



Taking charge

- a short guide to self-directed support
for people with dementia and their carers

This booklet on Self-Directed Support is for people with dementia, their families, friends and supporters. Professionals should refer to the latest Scottish Government guidance on operating self-directed support schemes which can be found at www.selfdirectedsupportscotland.org.uk

Acknowledgements

Alzheimer Scotland is grateful to the Scottish Government for the funding to enable this booklet to be written, printed and distributed.

Forthcoming legislation

The Scottish Government wants to change the law on direct payments and make a new law about self-directed support. To do this, it has introduced a Bill into the Scottish Parliament. The Self-directed Support Bill is expected to receive Royal Assent in early 2013. If the Bill is successful in reaching its Royal Assent then the next stage will be the commencement of the legislation. Commencement is the date when the legal duties and powers in the Act come into force.

Support from Alzheimer Scotland

Alzheimer Scotland has appointed three Self Directed Support Project Workers who provide support and assistance to people with dementia and their families to access and use Self Directed Support:

Ayrshire, Dumfries and Galloway Service

Lorna Sommerville
Mobile: 07780 477189
Email: lsommerville@alzscot.org

Renfrewshire and East Renfrewshire Service

Derek Oliver
Tel: 0141 887 4902
Mobile: 07791 168480
Email: doliver@alzscot.org

Dundee and Perth Service

Jewels Lang
Tel: 01738 215101
Mobile: 07786 237410
Email: klang@alzscot.org

People experiencing problems with accessing SDS may also contact:

Yvonne Stewart
Development Manager
National Self Directed Support Pilot
Alzheimer Scotland
81 Oxford Street, Glasgow G5 9EP
Tel: 0141 418 3930

Introduction

Imagine someone said they will pay for you to have a holiday, but you can only take it in the middle of January, along with complete strangers, at a resort you don't want to go to. You also won't be able to do any of the activities you usually do on holiday. Oh, and, by the way, you are expected to make a financial contribution towards the cost. Would you still want it? Would you think "It's better than nothing - I really need a holiday" or "It's not worth having - no thanks"?

While this scenario is a bit exaggerated, it is not too far from the actual experience of many people with dementia and their families who receive support and services through their local council's social work department.

Traditionally, people have been offered little choice over both the **kind** of support provided and the **time** it is delivered. They also haven't been told how much their care and support actually costs, apart from what they are asked to pay themselves.

There are other options available which could give people more flexibility, choice and control over the support and services they get to help them live at home more independently. These options all come under the term **Self-Directed Support**, which is not the name of a particular type of service, but is a way for individuals to work with the social work department, other organisations and paid workers to put together a package of care that suits their needs and the way they want to live their lives.

This leaflet explains how self-directed support works so you can decide if it could be for you.

What is Self-Directed Support?

Self-directed support is available to most people (including people with dementia) who have been assessed by a social worker or other professional as needing help from social work and/or housing. It allows you to plan and organise your own care in ways that suit you and to fit in with other forms of support you already have - from family members, friends and neighbours.

Getting an assessment of your needs

Most of the support provided to people with disabilities and long term illnesses living at home is given by family members, friends and neighbours. However, there is also a wide range of community care services available through health and social work services, all aimed at helping people stay independent and in their own homes.

Community care services include practical help and support at home, personal care, day care services, short-term breaks/respite care, counselling, advocacy and specialist health services such as support from a community mental health nurse.

To get these services you must first have an assessment of your needs. This will usually be carried out by a social worker or other professional who will talk to you, and your main carer if you have one, about the sorts of day-to-day things you need help with, how your illness affects you, whether your home needs any alterations or equipment to help you live there, and so on. After the assessment, you and the person who carried it out will agree a personal care plan which sets out how your needs can be met.

If you are not already receiving any services, but feel that you could benefit from support, contact your local Social Work Department and ask for a community care assessment. Your GP can also refer you for an assessment if you prefer. If you are already receiving support services and would like to discuss self-directed support, you should also contact the social work department.

