



Young Person's Guide to Personal Budgets in England

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What is this guide all about and who is it for?

This is a guide about personal budgets for young people. It is written for young people with life-limiting and life-threatening conditions, with your needs in mind. The guide aims to help you decide if a personal budget is right for you and to answer some of the questions you may have. It explains what a personal budget is, how it can be used and why personal budgets are needed.



Personal budgets were introduced because many people said that the system where professionals make all the decisions didn't work for them. With that approach, people had very little choice about what services they received, who provided those services, and the way they were provided. People didn't know who to talk to if things went wrong and it was hard to change things even if they did find the right person.

Instead, having a personal budget allows you to choose your support so it suits your preferences and your lifestyle, and you should be able to influence all the decisions that affect you and your life and to quickly put things right if needed.

This guide is for young people living in England. In Northern Ireland, Scotland and Wales the law is slightly different. Many of the same principles apply but personalisation does work differently in these places. You should check how your local system works.

You may not want or need to read this whole guide at one time: it is divided into sections which explain different parts of personal budgets. There are links to organisations and other information which might help you further – everyone is an individual and has different needs. Personal budgets are new and some places are more familiar in using them so your experience may be different depending on where you live.



The guide includes real life examples from three young people with personal budgets: Heidi, Leah and Chris.

Learn more about them in the [‘How do personal budgets work in real life?’](#) section.

What is a personal budget?

A personal budget is an amount of money which is available to an individual or a family to help them meet their needs for good health or social care or for parts of their education. It is money which is paid instead of (not as well as) some of the services you might otherwise have. It is not the same as a welfare benefit from the Department of Work and Pensions and it does not affect whether you qualify for such a welfare benefit.

A personal budget is not meant to replace all the services you get: so for example, everyone will still get to see their GP (family doctor) and to use the local Accident and Emergency services if they need them. But the personal budget can replace some of the services – exactly which ones it replaces will be agreed with you.

Personal budgets were introduced to give people more choice and control over their health and care and parts of their education. They do this because, by having money (instead of direct services) you can decide what type of support works best for you – and you can use your personal budget to buy these things. You will be able to find help to discover what support is available and to make good choices.



Leah says that using a personal budget has given her the freedom and means to explore life just like other people of her age. She says that when she got her personal budget it gave her choice and control over all aspects of her life for the first time.

Who can get a personal budget?

It is not always easy to know if you qualify for a personal budget and if it's the best way of getting the help you need. To decide this you will need to find out how things work in your local area and you will need to talk to the doctors, nurses and other professionals who are caring for you. It's also helpful to talk to your close family and friends, to get their views.

The doctors, nurses and other professionals will need to talk to you and decide if you qualify (or are "eligible") for a personal budget. They will also talk to you about which services it might replace. This can be complicated because there are three types of personal budget.



All of Heidi's family were involved in deciding her personal budget and an independent organiser oversaw the whole process. Although Heidi's family said that it was time consuming, they also said that they were extremely satisfied at the end. They really valued being able to record what Heidi is capable of, what she can do and what she wants from life – rather than the negative things they had been asked about in the past.



Are there different types of personal budget?

There are three types of personal budget:

