Making personal budgets dementia friendly
A guide for local authorities
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Context

The Care Act (2014) gives people a legal right to access a personal budget to pay for their care and support. This offers a unique opportunity to transform care for local people. Personal budgets not only give people choice and control over their care, but also enable support to be delivered in innovative and cost-effective ways.

Alzheimer’s Society carried out research into personal budgets and the experiences of people affected by dementia. We already know that personal budgets have clear benefits for people with dementia and their carers and are an important tool for giving people with dementia independence. Our recent research found examples of good practice across the country.

However, there were many situations where people affected by dementia were being let down by an inflexible and unresponsive personal budgets system. We concluded that there are some key issues local authorities need to address in order to make the personal budgets process dementia friendly.

The guide and charter

This guide contains easy and cost-effective actions local authorities can take to improve the experience of people with dementia and their carers. These actions have been developed following input from people affected by dementia, local and national government and the health and social care sector.

We have also created a charter for local authorities to adopt and follow to help make personal budgets dementia friendly (see page 13). The charter sets out a number of principles that will make personal budgets more accessible to people affected by dementia.
Our research into personal budgets

What is a personal budget?

A personal budget is defined as:

Money that is allocated to you by your local council to pay for care or support to meet your assessed needs. The money comes solely from adult social care. You can take your personal budget as a direct payment, or choose to leave the council to arrange services (sometimes known as a managed budget) – or a combination of the two.

An alternative is an individual service fund, which is a personal budget that a care provider manages on your behalf.

What type of personal budget works best for people with dementia?

Selecting the right type of personal budget will depend on a person’s preferences, situation and desired outcomes.

Our study of local authority data in England showed that most personal budgets given to people with dementia are managed budgets and very few receive direct payments.

However, direct payments enable the person to have flexibility and freedom of choice, ensuring the care they receive is person-centred. Carers of people with dementia who have direct payments often talk about the positive impact this type of personal budget has had on the person they care for.

Independent Service Funds also offer choice and control, but are not widely available.

I now get direct payments for mum’s care. Before this it was all dealt with by social services as I felt I didn’t want the extra work but it’s so easy and you can choose the care agency you want.

Carer

What makes a personal budget more accessible to someone with dementia?

To identify the barriers for people with dementia in accessing personal budgets, we carried out several areas of focus group research and commissioned Public Consulting Group UK to conduct an audit and evaluate the information available to people with dementia relating to personal budgets. They contacted 60 local authorities – more than a third of all local authorities with adult social services responsibilities in England.

This research identified the following areas that need addressing if personal budgets are to be more accessible to people with dementia and their carers:

- Communication
- Process
- Finance
- Understanding dementia
- Understanding the personalisation agenda

I looked at respite but having visited a care home I knew my husband was not ready for that – although he has no language, he is still very active. We tried a day centre but it made him very anxious, so my excellent social worker organised direct payments for 10 hours a week to allow me time to myself. It has made such a difference to my quality of life.

Carer
Making personal budgets dementia friendly

Knowledge and accessibility

Frontline local authority staff we spoke to had variable levels of knowledge about personal budgets.

– Nearly 60% of local authorities did not provide information related to personal budgets that included specific references to dementia or useful local signposting.

– 20% of local authorities chose not to provide any information, despite being pushed to just provide general advice.

– In 7% of local authorities, staff actively deterred the enquirer from personal budgets and direct payments, citing how ‘complicated’ the process was. One member of staff even said that they ‘don’t recommend personal budgets for people with dementia’.

Communication

Giving people affected by dementia the information they want and need

People with dementia and their carers need clear and concise information about the personal budget options available to them. This will help them to access and use personal budgets as early as possible. However, we found that often people affected by dementia do not know about personal budgets early enough, if at all.
Barriers to accessing online information

In general, local authorities provide information about personal budgets online, which can be problematic for people with dementia. People with dementia told us that they can struggle to use the internet, especially as the condition progresses. Some did not have access to the internet at all.

