

THE ROLE OF PERSONAL BUDGETS AND DIRECT PAYMENTS FOR PEOPLE LIVING WITH YOUNG ONSET AND RARE DEMENTIA

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What is a personal budget?

You may be given a personal budget to spend if your local council decide you are eligible for help with any social care and support you need. You can request an assessment from the council to establish your needs. Personal budgets help you to make more decisions about how your support is organised and delivered. Each council in Greater Manchester has its own process to follow in terms of eligibility criteria so it's important that you obtain the correct information and application forms from them.

The amount of money in your personal budget is decided by your local council after a needs assessment to work out:

- what kind of care and support you need
- how much it will cost
- how much you're able to afford yourself



Carers and personal budgets

If you're a carer, you may be entitled to receive a personal budget after having a carer's assessment to see what might help make your life easier. A carer's assessment is free and anyone over 18 can ask for one.

Choosing how to receive your personal budget

You can ask the council to either:

- manage your personal budget for you
- pay the money to another organisation – such as a care provider
- pay the money directly to you or someone you choose – this is known as a direct payment

You can also choose a combination of these options. For example, the council could arrange some of your care but send you the rest of the money. This is often called a mixed package or "mix and match". For more information visit the below website:

<https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/personal-budgets/>

Why could a personal budget be suitable for me?

People with a young onset (under the age of 65) or a rarer form of dementia and their families find personal budgets useful for a range of reasons. Both of these groups may have particular needs when planning support. For example, a younger person may still be in employment or have recently left employment and have school age children. They are more likely to be physically fit and able to enjoy sports. People with a rarer dementia may also be physically able and active in the local community but have language deficits or behaviours which pose a challenge.

Personal Assistants (PAs)

A personal budget can help a person continue to do the activities they enjoy by employing a **Personal Assistant (PA)** to support them. These PAs should have knowledge and experience in working with people with young onset and rarer dementias and be able to provide individualised, flexible and tailor-made support.

The local authority can help to advertise for and recruit PAs, or the budget holder can do this themselves. The person with dementia and their family should be fully involved in choosing their PA. The PA should have information and guidance from the professional working with the family to establish a rapport and set up a detailed support plan for that person.

Examples of activities people with young onset or rarer dementias could do with the help of their Personal Assistant (PA)

- Physical activities such as going to the gym, walking, golf, walking football, cycling, table tennis, swimming.
- Leisure activities such as museums, art galleries, painting classes, singing in a choir.
- Visiting drop ins, pubs and cafes.
- Home based activities such as cooking or baking, shopping, housework and gardening, DIY and car maintenance, life story work.



Here are some quotes from people with a young onset or rarer dementia and their families who have used personal budgets to fund a Personal Assistant (PA):

“The budget has really helped me. I was still working in my family business when I was diagnosed with Alzheimer’s, but I was struggling. My PA has really helped me get my confidence back and helped me focus on what I can do. I go into the office a couple of times a week now and do the bits that I can, and my PA and I do things in the house that I couldn’t do by myself. I’ve taught her how to tile a bathroom!”

Paul, diagnosed with young onset Alzheimer’s disease

“My budget means that I can go to the gym with my Personal Assistant and keep as strong as I can. I have a rare form of dementia which affects my mobility and so keeping fit is crucial. It has really helped my confidence too.”

Colin, diagnosed with a rare familial form of Alzheimer’s disease



“My husband developed really fixed behaviours after being diagnosed with a semantic dementia. He had to do certain things at certain times, such as feeding the ducks or going to the pub. He began to need supervision because other people couldn’t understand why he was doing things like collecting other people’s glasses in the pub and interrupting conversations. Throughout his dementia 3 PAs worked with him and they were brilliant. He saw them as friends, and they did their best to keep him out of trouble. This meant I could relax and get a break.”

Angela, whose husband Peter was diagnosed with a semantic dementia.



“As mum is fiercely independent, having a budget has meant that I’m able to sleep at night and know that she is being taken care of. Once it is set up, it’s easy to control and make payments through a bank account that is solely for the budget. It took a long time to get her agree to have PAs but they persevered and now she looks forward to seeing them. They go out walking or go shopping and then have hot chocolate with cream and marshmallows, mum’s favourite.”

Gabby, daughter of Rhonda, diagnosed with a young onset Alzheimer’s disease

GET IN TOUCH

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