Once your care plan has been agreed, the social work department will normally then tell you what services they will provide and how much you are expected to pay. If you need services for which there is a charge, you will be asked to agree to a financial assessment (means-test) to work out how much you may have to contribute towards costs.

Some services are free of charge, such as personal care for people aged 65 and over and nursing care for anyone who needs it, but there may be a charge for other services such as shopping and cleaning.

You can then, if you want, agree to receive services direct from the social work department, at the times and places they specify. But what if you don't want that?

Bob and Mary's story

Bob was diagnosed two years ago with Alzheimer's disease, although he'd probably had the symptoms for a good while longer. Mary can't leave him alone for any length of time but she needs a break from caring. She asks for a community care assessment and they are offered a place for Bob two mornings a week at a local day centre. They accept the place although Bob says he's not keen on going and Mary wonders how she'll get him up and ready in time for the transport to pick him up on those mornings.

For years, Mary had a regular night out at the Bingo with her friends but hasn't been able to go for months because of Bob's health. It would really give Mary a boost to be able to get back to the Bingo and it will help her stay in touch with her friends. If Mary and Bob were given the sum of money it would cost to send Bob to day care, they could use it to pay for a worker to come to the house to be with Bob while Mary went out. The worker could also support Bob to do things he'd like to do - take the dog for a walk, go to the pub for a pint, work in the garden, or play cards.

Self-directed support is aimed at helping people like Bob and Mary to live their lives as independently as possible, in ways that fit their needs, not the needs of the organisation providing the service.

How does Self-Directed Support work?

If you have been assessed as needing community care services, your social worker or other care worker can organise any services for you - things like meals on wheels, a support worker, attendance at a day care centre, personal care to help you get dressed or go to bed, help with preparing meals, and so on. This arrangement might suit you, but there are other options and your social worker or care manager has a duty to explain these options to you.

Instead of the social work department arranging your services and paying for them, they can give you the money that would have been spent on these services. You can then use this money to pay for the support you need, at a time and place that suits you. This option is called a **direct payment**. You can use your direct payment to:

- buy support from any service provider such as a private care agency or a voluntary organisation; or
- employ someone as your personal assistant; or
- buy services from your local authority if they sell their services.

You can also use your direct payment to buy equipment to help with mobility or other needs.

Although you can decide how and when you want to spend the money, the services or support you buy must be aimed at meeting your assessed needs - you can't spend the money on something else.

You can also decide to have a mix of services - some provided directly by social work and some which you arrange and pay for yourself.

Some local councils are trying another way of giving people more control over their own support by allocating each person an **individual budget**. The council tells you how much you have available to spend and you can then arrange your own support services, without having to manage the money yourself. The council (via your care manager or social worker) will act as a broker. Your individual budget may be made up of money from many different funds to help you meet different needs, perhaps including health and disability benefits. Not all Scottish councils are offering individual budgets yet so ask your social worker if this is available where you live.

Contracting with an agency or voluntary organisation

You should be able to find local agencies in the phone book under *Home Care Services, Nurses Agencies & Care Agencies, Nursing Agencies, or Home Help & Carers*. The social work department may be able to give you names of agencies in your area, or someone may recommend an agency to you. All organisations providing personal care have to be registered with the Care Commission, the national agency responsible for regulating and inspecting care services in Scotland.

When making your arrangements in this way, you should think about the tasks you expect the staff to do and the way in which you would like them done.

For example, you may want a service at a particular time of day or want an allocated worker who will provide most of the care required. Let the care agency know what your expectations are.

“Using an agency covers sickness and holidays. We also have very little in the way of paper work as the agency employs the staff.”

You should also check other terms and conditions such as:

- what the price quoted includes - some agencies add VAT on top or charge extra for travel costs
- what insurance cover does the agency have for their workers and the people they are supporting
- what training the staff have had
- what happens if you have to cancel the service suddenly
- what happens if the usual worker is on holiday or off sick?