Yet our research found that only one in 10 local authorities were prepared to email information about personal budgets and only 13% sent information out in hard copy.

Our research found that it was hard to find information on personal budgets on 20% of local authorities’ websites. Often, the only way to find information about personal budgets, direct payments and personalisation was to use these as search terms across the council’s entire site. This is obviously difficult for someone with no knowledge of this issue.

Being willing to adapt information and being flexible about how it is delivered is key to making the personal budgets process dementia friendly.

What people affected by dementia want to see

Carers told us that they need information about personal budgets in a simple format, using straightforward language. Information should be tailored to each person’s situation, based on what is important to them, and presented in bite-sized chunks with an obvious link to where they can go to for more information. Ideally, there should be an option to receive information face-to-face.

Only one in 10 local authorities were prepared to email information about personal budgets

Actions for local authorities

✓ Adapt information so that it is accessible for people with dementia. This includes being mindful of the font used and the size of the text. More information about dementia friendly language can be found at dementiavoices.org.uk

✓ Provide information in various formats, so you can email it or post hard copies.

✓ Offer people the option to meet face to face to discuss the process. Voluntary organisations, such as Alzheimer’s Society, may be able to take on this responsibility.

✓ Provide people with the name and telephone number of a person they can contact to discuss the personal budgets process, or find out the status of their assessment.

How Alzheimer’s Society can help you

– We can help you involve people with dementia and their carers in reviewing your processes and printed materials to make sure they are accessible.

– We can provide guidance on creating dementia friendly publications.

– We can supply printed and online resources for people with dementia and carers. Alzheimer’s Society Dementia Guide contains information on personal budgets.
People with dementia need clear and simple assessments, systems and processes to access personal budgets. National support charity InControl suggests that to produce the best results, the personal budget processes should be:

- **User friendly** – simple and straightforward for everyone involved
- **Transparent** about how much money a person is entitled to and how they can spend
- **Putting the person in control** of their own solutions to their own needs
- **Engaging** for the person taking control of a personal budget, as well as their families – often people will need help and support to plan and make decisions.

**Timing and transparency**

Councils are legally required to ensure that their personal budgets processes reflect some of the principles listed alongside. The Care Act states that local authorities should make their personal budget allocation process transparent to all people. This means they are required to make it available to everyone, including people with dementia, and ensure people understand how it has been calculated. It also requires local authorities to provide an indication of how much the personal budget will be upfront, so that people have time to plan for their care.

However, the experiences of people affected by dementia indicate that councils do not have transparent personal budget processes. They were found to be slow, with delays in completing assessments; and they were failing to provide upfront indications of personal budgets. People told us they were also frustrated by a lack of clarity over what a personal budget can be spent on.

These issues are resulting in significant numbers of people beginning the personal budget process but then withdrawing once they are informed of how much they will have to contribute themselves. This is because, like other community care services, the money provided is means tested so their value depends on a person’s income and savings as well as their care and support needs. Carers don’t want their first conversation to be about financial thresholds, but need to be aware at an early stage that they may be asked to make a financial contribution.

**Involvement, engagement and making care person centred**

The experiences of people affected by dementia indicate that local authorities are failing to engage them in the process and ensure they are involved in decisions. This has to change.
Resources, organisation and adaptability

The experiences of people affected by dementia indicate that councils do not have well-organised or well-resourced systems to support the personal budget process. The roles and responsibilities of staff involved in the process are often confused and there can also be a lack of agreement on how much time support planning should take, with pressure from senior colleagues to get the work done. There has also been a recent shift in many local authorities towards self-assessment, usually online or via telephone, which may be challenging to some people with dementia.

Local authorities often treat the personal budget process as a one-off, as opposed to an on-going process. Dementia is a fluctuating condition. It can deteriorate fast, which means people may need extra support quickly. This can often require adjustments to be made to a personal budget.

