

Personal Budgets in mental health – a guide for families and carers

About this guide

A Personal Budget is money from a local authority that can help a person with mental illness pay for the social care, services and support they need. The money may be managed by the local authority or may be given directly to the person to spend on agreed services and activities.

This guide is for family and friends who support someone with a severe mental illness who has, or is thinking about applying for, a Personal Budget. It draws on people's real experiences. We have brought these together in this booklet to offer you advice and guidance on supporting the person in this process.

It tells you about:

- Ways to support the person through the process of getting a Personal Budget
- Your role in the assessment and support planning
- Ways to support a person to manage a Personal Budget
- How a Personal Budget might impact on you



In creating this guide, we asked 54 people with a **severe mental illness** about what it was like to get and use a **Personal Budget**. We also spoke to 18 family members of people with a mental illness and 30 mental health practitioners. Each group told us the good and the bad things about getting and using Personal Budgets. They told us that some steps were easy but others were more difficult.

For more information about the study see our website www.rethink.org/personalbudgets

As you read, you can click on the videos to hear about someone who has been in this situation. The words and phrases in **blue** are explained in a glossary on page 10. You can find out more about our study and see more resources on our website.



Personal Budgets are a way of paying for social care support that allows the person to take more control of what help they get. People may be able to get a Personal Budget if it is decided that they need social care support. This is decided by the local authority through an assessment.

To find out more about what Personal Budgets are and how they are different from traditional social care support, go to:

<http://www.rethink.org/diagnosis-treatment/treatment-and-support/personalisation-in-community-care/personal-budgets>

How could a Personal Budget help?

The people we spoke to had different experiences of **Personal Budgets**, but for most family members the support made a real, positive change to their lives as well as in the life of the person they cared for.

Reducing the worry

Caring for someone does not just involve practical tasks. Often it means worrying about someone even when you are not there. Support provided by a Personal Budget can help to reduce this constant anxiety.

Better, more personal support

It can be frustrating for families, as well as those needing support, if services do not quite meet their needs. Personal Budgets can allow a person to tailor their support to better suit them.



Rachel: “It definitely does make you feel, as a carer, that there’s support there for him, and it’s not money you have to be told what to do with, or it’s providing services that are not required.” [Mother]

Beth: “That’s the thing that’s made the biggest difference to my son’s life. And my life, to be honest. I am far less worried about him on a day to day basis because I know he’s got support there that he didn’t have before.” [Mother]

Owen: “It ensures that she has choice, and can do what she wants, so she doesn’t feel frustrated, and as if she is losing control over her life.” [Husband]

Easing the financial pressure

Caring for someone can put financial pressure on family as they may have to pay for activities, travel and other items. A **Personal Budget** may be used to pay for this type of support and make it easier to manage the costs.

Beth: “I think we have better kind of social times together. I mean, he’s coming up this weekend and we’re going out to the cinema. So we have some nice times, whereas before it was more, kind of, stuff that had to be done. I was firefighting.” [Mother]

Rosalyn: “Before [he had a Personal Assistant] we were driving everywhere, wherever he needed to go. We weren’t able to get any money back, so it was taking a big squeeze of money out of us. So we couldn’t really, we were struggling to afford it.” [Mother]

Improving relationships

Caring for someone can put a strain on your relationship. People told us how Personal Budgets had helped the relationship by giving them a break from caring and an opportunity to do something more fun together.



Applying for a Personal Budget

Applying for a Personal Budget can seem like a long and complicated process. Before a Personal Budget will be approved, the local authority will need to see:

1. Whether the person has high enough needs because of their mental illness to qualify for a Personal Budget – an **assessment**
2. Whether the person has a good plan for how they will get the support they need – a **Support Plan**

Families and friends who provide support for the person applying can have an important role in these stages.

Carmen: “They put ‘*My wife supports me around the home.*’ My husband is very particular about personal care. I know he won’t let nobody in on that area, and there’s only me would help him in that. But with cooking or staying safe, anybody else could help; it didn’t necessarily have to be me.” [Wife]

The local authority may ask financial questions to work out how much they expect the person to pay themselves, and how much extra money they will give the person to make sure they get the support they need.