Employing your own personal assistant(s)

This option gives you the greatest choice and control over your services. For some people, the thought of being an employer may cause worries as it also carries the most responsibilities. However, many people who already receive direct payments have found this to be a successful way to arrange their services and find that they run smoothly, once systems have been set up.

Your local support scheme (see *Managing your own support and funding* section below) may offer training, support and payroll services which help with the tax and National Insurance aspects of being an employer. There is also a national New Employer’s helpline: Tel 0845 60 70 143 (lo-call rate) or Textphone 0845 602 1380. The Scottish Personal Assistant Employers Network can also offer support to employers of personal assistants. See *Further help* section below.

Buying equipment

Self-directed support can be used to buy equipment or adaptations that would otherwise have been provided by social work departments. If you are given a direct payment to buy equipment, it is very important that you get advice to make sure that the equipment you buy is safe, suitable and cost effective. Your local occupational therapy service or nearest Disabled Living Centre can advise on suitable equipment and may have demonstration models you can look at. Your social worker will be able to give you information about local sources of advice on equipment.

If you buy equipment, you will be responsible for arranging its maintenance.

Managing your own support and funding

To get self-directed support, you must be able to arrange the services and manage the funding process yourself, or have someone who is authorised to manage it for you, such as an attorney or guardian. Even if someone else manages things for you, you will still be free to say how you want your funding spent.

There is a support organisation in each local council area providing information and help for people who choose self-directed support. If you would like more information about this, ask the social work department for the name of your local support organisation. You can also find contact details on the Internet at www.selfdirectedsupportscotland.org.uk

If the social work department decides you are not able to manage self-directed support, they must explain their reasons in writing. If you disagree, you can use the local authority complaints procedure. You cannot be refused self-directed support just because you need help to manage it now or because you may need help in the future; social work should consider what help would enable you to manage it.

Dealing with emergencies

Whatever arrangements you make, they can sometimes break down because of staff illness or other emergencies, so it is important to have a back-up plan in place. You should tell the social work department about your back-up plan so they know you will not be left without support if you need it. If you employ your own personal assistant, your back-up plan could involve making arrangements with an independent agency to provide emergency cover. If you get care through an agency, you should ask what their back-up arrangements are.

Uptake of Self-Directed Support

The Scottish Government gathers information each year from local councils about the numbers of people receiving self-directed support. These figures show that few people with dementia and their carers are receiving support in this way. There could be several reasons for this low uptake:

Lack of awareness

Many people don't know there are other options available to them. Your social worker must tell you that you have the option of receiving self-directed support, particularly in the form of a direct payment. Even if you can't manage a direct payment yourself, if someone has power of attorney for you or guardianship, they can help you. You should still be able to say what support you want.

“Nobody told me anything. I had to go through the Yellow Pages trying to find some kind of care for my mother. It was only by chance that a friend told me about an event she'd been to where direct payments were mentioned.”

Concerns about becoming an employer

Many people would like greater flexibility in their care arrangements or dislike the experience of having different support workers turning up at different times. This can be particularly unsettling for people with dementia. Employing a personal assistant can provide continuity but it can be daunting being an employer. There is help available to would-be employers.

“To begin with, I thought the paperwork might be a bit complicated, but it's fine once you get used to it. I've had a lot of help from our local Direct Payments Support Agency who gave us advice on being an employer and keeping everything right.”

Concerns about the time needed to manage self-directed support

This is a particular issue for carers who have enough to do without taking on additional responsibilities and more paperwork, but being in greater control of services may well save time and stress.

“My mother doesn't want strangers helping her to bathe or get dressed. Direct payments allow me to buy help with housework so I can provide the personal care my mother needs without having to do all the cooking and cleaning as well. I work full time, but I can now also pay someone to check my mother is OK while I'm at work.”

Are there any restrictions to Self-Directed Support?

