Dementia and self-directed support

Information for people living with dementia, their family and friends.

This information leaflet has been produced for people living with dementia and their family carers. It is one of a range of information and resources from the Mental Health Foundation’s Dementia Choices project.

Dementia Choices was set up to explore self-directed support for people living with dementia and their family carers. Throughout the project we found that there was a very low level of awareness and understanding of self-directed support among people living with dementia and their family carers.
What is self-directed support?

1. Self-directed support is a new way to regain and remain in control of your life.

Self-directed support enables people living with dementia (and their carers) to have more freedom and choice about the social care services you receive.

- You can benefit from more flexible local support, which is paid for by social services.
- Self-directed support is for anyone who already gets services paid for by social services. It is also for anyone who is eligible for social care from social services.
- Self-directed support is different because you can decide how to spend the money from social services. You choose the support which is right for you to help you live the life you want.

2. Self-directed support is a new personal flexible system.

In the previous system of social care individuals were rarely told how much money was being spent on the services they were receiving or had the opportunities to decide how it should be spent. The system often wasn't very flexible or open.

Self-directed support gives people living with dementia power to decide how to spend the money or 'budget' that has been allocated to meet their social care needs.

Social services often spent this money on traditional services such as day centres or home care services.

You can now be much more flexible and creative with the use of social services money allocated to you. This money is called your ‘personal budget’. You may also hear it being called a ‘direct payment’. With this money you can choose the right support to live the life you want.

You can also get assistance from the local authority or other organisations to put support in place for you to manage these arrangements. If you have difficulties deciding how to spend the money someone you trust, like a family member, could help you decide or manage the money for you.

Here is a short list of things other people living with dementia said they would like help to achieve with self-directed support:

- ‘Transport to get to the pub’
- ‘Go out and meet friends for lunch’
- ‘Choices over day to day living’
- ‘Extra care’
- ‘A holiday’
- ‘To go out with my family’
- ‘Someone to talk to’

3. Self-directed support is a new system of social care.

Your local social services should have someone you can talk to about this. You may also want to talk with your family, carers, friends and other people who know you well before deciding if self-directed support is right for you and how they may help you with it.

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How to get self-directed support

In order to get self-directed support you need to be eligible for social care.

If you have not had one already, ask for a community care assessment. During this assessment, ask your local social services about self-directed support and tell them you would like to be assessed for this support. If you are receiving services tell the local social services you would like to be assessed to manage your own care.

They may send you a self assessment form or the assessment may begin over the phone. You can get help from someone who knows you well to fill out the form or fill out the form yourself. You can complete the form with your social worker (if you have one). Someone should come and talk to you (and if possible anyone else involved in your daily life) face to face about your needs.

If you have a person caring for you then they should get a carer’s assessment at the same time to make sure that what they do for you is properly taken into account. Your carer may be entitled to receive self-directed support to help them too.

Having a diagnosis of dementia does not automatically make you eligible for self-directed support.

The local authority need to be sure that you are capable of managing your own care or that there is someone trustworthy who can do this on your behalf. Talk to your local social services about eligibility for self-directed support.

Finally, self-directed support is a choice, it should not be forced upon you. You can still have social services delivered in the traditional way if you prefer.

When I used my personal budget to pay to see the game I meant a football match - not a safari!
Support and information

Social services

If you require specific information or support about self-directed support where you live please speak to your local social services.

Mental Health Foundation

This information was produced by the Mental Health Foundation’s Dementia Choices project. To find out more about the Mental Health Foundation’s work on dementia please call the Mental Health Foundation on 020 7803 1100 or go to our website at www.mentalhealth.org.uk/dementiachoices.

Alzheimer’s Society

For general information or to request a factsheet about Direct Payments please call the Alzheimer’s Society helpline on 0845 300 0336. A Direct Payments factsheet is also available online at: http://www.alzheimers.org.uk/factsheets

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