Assessment

In an assessment, the person will have to say what support they need and what they already have. For some people, much of the support they get from day to day is from family and friends. Providing this support can be rewarding. Equally, it can be exhausting and difficult. Some family carers struggle to provide all the support that is needed.

As part of the assessment, you may have to talk about the support you give. You need to be clear and realistic about what support you currently provide, whether you can continue to provide that support in the future, and what extra support you cannot offer.

As long as the person you support is comfortable, it can be helpful to be there during an assessment to help the **support planner** to understand what support you give and whether you expect anything to change.

Marianne: “I can see to her personal needs and I can do her washing, but, when it comes to all the housework and all that, because of my illness I can’t do it and I’m struggling. And I said, if only we could have a few more hours that we can have a cleaner in.” [Mother]

Support Planning

Once a person has been assessed as having high enough needs, they then have to consider what support they want to get and how this will help them. Family and other supporters can again play an important role in helping to think through these decisions.

- **Setting realistic, personal goals** – many people find it hard to set goals for themselves, especially if they have been unwell for a long time. It is easy to make goals too cautious or too ambitious. It can help to think about the wider picture. For example, learning to drive might be a realistic goal but it is useful to think about what happens after – can they afford to buy and run a car? How will it help them? Discussing plans, asking questions and making suggestions can help the person to decide on realistic goals that matter to them.
- **Finding creative solutions** – Personal Budgets give people choice, but it is not always easy to come up with ideas. Families can be a good source of ideas because they know the person well. For example, what has the person enjoyed previously?
- **Considering practicalities** – Does the person need help to make the most of the support? Sometimes families can provide this help, but if you can't, think about what other help can be put in place.
- **Looking ahead** – If the person reaches their goal, or is no longer assessed as having high enough needs, their Personal Budget may be reduced or stopped. If the Personal Budget ends, think about how the person will keep up the progress they made. Will you be expected to offer more help? Will you be able to?

Anne: “My mum’s the one that said to my mental health worker ‘I think my daughter would benefit from doing horse riding, can we get her a hobby.’”



Managing a Personal Budget

There are different ways to receive and manage Personal Budgets.

- Personal Budgets can be a **one-off payment** to spend on an agreed item, or on-going regular payments;
- The **local authority** can manage regular payments so that the person does not look after the money themselves (**managed budgets**);
- The person can receive regular payments into a bank account (**Direct Payment**) so that they can access it to spend on the things agreed in the **support plan**;
- Sometimes a nominated person, such as a family member, can look after the money and spend it on the things agreed in the support plan on behalf of the person (**Indirect Payment**).

Managing money can be difficult for people, but it can also be a good way to help them feel in control and to use the money wisely. Many of the people we spoke to needed some help to manage their Personal Budget, at least to start with. Although most places have organisations that can provide some of this support, many people rely on their family to help them with important tasks:

Geoff: “I know what goes on roughly, but I like to let my wife deal with all the finances because it gives her the feeling that she’s worthwhile. But if there’s a decision to be made we make it together.” [Husband]

Budgeting

It is important for the person to keep careful records of what money they have received and what they have spent. The person may need to show receipts or bank statements to the local authority every few months. Some people struggle to manage this and may need help. However, it can also be a good opportunity to develop money management skills, and some of the Budget holders we spoke to found it helpful to do this themselves.

Employing someone

If the Budget holder uses their Personal Budget to pay for a **Personal Assistant** or **Support Worker**, they may need to find and employ a suitable person, check and sign timesheets and make sure that the Personal Assistant is correctly paid. Unless they employ an organisation to do this for them.

Kirstin: “We have been through different experiences with personal assistants where the tax and insurance has been involved. But my husband’s really good at that sort of thing. We’ve never really had a lot of problems. I think a lot of carers are frightened to take on Direct Payments because of the added burden.” [Mother]

Beth: “The mental health team told me about this organisation who do the payroll. I manage the bank account, the personal assistants phone in their hours, I phone this organisation, they send me the pay slips, and I pay them from the bank account.” [Mother]

Advocacy

Personal Budgets are meant to support a person with a mental health need in achieving their own goals. Some people find it easy to make their own choices and to tell professionals what they want. Other people find this extremely hard particularly if they are unwell at the time. Families can have an important role in making sure that the person gets heard, by:

- being there to give them the confidence to speak;
- helping them to prepare what they want to say before a meeting;
- attending the meeting to support the person if they want it;
- backing them up if they don't get what they think they need at first.