- Self-directed support is only offered in place of services that the social work department assess you as needing. It cannot be offered to people who are assessed as not needing any services, or as a way of meeting needs that social work are not prepared to meet.
- Each local council has its own 'eligibility criteria' to decide who can get services. You can ask your social worker to give you information on this.
- In most cases, you cannot use self-directed support to pay certain 'close relatives' who live with you to provide care. However, the local council can exercise discretion to allow this, if it is satisfied that paying your relative is the best way to meet your needs.
- In most cases, you cannot use self-directed support to pay for services which the NHS has duty to provide. If you employ a personal assistant, he or she may be paid to carry out some health care tasks rather than you receiving these from a stranger.
- You cannot use self-directed support to pay for permanent residential care, although it can be used for short stays of less than four weeks at a time.
- You must have a bank account for the money you receive. If you don't have one, you can ask for help to set one up. You, or your representative, will also need to write down how you spend the money. Lots of people get a book-keeper to help with this.

Will getting Self-Directed Support affect my benefits?

Self-directed support should not affect any state benefits you receive. However, if you pay a family member to support you, it may affect any benefits they receive and they may have to pay tax on what you pay them, so take advice on this from an independent welfare rights service or your local Citizens Advice Bureau.

When do I have to decide about Self-Directed Support?

If you are still thinking about having self-directed support, or have decided you want to use a direct payment or individual budget but have not yet had time to arrange your own services, you should not be left without the services you need. You may need to have services arranged by the social work department until you are able to put your own services in place.

Getting help with managing Self-Directed Support

Your social worker (or the freephone 24hr Dementia Helpline on 0808 808 3000) can give you details of local support services and organisations offering advice, information and services, like help with recruitment and payroll.

Scottish Personal Assistant Employers Network (SPAEN)

Suite G.4, Dalziel Building, 7 Scott Street, Motherwell ML1 1PN

Tel: 01698 250280 E-mail: info@spaen.co.uk Website: www.spaen.co.uk

SPAEN can guide you through the process of recruiting a personal assistant, becoming an employer, and making sure that you comply with your legal responsibilities.

HM Revenue & Customs

New Employer Helpline 0845 60 70 143

Monday-Friday 8.00am-8.00pm, Saturday-Sunday 8.00am-5.00pm

Text phone: 0845 602 1380 (for employers who are deaf or hard of hearing)

Website: www.hmrc.gov.uk/employers/new-emp-telephone.htm

Self-Directed Support Scotland

(formerly Scottish Consortium of Direct Payments Support Organisations)

c/o Glasgow Centre for Inclusive Living

117-127 Brook Street, Glasgow G40 3AP. Tel: 0141 550 7459

Email: sdsscotland@btinternet.com Website: www.sdsscotland.org.uk

Useful reading

The Scottish Government has set up a website containing information about self-directed support:

www.selfdirectedsupportscotland.org.uk/

This is a one-stop-shop for information about self-directed support for the public and health and social support professionals. There you will find guidance, useful links and a Frequently Asked Questions section for new and existing users and professionals.

The website also features video case studies, an eligibility checker, and links to support organisations.

ISBN 978-0-948897-62-7

© Alzheimer Scotland, 2010

This document is also available on the Scottish Government's Self-Directed Support website at:
www.selfdirectedsupportscotland.org.uk/

and the Alzheimer Scotland website at:
www.alzscot.org

Further copies of this leaflet are available from:

Information Department
Alzheimer Scotland
22 Drumsheugh Gardens
Edinburgh
EH3 7RN
Tel: 0131 243 1453

People with dementia and carers can request a copy via the Dementia Helpline on
0808 808 3000



Alzheimer Scotland - Action on Dementia is a company limited by guarantee, registered in Scotland 149069. Registered Office: 22 Drumsheugh Gardens, Edinburgh EH3 7RN. It is recognised as a charity by the Office of the Scottish Charity Regulator, no. SC022315.