioning - 2017 – NHS England)

Our experience suggests that the best training is that which is geared to the very specific needs and circumstances of the individual.

Contingency planning and Risk Management

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 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.

It is important to plan for any sudden changes which may mean that you require additional support, and consider what you'd do if your regular support were unavailable.

For example, if you are going to employ your own staff what will you do when they are on annual leave or off sick? What happens when you become unwell? Include risks that you are happy to take because this enhances your quality of life, risks you are prepared to tolerate, and risks you want to minimise.

“Successful delivery of personalised care and support requires a balance between enabling individual choice and control and managing risks of all types... It requires a change from a risk-averse approach to one in which individuals and organisations are able to identify and manage risk in order to improve people’s outcomes...”

Good conversations about risk and risk enablement also mean that people can develop contingency plans so they have systems in place to get support at an early stage to avoid a crisis....

CCGs and local authorities should not become so focused on managing all the risks that they lose sight of what they are trying to achieve – enabling greater choice, control and flexibility over care and support.”

(Integrated Personal Commissioning – Personalised Care and Support Planning – 2017 – NHS England)

Budget Details

This is a breakdown of how your personal health budget funding is going to be used, and how your personal health budget will be held and managed.

Sometimes people are asked to make a choice about how they want to hold their budget when they’re first offered one. We believe that the best time to make the decision about how you would like to manage your own personal health budget is when you have drafted your plan. This is because it’s only then that you’re clear about what you want to achieve, what that

will involve and the degree of control that you want.

There is more detailed information on the different ways to hold a personal health budget in the third guide in this series.

Each local area will have its own approach to the amount of detail required in the budget breakdown and the format for recording it. It’s useful to think about:

- The total amount of money
- How the money will be used to meet the outcomes agreed
- What records need to be kept
- Where the money is held, how the budget will be managed and who is responsible for it

The spend needs to be sure to cover things like insurances, training costs, payroll costs and third party organisation charges if you are having a third party budget.

“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 – 2014 - NHS England)

Reviews

Reviews are an essential part of the care and support planning process. In terms of frequency, the direct payments guidance states:

“As a minimum, all care plans must be

reviewed formally within three months of the person first receiving a direct payment. Following this, reviews should be at appropriate intervals, but at least yearly.”

The purpose of reviews is to make sure that things are working well for you and that anything which isn't working well is identified and can be changed.

“Reviews that focus on outcomes rather than processes can be the most effective way of identifying what works well and what doesn't work well for the person...”

The ultimate aim of review is to strengthen the person's ability to achieve the outcomes they want...

Reviews should be proportionate to the person's circumstances, and should place as few burdens on people receiving care, representatives and nominees as possible.”

(Guidance on Direct Payments for Healthcare: Understanding the Regulations – 2014 - NHS England)

Ideally your care and support plan should identify a key point of contact or named care coordinator from the NHS. It should have the date of your next review. Given that unexpected things can happen and health can change, your plan should also outline how to ask for a review at any time you feel it is necessary.

Sign off

Each local area will have its own process for authorising care and support plans. The document will need to have a place for the relevant sign off from within your local health system and yourself or your representative.

You may want to include a statement here about information sharing - that is who you give permission for your plan to be shared with.

6. Developing your outcomes

“Outcomes” is a word that many of us don’t use or come across much. Another way of thinking about them is to think about “goals”. Outcomes should describe what you wish to change or achieve. They are not services, treatments, therapies or items. An outcome is the “what” not the “how”.

It is important to record the outcomes that you wish to achieve and your ideas on how to do so. It is also important that these outcomes are linked to the health/care needs for which you have been assessed.

An outcome:

- Is a personal goal not a service or treatment
- Is something which can be influenced
- Can be seen in behavioural change, or maintenance of a physical or emotional state, including relationships
- Can be seen to make a useful difference, including subjective views of pain relief or improved mental wellbeing
- May have obstacles in the way of achieving it
- Should be measurable and specific

“Outcomes are changes in, or sustainment of, physical behaviours, health conditions or mental states or emotions. Therefore, outcomes may relate to both health and wellbeing.

People may need help to identify their outcomes and to ensure they are as specific and individually relevant as possible. The personalised care and support plan must clearly describe what is being aimed for, and in specific terms, what will be working better, be maintained or be avoided. This can include what is hoped for when someone has a degenerative condition or as their health deteriorates and they approach the end of life.

Outcomes must be recognised and owned by the person. A good outcome changes something that isn’t working and builds on/maintains something that is working. It should be specific and personal to the person and be something the person or those around them have some influence or control over.”

(Integrated Personal Commissioning – Personalised Care and Support Planning – 2017 – NHS England)

There are some questions that can be useful to think about when developing your outcomes:

- Does it keep something that is working?
- Does it change something that isn't working?
- Does it move you towards a future you want?

The table below can also be a useful way of approaching it.

Outcomes do need to link to your assessed health needs, and don't forget that mental health and well-being is just

as important as your physical health, and your outcomes should also include these.

Examples of Outcomes

It can sometimes be useful to have examples of outcomes to stimulate your thinking when developing your own.

Here are a range of people's own outcomes gathered from people with lived experience of personal health budgets. Note that these are solely outcomes – the "what" not the "how" – as the solutions could be achieved in any number of ways which will be unique to each person and their own circumstances.