What people affected by dementia want to see

Carers told us that systems need to have a built-in ‘rapid response’ to deterioration of a person’s condition. There should also be more regular reviews. This could be carried out by a voluntary sector organisation, such as Alzheimer’s Society, who can update the council’s personal budget team when necessary. The process needs to be easy to follow so that carers and people with dementia feel confident and able to interact with it. This will help ensure their voices are heard and they receive the personalised care they want and need.

I can never get in touch with anyone to answer my questions about how his personal budget can be spent. I wasn’t involved in the Care Plan Assessment so I’m not sure where social services got their information from. I feel like I’m just muddling along, the process has been so confusing.

Joy, who looks after a personal budget for her husband

Actions for local authorities

- Make sure the person with dementia and their carer understands the process of personal budgets and what will happen at each stage.
- Carry out regular reviews for people with dementia as their needs can change rapidly.
- Ensure people with dementia know from the outset that the financial assessment is means tested.
- Ensure people with dementia know from the outset that personal budgets can be a time limited intervention. If a personal budget is time limited, the length of the intervention should be communicated clearly at the start.
- If a person is deemed ineligible for a personal budget they should be signposted to appropriate and affordable services in the local area.

How Alzheimer’s Society can help you

- We can provide information and support to people with dementia through local Alzheimer’s Society services at alzheimers.org.uk and via our helpline 0300 222 1122.
- We can signpost people with dementia and carers to other relevant local services.
- We can enable you to help people with dementia and carers to search for local dementia services via Dementia Connect at alzheimers.org.uk/local-information/dementia-connect. You can embed our Dementia Connect widget free of charge onto your local authority website.

Carer from Nottinghamshire

It’s not just about personal budgets but about all the practical information that you need to know, particularly when someone is newly diagnosed with dementia. Information about universal services and practical preventative provision, such as disabled bus pass, benefits advice, Carers Hub, dementia cafes. It is also important for carers to understand why they might want to know this information. It isn’t always obvious. Case examples help.
Making personal budgets dementia friendly

If we are going to ensure that personal budgets allow a person with dementia to pay for the care and support they need, adequate funding from central government is essential.

The amount that the local authority calculates for the personal budget must be sufficient to meet the person’s needs. This is a legal requirement under the Care Act.

The National Audit Office has found that some councils are finding it challenging to make the personal budgets process person-centred, which is crucial for people with dementia. They found some local authority’s approaches have been constrained by reduced funding and that some people are receiving non-personalised services through block contracts with service providers. Additionally, some services may be less flexible and require the person to fit into the service rather than the service fitting around their needs, routines and preferences.

Budget caps and higher charges

Some people’s personal budgets are being capped in line with prices councils are charged for services. Yet individuals are being charged higher prices, so their budgets are not covering the services they need. Alzheimer’s Society is concerned that the Health and Social Care Act will set personal budgets at the local authority care home rate, which is often not enough to pay for dementia services. For example, one local authority proposed capping the cost of care at home at the cost of a residential care placement. The local authority withdrew this proposal following warnings that it could force more people into residential care.
We are also concerned that the Health and Social Care Act will continue the abuse of top-up payments to make up the difference between the cost of care and support and a person with dementia’s personal budget. There is a difference here between people choosing a more expensive service and using a top up to pay for it, and the council restricting choice through budget caps.

**What people affected by dementia want to see**

Carers of people with dementia told us that they did not want their first contact with Adult Social Care Department to start with a question about their finances. People want to have the benefit of the care assessment first, without finances coming into play. Alzheimer’s Society is also aware of instances where people with dementia have gone into debt as a result of being unaware that their personal budget is not backdated to the start of their engagement with a service. It is important to make this clear from the outset and that assessments happen quickly and efficiently to reduce the risk of this misunderstanding occurring. There is also a lack of awareness of what people can do if they do not agree with the decision on how much money they have been allocated. The option for appeal should be promoted and made accessible to people with dementia.