Reviews

Reviews are used to check how things are going and to see if the Personal Budget is helping the person to meet their needs. They are also used to check whether the Personal Budget is still needed. A review may lead to changes in the amount of money or the way it is used. It might involve a special meeting between the Budget holder and the professionals involved in their support. Often they are quite informal and might be part of a regular meeting with the mental health worker. Family members can be invited to these reviews.

Of course, reviews can feel very stressful. They might feel like a test or a way to check up on what the person is doing. People also feel concerned about the support they receive ending or being reduced. Preparing for reviews can help to address these issues and help the person to make the case for the support that they need. Families play an important role in this.

Helping the person to see how things have changed

Many people find it hard to look back at times when things were difficult, but this is sometimes needed to see how far they have come. Sometimes this is easier for the people around them to see.

Marianne: “Even the mental health worker said: *‘I’m amazed at how much you are achieving.’* She said to my daughter, *‘I know you can’t see it, but I can see it and your Mum can see it.’* And then she actually said, *‘Well, yes, when I think back to two years ago, yes, I am enjoying things more.’* So, for her to notice is amazing.” [Mother]

Helping the person to think about problems and find solutions

If things are not going well, it can be hard to find out why and to work out the best way to feel better. If a Personal Budget isn’t helping then it might not be the best way to support them. Equally, it might just need some changes to help the person to manage, for example:

- the Personal Budget could be put on hold if the person is temporarily unable to use it for any reason
- the way a person receives the money could change if they are struggling to manage the Personal Budget
- the amount and type of support could change to help overcome a problem

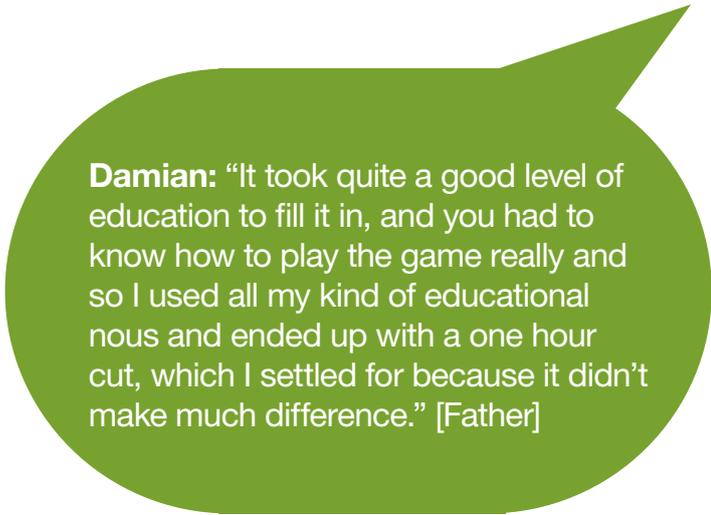
Lisa: “I had [my Personal Budget] suspended...because it was just overwhelming because I was so low and although it’s a separate account, having it keep coming in was a reminder of what I wasn’t doing. I didn’t want all this money when I wasn’t using it.”

Helping the person think about what will happen after a Personal Budget ends

A Personal Budget should end when the local authority thinks that:

- the person no longer needs the support
- the Personal Budget is not helping them to reach their goals, or
- they have already achieved what was agreed in the support plan.

If the Personal Budget has been helpful, it can be hard to know how the person will cope when it is not there anymore. Families can help the person to think about different types of support which are free, or which they can afford for themselves, to help them maintain the improvements they have made.



Damian: “It took quite a good level of education to fill it in, and you had to know how to play the game really and so I used all my kind of educational nous and ended up with a one hour cut, which I settled for because it didn’t make much difference.” [Father]

Helping the person to make their case

Sometimes the mental health worker and the Budget holder might have different ideas about how the Personal Budget is going or what is needed. Most professionals will be good at listening to the person and talking through the differences.