- 1. There are **personal health budgets**.** These are to help people with specific continuing or long term health conditions stay as well as possible: physically and mentally. So these budgets might be instead of some of the services or equipment provided by the NHS. It might be agreed that you can use your personal health budget to pay people to help provide care for you at home, or to buy a gym membership, hydrotherapy, a wheelchair or other equipment. Not everyone will be able to access a personal health budget; you would need to be classed as having “continuing health care” needs or a “long term health condition”. Anyone with these needs can request a personal health budget and the NHS have a duty to consider it where it is practical and reasonable. You can find out more about who qualifies for a personal health budget from the [NHS Choices](#) website.
- 2. There are **personal budgets for social care**.** Social care is the practical or emotional help some people need due to illness or disability. This is the responsibility of local councils (local authorities) in England. Each local council has a children’s social care and an adult social care department (sometimes called “social services”) and they pay for help in the home, short breaks, equipment and other things so people can live well. If you qualify (are eligible) for social care your council will complete an assessment and then should inform you of the cost to meet your assessed needs – this is your personal budget. You will have to spend this to meet your assessed needs and the money is monitored by the council. You can find out which local authority you live in on the [Directgov](#) website. You can find out more about personal budgets for social care from the [Community Care](#) website.
- 3. There are **personal budgets for education**.** These are for children and young people with special educational needs or disability. These budgets are to pay for support which is instead of some of the services which a local education authority or school would otherwise provide. This could include special equipment to help someone see or hear better, or school transport to take them to school and back home. This does not include school places, which all children of school age will continue to have. You will need to meet with someone from the local education authority to discuss whether you qualify for a personal budget for education. You can find out more about personal budgets in education from the [Kids](#) website.

How can I manage my personal budget?

Are personal budgets right for you?

The personal budgets system in England is new; it is a big change and everyone is still getting used to it. The government has said personal budgets must be as simple as possible. So although different professionals may have to ask you about different parts of your life (health, social care, education). What you need to think about is “what is a good life for me?”

Thinking in this way and talking to your close friends and family will also help you decide if a personal budget is something you want. How important are choice and control to you? You may prefer professionals to make choices for you – or you may worry about taking on too much responsibility, or that the services you want and need won't be there to buy with a personal budget.

Planning: preparing for your personal budget

It is very important when thinking about personal budgets that you give some thought to what you need to live a good life both now and in the future. Everyone has different ideas and ambitions and everyone will want to use their personal budget in a different way to achieve them. These ideas and ambitions are sometimes called “outcomes”.

When you have your personal budget and the professionals ask you about whether it is working or not, they will focus on these outcomes – is your life better in the ways you had hoped and is the personal budget helping with this? Or do a few things need to change?

This is why making a **support plan** or a **care and support plan** is so important. This shouldn't be too complicated. Your close family and friends should help you make your plan. You could also get guidance from local people who have experience of making similar plans. The professionals who are advising you should be able to tell you where to get this advice.

Managing your personal budget: getting it right for you

Some people worry that having a personal budget will be a lot of work, that it will involve complicated accounts - and even perhaps mean that you are responsible for employing staff who you pay to help you. It is true that some people do spend quite a lot of time and energy on these things, especially some of those who have complicated health conditions, large personal budgets and who choose to take their budget as a direct payment. But a direct payment is only one of the options and it is important that you find a way of managing your personal budget, one that suits you.

Chris' parents found it difficult at first, not providing support for him. But this has changed over the years and Chris now believes his relationship with his parents is much healthier and he is able to look out for them, just as they do for him.



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How can I manage my personal budget?

Managing your personal budget: the options

There are three ways to manage a personal budget:

1. A direct payment is an amount of money which is paid directly to an individual to allow them to buy the care and support they need. The money is transferred to you, usually into a special bank account, and you can buy the services and support as agreed in the plan.

2. A third party arrangement is where money is paid to an organisation that holds it for you. The organisation is called a "third party" and could be an independent user trust, a voluntary organisation, a user-led organisation or community interest company. The third party might also be an ordinary care provider organisation, in which case that organisation will have to look after your personal budget separately from the money for everyone else. You can get more detailed information in the [resource list](#). The organisation you choose will vary depending on where you live and on your personal preferences.

3. A notional budget. This is where the NHS or the local council holds your personal budget for you: there is no transfer of cash. You should still know what your budget is, including the amount of money allocated to you and which bits of your care and support it is to cover (the services it is instead of). The NHS or the local council must involve you in all the important decisions. The main difference from the other options is that it is the NHS or council which arranges and pays for the services, including employing staff if it is part of the plan.

