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Stroke
association

Getting the support you need

A guide to Self Directed Support



Getting the support you need

If you've had a stroke recently, you might find that you now need help with some day-to-day things that you used to do yourself. This booklet has been produced with stroke survivors and their families to provide information about Self Directed Support and the options available to you.

What is Self Directed Support?

From April 2013, everyone in Scotland who needs it will be offered Self Directed Support.

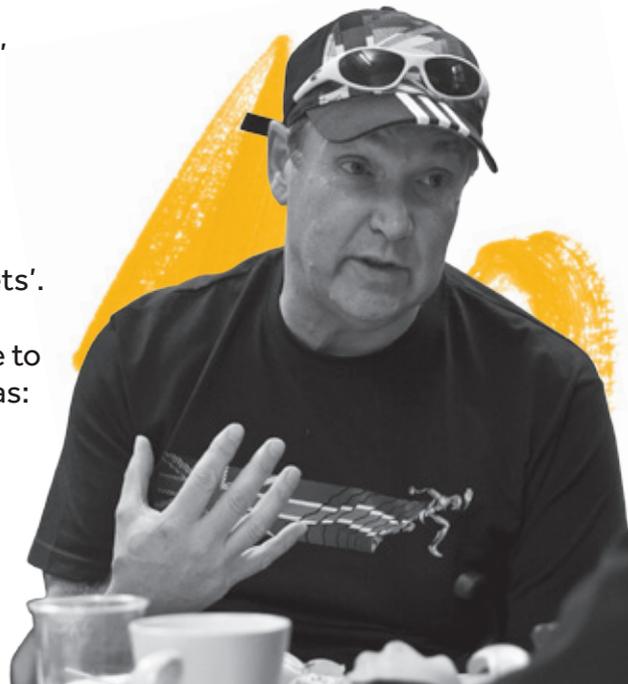
Self Directed Support, or 'SDS' for short, puts you in charge of what sort of support you receive and how you receive it. It's also sometimes called 'personalisation', 'Direct Payments' or 'individual budgets'.

This might be support at home to help you with daily tasks such as:

- washing
- eating
- housework

Or things outside the house such as:

- shopping
- going to college
- visiting friends and family



Self Directed Support is there to help you maintain your independence by putting you at the centre of decisions about what and how you do things. It's about supporting you and your hopes for the future.

Self Directed Support may be very new to you. It might be a good idea to get some independent support right from the start.

An independent advocate can help you to go through your options and work out what is best for you. It's a free service. Independent advocates make sure you have all the information you need and that you're listened to. You can contact the Scottish Independent Advocacy Alliance for information about advocacy in your area (**see the Useful contacts on page 11**).

Here's how Self Directed Support works

You contact your local council social work department and ask for a community care assessment and/ or a carer's assessment.



Think about your needs ahead of the assessment.



Have the assessment and discuss your options.



Agree your personal support plan.



Agree how services will be arranged and managed (choose one or more of the four options for Self Directed Support).



Your support starts.



Review and renew.

Step one: Ask for an assessment

If you need support for daily living you should contact your local council social work department and ask for an assessment of your needs. Or ask a friend, family member or carer to do this on your behalf.

You can get contact details for your council's social work department on the council's website or from your local Citizens Advice Bureau.

You can also ask your doctor about getting an assessment or, if you're in hospital, you can ask the hospital social work team.

The assessment might be referred to as a 'community care assessment', 'joint needs assessment' or a 'shared assessment'. It involves a social worker coming to see you and looking at how well you cope with day-to-day living. Your assessment should be about your life now and your hopes for the future.

If you have a carer, then they can have an assessment too. This is called a 'carer's assessment' and it looks at your carer's needs and whether they need support.



Step two:

Think about your needs

It's important to think about what you want to say before your assessment. You could get help with this from friends and family or from an independent advocate.

We worked with stroke survivors and carers to put together a list of things you should think about before your assessment. This is based on some of the common effects of stroke but not everything on the list will apply to you.

You should think about the following things.

At home:

- what can you do yourself?
- what would you like some support with?
- what do you think would help?

Your aims:

- what would you like to do?
- what are your goals?
- what would you like to do in the future?

Managing your money:

- budgeting and banking
- benefits check
- do you have financial worries?

Help from your friends and family:

- have they offered help?
- do you want this?
- are there things you would prefer a paid carer to do?