- Being able to breathe more easily and keep my oxygen levels correct
- Making my sure my skin is well-maintained and pressure damage is avoided
- Being able to take emergency medication immediately to manage crises
- Being able to see my friends and family
- To keep my pain at a manageable level
- To be able to communicate effectively
- Being able to attend school/continue my education

Area of eligible need	My outcome – what I want to achieve	What is getting in the way of achieving it now?	What is the risk if I don't achieve it?	My solutions for achieving it	What (if any) risks are in those solutions and how will we mitigate those?	Rough cost for solution – to help with prioritising

(Jo Harvey, NHS England)

7. What format should I use?

There will be certain elements that your health professionals will need to ensure are included, but at the end of the day it is your plan for your life.

Many people may be given a standard template or form, which may work for you, but don't let a template or form limit your thinking.

Some people prefer a blank page to design their own from scratch; some choose illustrated or graphic plans, or even a video or digital recording of their plan. It needs to make sense to you.

8. Are there any agreed criteria for plans?

As we said earlier, there is no one template or nationally agreed criteria for care and support plans in personal health budgets. Your local Clinical Commissioning Group should have its own criteria and decision making process for agreeing and signing off plans, and it can be useful to ask for these.

The 2012 Department of Health document Personal Health Budgets Guide – Implementing Effective Care Planning offers:

“In order for a person to be able to write their care plan and for their health team to authorise it, a straightforward summary of what it should contain must be shared with the person. Experience suggests that a care plan should achieve the following:

- *Show who the person is – their strengths, skills and personal social context as well as their health needs.*
- *If the person lacks capacity to make their own decisions, the plan must show how this decision was reached and identify who will speak on their behalf.*
- *Describe what is working and not working from their perspective.*
- *Detail what is important to the person and what is important for their health.*
- *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.*
- *State the desired health outcomes and how they will be achieved.*
- *Describe in broad terms how the money will be held and managed, and show how it will be used to achieve the outcomes.*
- *Contain an action plan that details who will do what and when.*
- *Include the name of the person's care co-ordinator.*
- *State how and when the outcomes, and the money, will be monitored and reviewed. This includes describing how people will know if the plan is going well or if things are going wrong.”*

The key features of personalised care and support planning

The key features of personalised care and support planning were developed by the NHS England Personalised Care Strategic Co-production Group, who are people with lived experience of personalised care, including personal health budgets. They are described under 3 headings – Perspective, Process and Plan. While these key features are not criteria as such, they serve as a useful example of what good looks like in terms of the conversation and the process.

Perspective – this is a way of ‘seeing people’ and attitude towards them that is fundamental to good Personalised Care and Support Planning.

The changed relationship and different conversation will mean that the person:

- *is empowered and builds knowledge, skills and confidence*
- *experiences hope and feels confident that the process and the plan will deliver what matters most to them*
- *is central in developing their Personalised Care and Support Plan and will agree who is involved.*
- *is seen as a whole person within the context of their whole life, valuing their skills, strengths, experience and important relationships*
- *is valued as an active participant in conversations and decisions about their health and wellbeing.*

Process – this is the overall process of personalised care and support planning.

A good personalised care and support planning process will mean that the person:

- *has the time and support to develop their plan in a safe and reflective space*
- *is able to access information and advice that is clear and timely and meets individual information needs and preferences*
- *feels prepared, knows what to expect and is ready to engage in planning supported by a single, named coordinator*
- *is listened to and understood in a way that builds trusting and effective relationships with key people*
- *is able to agree the health and well-being outcomes (and learning outcomes for children and young people with education, health and care plans) they want to achieve, in dialogue with the relevant health, education and social care professionals*
- *has the chance to formally and informally review their personalised care and support plan.*

Plan – this is what a good plan looks like.

A Personalised Care and Support Plan:

- *is a way of capturing and recording conversations, decisions and agreed outcomes in a way that makes sense to the person.*
- *should be proportionate, flexible and coordinated and adaptable to a person’s health condition, situation and care and support needs.*
- *should include a description of the person, what matters to them and all the necessary elements that would make the plan achievable and effective.*

(<https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning>)

FURTHER READING

This is the second guide in a series of information guides about personal health budgets.

The other guides are:

- 1 – An introduction to personal health budgets
- 3 – Choosing how to hold a personal health budget
- 4 – Top tips for personal health budgets

Available from www.peoplehub.org.uk



Guidance on Direct Payments for Healthcare: Understanding the Regulations (2014) NHS England

<https://www.england.nhs.uk/wp-content/uploads/2017/06/guid-direct-paymnt.pdf>

Integrated Personal Commissioning – Personalised Care and Support Planning summary guide – 2017 – NHS England

https://www.england.nhs.uk/wp-content/uploads/2017/06/516_Personalised-care-and-support-planning_S7.pdf

NHS England's Personalised Care and Support Planning pages

<https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/>

Delegation of healthcare tasks to personal assistants within personal health budgets and Integrated Personal Commissioning - 2017 – NHS England

https://www.england.nhs.uk/wp-content/uploads/2017/06/516_Delegation-of-healthcare-tasks-to-personal-assistants_S7.pdf