It may be possible to choose a combination of the three options. It is important that the way your personal budget is managed should suit you, it should not be difficult and it should help you feel in control of your life.

Heidi and her family manage their own personal budget and use a payroll company to process wages. They say that they find this process very easy.



Leah decided that she wanted to manage her personal budget herself as she felt this would give her the most freedom and flexibility.



Chris had never employed people before and he wanted help to find and then manage the people who would care and support him. So Chris looked for a company that offered a service for people with similar conditions.



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Spending your personal budget

When getting a personal budget some people worry how they will identify the things they need and how they will buy them. Some of the things they need might be simple, like a taxi service or swimming lessons. However, some may be specialist and need trained and qualified staff or special equipment. People may also worry about how they can monitor the quality of what it is they are buying – is it doing the job, and if not what can they do about it?



Getting the right people to help you with your personal budget

It may be that everything you hope for from your personal budget cannot be found when you first start planning. You might therefore decide to receive some of your support in the existing (or “conventional”) way, as a direct service.

You may find it helpful to talk to people with expertise in your particular condition or situation – perhaps an agency or service provider will be willing to change or extend what they do to meet your needs. Or you could talk to other people in your area with personal budgets about how they found the care and support they were looking for.

You will need to talk to the professionals supporting you about how you check on quality. They will be able to advise you. They will want to make sure that you stay safe and well and that your personal budget provides good value for money.



**It is important that you ask yourself:
“Is my personal budget doing what
I want and need, and am I achieving
the things set out in my plan?”**

How do I understand and review my personal budget?

Personal budgets and young people: what is different?

Most of what we've said so far applies to people of any age who are thinking about a personal budget. What is it that is special for young people, and particularly for young people with life-limiting conditions or other serious health problems?

- As a young person, you should be able to learn, enjoy life and do something helpful for other people if you want to. Your plan needs to reflect this: make sure it shows who you are, what is important to you and how you want to live your life.
- Most young people have families who care about them and worry about their health and safety and want them to be happy. For young people with serious health problems, families are often very important. They may have been their main carers and helped them to make decisions and choices over many years. Some young people may want their families to stay involved. Sometimes a parent or other family member will take responsibility for managing someone's personal budget: this works for many families, though it is very important that your needs are the main thing when planning and maintaining a personal budget.

- Many young people in this category have complicated health conditions which mean they see lots of different doctors and nurses and may spend regular periods away from home in hospital or at a hospice. Payment for some of these things may not come from your personal budget and the funding arrangements may continue as in the past. Talk to the team at the hospice and they will help you. Making a plan and having a personal budget is a great opportunity to think about and influence all of the services that you need, and how they fit together and help you in the ways that you want.



Keeping your personal budget under review

It is really important to keep on checking that the personal budget is working for you. It needs to work in two ways: the personal budget should help you live the life you choose, and the way it is managed needs to work for you. Everyone is different and something which doesn't work for one person may work for someone else. The professionals who support you will tell you about the review arrangements which they use to check on how your personal budget is working. If something important changes in your life – for example your health condition changes or your needs change you may need to tell the professionals about the changes outside of these official review arrangements.

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How do I understand and review my personal budget?

What is personalisation?

This approach, where support is tailored to what people want and need is sometimes called personalisation.

Personalisation is about all the support someone gets working together for the benefit of the person, so that they get the life they choose. Personal budgets are an important part of this – but all aspects of the support a person receives needs to change to become more personal.

Finally

Personal budgets are a fantastic way to help people take more control and have more choice. They make things more equal between professionals and the people they help. But they are still new and not everyone understands them fully or even thinks they are a good idea. Personal budgets do mean that young people and their families have to take on more responsibility. However, most people who have started to use personal budgets are very enthusiastic, often saying that their lives are greatly improved. Most of them would say that if done thoughtfully and carefully, personal budgets are most definitely worth the effort.