Relationships:

- are you keeping in touch with people?
- would you like support with your existing relationships?
- do you have the chance to make new connections with people?

Being active:

- can you move around ok outside?
- are you getting out and about?
- would support help?

Emotional life:

- how are you feeling?
- do you feel sad or think you might be depressed?
- are you laughing or crying a lot?

Thinking and concentrating:

- are you remembering things ok?
- if not, what are your coping strategies?
- what support might help?

Communication:

- can you communicate your thoughts and needs?
- what are the effects on your life?
- what might help?

Work:

- would you like to return to work?
- would you like a new job?
- are you interested in volunteering?



Step three: Have the assessment

The person who visits to do your assessment might be a social worker, district nurse, occupational therapist or another care professional. They will ask you questions to work out what level of support you can have.

You can also give them your own assessment of your needs. This is sometimes called a 'self-assessment'. It could be a written summary, or it might be a weekly breakdown of what you need and when. Some councils have a form you can use for this.

The person assessing your needs should talk to you about the different options for Self Directed Support. Together you will produce a 'personal care plan' or 'support plan' which sets out your needs and how these will be met.



The options for Self Directed Support

If the council agrees that you need support, you'll be offered four options. You can choose one option or have a mixture.

Option 1: You take a cash payment from the local authority, called a 'Direct Payment' and arrange your own support.

Option 2: You choose the support you want and your local council arranges it for you.

Option 3: Your local council decides what sort of support is best for you and arranges it for you.

Option 4: A mix of options 1, 2 and 3 for different aspects of your support.

You should think carefully about the four options and discuss them with your local council. You should be at the centre of these discussions.

You can get help from an independent advocate, Citizens Advice Bureau or from the Stroke Association helpline to make sure you make the best choice for you **(see the Useful contacts on page 11)**.

If you choose to take a Direct Payment to pay for some or all of your support you must be careful that the money is spent on what is in your support plan. If not, the council could ask for the money back.

Taking a Direct Payment has some other issues you need to be aware of and can be quite complicated. You can get help and advice from the Scottish Personal Assistant Employers Network **(see the Useful contacts on page 11)**.

Case Studies

Mary

Mary is 45 years old and has just left hospital following a stroke.

She lives on her own and is assessed as needing two hours of support per day for personal care and meal time assistance.

Mary decides to let the council arrange this for her because she is coming to terms with the way her life has changed following her stroke and doesn't want the added complication of employing a personal assistant.

Mary is assured by her social worker that she can always change her mind in the future.

Philip

Philip is 22 years old and had a stroke during his gap year when he was travelling abroad.

He's moving out of his parents' home and into his own flat.

He wants to be as independent as he can be, go to college and go out with his friends.

Philip decides that employing his own personal assistant is the best option for him as it would give him the greatest level of control.

What will I have to pay?

The assessment of your support needs is free and any services or equipment supplied by the NHS are also free.

If you're assessed as requiring services from the social work department such as help preparing meals, personal care or help going shopping, then you might have to pay towards these. You will have to have a financial assessment to work out what is reasonable for you to pay towards the cost of the support. The financial assessment will look at your income and savings. If you don't agree with the assessment you can ask them to review it.

What happens next?

Once your needs have been assessed and you have chosen your options for Self Directed Support, you should receive a letter from your council. This will include information about:

- how much they think the support you need will cost
- how much the council will pay
- how much you are expected to pay
- when the next review will take place.

What if I'm not happy with the assessment?

If you're not happy with your assessment, seek advice from one of the Useful contacts listed on the next page.



Useful contacts

As a stroke survivor, your needs may change quickly or may change over time. It's important that your care plan is reviewed to take account of these changes. Your council will set review dates but you can also tell them if anything changes between reviews.

You should have a key, named person to contact at the council and if something changes or is not working as well as you hoped, you must tell them. Don't keep it to yourself.

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Citizens Advice Scotland

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Self Directed Support Scotland

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Scottish Independent Advocacy Alliance

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Scottish Personal Assistant Employers Network

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We are the Stroke Association

We believe in life after stroke. That's why we support stroke survivors to make the best recovery they can. It's why we campaign for better stroke care. And it's why we fund research into finding new treatments and ways of preventing stroke.

We're here for you. If you'd like to know more please get in touch.

Stroke Helpline: 0303 3033 100

Website: stroke.org.uk

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