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**Actions for local authorities:**

- Explain clearly and carefully how you decide on the amount of money that a person will receive.
- Take into account the person’s reasonable preferences to meet their needs as detailed in the care and support plan, or support plan.
- Inform people from the outset that their personal budgets will not be backdated to when they first contacted the service.
- Review the appeals process for people wanting to contest a decision on how much money they are allocated. The appeals process should be promoted and made accessible to people with dementia.

**How Alzheimer’s Society can help you**

- We can provide localised feedback on how well the system is working for people with dementia and carers at the moment, and support you to develop solutions to current barriers.
- We can work with you locally to review your appeals process and ensure that it is timely and accessible to people with dementia and carers.

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My borough is in crisis, they don’t have enough resources and the new living wage means that the gap in pay for staff might have to be met by the council reducing vital funding for personal budgets. I’ve recently lost my job which has added to the stress of the situation.

Robert, who was awarded a personal budget for his wife’s care
Making personal budgets dementia friendly

Confidence and attitudes

Previous Alzheimer’s Society research in 2011 has found that professionals are concerned about whether direct payments are suitable for people with dementia, particularly when people are already struggling with the condition. In some cases, these concerns are valid. But evidence also shows that professionals can be over-cautious about direct payments.

The research identified professionals’ lack of knowledge, confidence and negative attitudes as barriers to personal budgets for people with dementia. The Mental Health Foundation found that the negative attitudes of staff can put people with dementia and carers off personal budgets. We found examples of this when we were told by one local authority that ‘direct payments are quite complicated, we don’t advise them for people with dementia’.

Underpinning these issues is a lack of understanding and knowledge about dementia and how people with the condition can engage with the personal budgets agenda. This concern was raised by a number of carers we spoke to. Also, professionals may not have a full understanding of the agenda, including the difference between the types of personal budgets, personal health budgets and personal independence payments.

Understanding dementia

Improving dementia awareness among health and social care professionals

Attitudes of health and social care professionals, and a lack of specific knowledge, can be a barrier to personal budgets for people with dementia, in particular direct payments. It is vital that professionals fully understand how to include people with dementia and carers in the personal budgets system.
What people affected by dementia want to see

People affected by dementia told us that they want local authority staff to be knowledgeable about dementia and how it affects people’s lives and social care needs – especially in relation to the personalisation agenda. This will ensure people with dementia are given accurate information in an appropriate way, and their specific needs are taken into consideration.

Actions for local authorities:

- Arrange for frontline staff in local authorities to receive training on dementia, especially in relation to the personalisation agenda and the personal budgets process. This will ensure people with dementia or their carers are communicated with appropriately and are provided with accurate information.

How Alzheimer’s Society can help you

- We can provide training for your staff to improve their knowledge and understanding of dementia – from those working on your helpline, to frontline staff involved in assessments.
- We can arrange Dementia Friends sessions, which are free of charge and will help staff gain an awareness of dementia and how to be dementia friendly. More information about Dementia Friends can be found at dementiafriends.org.uk

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Our social worker didn’t understand my aunt’s dementia and her needs. I had to fight to be able to input into the process. The second time. I got a great social worker and was awarded a personal budget which I used to employ personal assistants via a continuing care budget. Having these assistants changed my aunt’s life as it allowed her to stay at home and do the things she enjoyed.

Cath, who had to apply twice for a personal budget
Understanding personalisation

Making sure professionals have the knowledge they need

People with dementia and carers need to be able to speak people who have in-depth knowledge of personalisation in order to make the right decisions about personal budgets.

Staff awareness

Our research found concerning evidence of poor staff awareness of personalisation. In two local authorities, advisers referred to personal budgets and direct payments as ‘personal health budgets’ and one adviser said that the enquirer needed to search on the local authority website for ‘personal independence payments’. Another adviser asked our researcher ‘Do you mean personal independence payments?’, referencing a different type of welfare support. Confirming this, one carer told us that ‘Even the social worker didn’t know anything about personalisation’.