If you are worried about planning your care and support over the year and making sure there's enough money to pay for everything you need – then there are lots of places to get [help](#).



Heidi and her family feel that her personal budget has been life-changing and they were very happy to be part of the pilot. They felt that the services they were offered previously were not suitable. Now they have the freedom to choose Heidi's own activities, services and support.



Leah feels that although it has been a struggle at times, a personal budget has changed her life. But she also feels that government and local authorities still have a long way to go until the system is truly personal and individual.



Chris says that his budget has enabled him to have a much better quality of life than he would have otherwise had.



How can I get more information about personal budgets?

If you need more help or support with personal budgets talk to your doctor, nurse or social worker. They may suggest someone else in your local area that has specialist knowledge to help you. There may also be a group of personal budget holders who you can contact for support.

There are a number of national organisations that may be able to help or advise.

Together for Short Lives

The leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love or care for them.

www.togetherforshortlives.org.uk

In Control

A charity which works for a society that includes everyone equally. Personal budgets are a part of this. In Control wrote this guide.

www.in-control.org.uk

www.facebook.com/groups/881145328613668/

Peoplehub

A charity which brings together people using personal health budgets and others with long-term health conditions.

www.peoplehub.org.uk

Council for Disabled Children

A body which brings together organisations working for disabled children in England.

www.councilfordisabledchildren.org.uk

Disability Rights UK

An organisation of disabled people, working to create an equal society.

www.disabilityrightsuk.org

Person Centred Care

Website explaining person-centred care and personal budgets in health.

personcentredcare.health.org.uk



How do personal budgets work in real life?

These real life examples are based on questionnaires completed by three young people who use personal budgets. We have edited their words only where necessary to ensure consistent terminology or to make the meaning clear.



Heidi

Heidi is 19, lives with her family in East Sussex, and attends a residential college during term time. Heidi's family helped her answer these questions.

Heidi's interests include performing arts and sports. She would love to be an astronaut. Heidi has complex physical disabilities and health needs, and requires one to one support at all times.

Heidi has had a personal budget for nearly four years. Heidi and her family say that a personal budget has really improved their lives. They now have more flexibility and access to activities, services, and provision, that meet Heidi's needs better than those on offer from the local authority. They say that the only difficult thing is finding suitable Personal Assistants who are able to work with Heidi. Her personal budget is spent on directly employing Personal Assistants for social activities, accessing overnight stays in her school, transport costs, and for short breaks without her family.

Heidi was part of a personal social care budget pilot in her area. What outcomes Heidi wanted from having a personal budget, and how these outcomes could be achieved was looked at and agreed. Heidi's needs were then scored using a resource allocation system (RAS) which decided the amount of money that she had to spend. All of Heidi's

family were included in the discussions, and there was an independent organisation who helped throughout the whole process. Although Heidi's family say that it was time consuming, they also said that they were extremely satisfied at the end. They really valued being able to look at what Heidi is capable of, what she can do and what she wants from life – rather than the negative things they had been asked about in the past.

Heidi and her family manage her personal budget and use a payroll company to process wages. They say that they find this process very easy. Although they haven't had any problems with the personal budget, they wouldn't know who to contact if they did. This is an issue which the local authority needs to consider.

Heidi and her family feel that they have full choice and control over the personal budget. But they do worry that if they had to make any changes, would professionals that they don't know would be as accommodating? They feel that having full choice and control over a personal budget is the only way it can work effectively.

Heidi and her family feel that their personal budget has been life-changing and they were very happy to be part of the pilot. They felt that the services they were offered before this were not suitable. Now they have the freedom to choose Heidi's own activities, services and support.

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How do personal budgets work in real life?



Leah

Leah is 24 and lives independently in her own home in Blackburn, Lancashire. Leah has a degree in criminology and has had many volunteer roles including working with her local self-directed support team; and working alongside Lancashire Police as a member of their Independent Advisory Group. Leah is passionate about travel and hopes to do a road-trip around America in the future. She loves spending time with her family and hopes to have a family of her own one day.