Sometimes the person needs help to make sure that their views are heard and understood. Families can be important in helping them to do this.

Glossary

Below is a list of terms that appear in this guide that are highlighted in blue. You can find a full list of terms we use in all our guides [here](#).

Assessment

Where information is gathered to help the local authority make decisions about what help you need. Often this involves speaking to a mental health worker about your circumstances using a questionnaire or form to record what is discussed.

Direct Payment

An amount of money paid directly to a person to pay for the support that has been agreed. The person spends the money and keeps receipts or bank statements to show the local authority what they have used the money for.

'Direct payments' are just one way that a Personal Budget can be used to meet someone's needs.

Indirect Payment

Indirect Payments are similar to Direct Payments, but the money is given to a nominated individual or put into a trust fund instead of being paid directly to the individual who needs the service. The nominated people or trustees must use the money to arrange the services an individual has chosen to meet their needs.

Local authority

Your local authority or council is the local government that provides services in the area where you live. The local authority is responsible for providing social care services.

Managed budget

A Personal Budget that is managed by someone else, usually the local authority, instead of being given directly to the person.

One-off payment

A Personal Budget which is received just once and which is to be used to buy a specific thing. Usually, this is used because the person has chosen an item which will continue to help them after they have bought it, for example a bike or a computer.

Personal Assistant

Someone employed to help with everyday tasks and activities. They can be a professional, a friend or a family member who does not live with you. Personal Assistants can be employed directly or through an agency.

Personal Budget

An amount of money which the local authority has agreed is enough to help you get the services and support that you need. The money can only be spent on meeting your needs which will be written in your Support Plan. There are different ways to receive and use a Personal Budget: Direct Payment; Indirect Payment; One-off payment; Managed Budget.

Severe mental illness

Severe or serious mental illness including diagnoses such as: major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, post-traumatic stress disorder (PTSD) and borderline personality disorder.

Support plan

A document that describes how a Personal Budget will be spent to help meet individual's social care needs and achieve what is important to them. A Support Plan includes information about daily life, goals you want to achieve, and how the money will be used to make these happen. Support Plans must be agreed by a local authority before the money is made available.

Support planner

A person trained in writing and costing support plans, often called a broker. Support planners can be anybody from mental health workers or members of a local charity to people who have used mental health services themselves in the past.

Support worker

Support Workers are usually employed by a local authority or an organisation and are trained in providing care and support.

Where can I find out more?

This resource was developed from the experiences of people who were getting Personal Budgets, their families and their mental health workers. If you would like to hear more of their stories, go to www.rethink.org/personalbudgets.

Your local authority will often be the best place to get information that is relevant to you. Below are some other resources you might find helpful when thinking about Personal Budgets.

About Personal Budgets and Direct Payments

- www.rethink.org/diagnosis-treatment/treatment-and-support/personalisation-in-community-care/personal-budgets
- www.mind.org.uk/assets/0002/2969/The_Mind_guide_to_Personal_Budgets_for_social_care_2012.pdf

Direct Payments for carers

As well as being used to support people with a mental illness, Direct Payments can also be given to carers to help provide them with support. To find out more about these, try the links below.

- <http://www.carersuk.org/help-and-advice/practical-help/care-and-support/direct-payments/direct-payments-as-a-carer>

Managing money and employment issues

Your local authority may have published guides to help you manage your Personal Budget or Direct Payment.

- www.yor-ok.org.uk/Downloads/Disability/Personal%20Budgets/Direct%20payments%20employing%20a%20PA.pdf
- www.in-control.org.uk/media/16717/08.%20organising%20my%20money%202011%20v1b.pdf

About this project

This booklet was developed by researchers at The McPin Foundation and Rethink Mental Illness. We conducted interviews with people using Personal Budgets, families and mental health workers in four areas of England.

The project was paid for by the Big Lottery Fund, and supported by King's College London and the University of Birmingham. For information about how this research was done, visit our website: www.rethink.org/personalbudgets



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