What people affected by dementia want to see

Carers of people with dementia told us that they want to be able to speak to people who are knowledgeable about the personalisation agenda, especially in relation to dementia. They need to be confident that the information they are receiving about personal budgets is accurate so that they, and the person with dementia, can make the best possible decisions – for example deciding on which type of personal budget to go for.

Actions for local authorities:

✓ Arrange for frontline staff to receive training on personalisation and its different aspects, including the different forms of personal budgets. This will ensure people with dementia or their carers are provided with the most accurate and appropriate information.

How Alzheimer’s Society can help you

– We can provide training for your staff to improve their knowledge and understanding of dementia and personalisation.

Case study: Nottinghamshire County Council, innovate practice for delivering personal budgets for people affected by dementia

Nottinghamshire County Council worked with Alzheimer’s Society to produce a leaflet about personal budgets for people living with dementia.

The dementia-friendly leaflet is clear, concise and accessible, outlining what people should expect from the personal budgets process and where they can go for more information and advice.

The council have also produced a Care and Support Services Directory that references personal budgets and includes a case study of someone with dementia using a direct payment.

Download the leaflet and directory at nottinghamshire.gov.uk
Dementia-friendly personal budgets charter

We have developed a set of principles that we believe will ensure personal budgets work effectively and improve the lives of people affected by dementia.

We want every local authority to sign up to these principles and demonstrate their commitment to dementia-friendly personal budgets.

We want every person with dementia to have choice and control over their lives through their personal budget.

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1. Communication

We co-produce relevant, easy-to-find information about personal budgets with people with dementia.

We give people the opportunity to prepare for the personal budget assessment and support planning before the process begins.

We always explain all the available methods for receiving a personal budget, so people can choose the one that best suits their needs.

We will offer people affected by dementia real examples of how personal budgets could help people to live well with their condition.

2. Process

We always explain clearly and carefully how we decide on the amount of money that a person will receive.

We will ensure that the process – from initial assessment to giving a person their personal budget – is timely and that any changes to packages are processed as simply and quickly as possible.

We train all our care and support planning staff to have consistent person-centred, outcomes-driven conversations about how personal budgets could be spent.

We always explain how a Direct Payments Support Service can help to manage a direct payment, and put people with dementia in touch with a fit-for-purpose, dementia-friendly provider if they want one.

3. Understanding dementia

We collect robust data on the uptake and outcomes of personal budgets for people with dementia to help us continuously improve our services.

We will work with people with dementia to ensure that our personal budget process meets their needs.

We train all of our staff involved in care and support planning to understand dementia, personal budgets, fluctuating needs, person-centred risk and mental capacity.

We have developed a wide range of dementia-friendly support in our area and we keep our staff continually informed about new services.

4. Understanding personalisation

We train all of our staff involved in care and support planning in the personalisation agenda so we can ensure they are providing accurate and appropriate information.

We audit and review our performance and provide opportunities to share best practice between teams.

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How can local authorities demonstrate their commitment?

✔ Adopt our dementia-friendly personal budgets charter. 
Email stakeholderrelations team@alzheimers.org.uk to make your pledge.
Alzheimer's Society website has lots of useful information and factsheets for staff to learn about dementia and how it affects people.

To find out more visit alzheimers.org.uk and search:
- Personal Budgets factsheet
- Talking point
- Dementia Guide
- Dementia Connect (dementia services directory)
- Dementia Friends

or call our national helpline on 0300 222 1122

Other resources
- The Dementia Engagement and Empowerment Project: Includes guidance on dementia-friendly language at dementiavoices.org.uk
- Think Local Act Personal (TLAP) Personal Budgets Minimum Process Framework thinklocalactpersonal.org.uk
- Dementia Action Alliance dementiaaction.org.uk

If you are keen to explore any of the options outlined in this guide, please contact stakeholderrelationsteam@alzheimers.org.uk for further information.

1. Getting personal? making personal budgets work for people with dementia Alzheimer’s Society, 2011
2. thinklocalactpersonal.org.uk
Registered charity number 296645.