Leah has had a personal budget since 2008, although this has varied in amount – from funding for just a few hours support, to 24/7 support. Leah says that using a personal budget has given her the freedom and ability to explore life like other people of her age. She says that when she got her personal budget it gave her choice and control over all aspects of her life for the first time.

Leah employs six Personal Assistants to provide her with support around the clock. They support her personal, social and domestic activities. She hires them herself and is their employer. Finding good, dedicated Personal Assistants can be difficult and stressful for Leah. She normally goes through the local Job Centre, which tries to match people already on their system with what Leah wants and needs.

When Leah was first assessed back in 2008 it was by her Social Worker, with very little involvement from herself. As a result, the process did not work. However, since moving into her own home, Leah has been re-assessed with more involvement, and she is happy as she gets a lot more say in everything. Leah decided that she wanted to manage her personal budget herself as she felt this would give her the most freedom and flexibility. She says it is hard managing the staff, wages, tax, holidays and, monitoring

accounts and sometimes it feels like a full time job. She has little or no support from Social Services or the self-directed support team. She gets most of the support she needs to manage her personal budget from her mum.

However, Leah does have legal contacts that she can refer to for anything that relates to her personal budget; there is also an organisation that helps her manage payroll and National Insurance issues. Although Leah knows she can contact the self-directed support team, she feels that they often can't help her so she tends to try and sort things out for herself.

Leah feels that she now has choice and control. But it hasn't always been like that: it took a long time to get the right support package at first, and this was repeated as her circumstances changed and she needed to go back and argue that these changes needed to be reflected in her support package. Leah now feels worried that things are in danger of changing in a negative way as personal budgets are reduced as a result of funding cuts, and she fears that she may become less able to do what she wants.

Leah feels that although it has been difficult at times, a personal budget has changed her life. But she also feels that government and local authorities still have a long way to go until the system is truly personal and individual.

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How do personal budgets work in real life?



Chris

Chris is 26 years old and has Spinal Muscular Atrophy Type 2. When Chris was 16 he decided he wanted to go to university but he would need 24 hour care seven days a week to support him to live independently on a university campus. To get the funding required, Chris and his family had to go through a long process of assessment. Chris experienced this process as very degrading and very difficult as the local authority and health authority argued about Chris' personal needs and who was responsible. After 18 months of pressure from his family and MPs he was eventually granted a personal budget that met his needs and enabled Chris to live independently.

Chris had never been an employer and he wanted help in particular with recruitment and Human Resources. Chris looked for a company that offered a bespoke service for people with similar conditions. The company, Care Preference, that he currently uses gives him the control to choose staff and to shift rotas around his lifestyle and they do this in ways that are able to take away the stress and responsibilities of being an employer. They also give him the reassurance that all shifts will be covered by someone Chris knows; and that training of the staff will be done with his full involvement. As Chris, says: his routine is unique to him and he needs to be involved.

Having a personal budget has meant that Chris has been able to study at university and to achieve a degree in accountancy. He has lived independently since he was 18 years old and this has made him feel more involved in his community. Chris has worked for the health authority and at a local university. The personal budget has enabled him to explore the world and has travelled to places like New York, Las Vegas, Sweden and Germany. His budget has also been used for hydrotherapy. Chris says that his

budget has enabled him to have a much better quality of life than he would have otherwise had.

When speaking to other young people and their families, Chris often feels there is a concern that close family relationships will be adversely affected as young people get older and become independent. At first Chris' parents found it difficult, not providing support for him. But this has changed over the years and Chris now believes his relationship with his parents is much healthier and he is able to look out for them, just as they do for him.



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This guide was written by In Control on behalf of Together for Short Lives. In Control is a charity which works for a society that includes everyone equally.

www.in-control.org.uk

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