

# Self Directed Support:

*a guide for carers*



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# Introduction

## What is a carer?

A carer is someone of any age who looks after a family member or friend who could not manage without this help. This could be caring for a child, parent, sibling, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. The care they provide is unpaid.

All carers are in different situations – they may be looking after a parent with Parkinson’s disease, a child with learning difficulties, a sister with an addiction to alcohol, a brother with bipolar disorder or a partner who has fibromyalgia, but all carers will share some basic needs. All carers need professionals and services to be able to recognise them as an individual and the changing needs they will have throughout their lives as they provide care. Carers are the experts in providing care to the people they are looking after, and should be treated as equal partners in care by professionals and services.

Good support for the person who is being cared for can also make the carer’s role easier, as it means they can have a break, and a life outside of caring. This guide looks at how a carer can be involved in helping the person they look after decide on what sort of support they want and make sure it suits both of them, as well as how they can get support for themselves.

## Who is this guide for?

This guide is for carers who are looking after someone who gets support from the local Council. If the person you care for gets support from the Council, part of what you do in caring for them could be helping them to decide what kind of support they want, or making sure that the support they get works for both of you and complements the care you provide to them.

This guide is also for carers who get, or who want to get, support from the Council to help them with caring. Carers can get support for themselves as part of the **Social Care (Self-Directed Support) (Scotland) Act 2013**. Carers should also have choice and control over support to help them in their caring role, and this law means that Councils can offer carers support in their caring role.

The Social Care (Self-Directed Support) (Scotland) Act 2013 is an Act of the Scottish Parliament that ensures that local authorities offer self-directed support to anyone who requires support services, including unpaid carers who require support to help them maintain their caring role.

**Self-directed support (SDS)** is a way of providing support that means people are given choice and control over what kind of support they get. It means that people can choose and arrange some or all of their own support instead of having it chosen and arranged by other people.

It is not the name of a particular type of support service, but a way to make sure that care and support is better suited to the people who need it. It means that more choice will be available for:

- Who supports you.
- When you want to get support.
- The kind of support you want.

SDS has been one of the biggest changes in the way care is provided, and many Councils have been offering a form of SDS to people for a number of years. From April 2014 all Councils in Scotland will have to offer SDS to people and their carers if they are going to provide them with support following an assessment.

## How to use this guide

This guide shows carers

- How they can direct their own support, looking at the whole process from assessment to support planning.
- The full range of options for how people get support.
- How support is reviewed.
- How they can be involved in choosing and planning the support for the person they are looking after and how they can help the person they look after to direct their own support.

You can read the guide from start to finish to get an idea of how the assessment process will work and the SDS options that are offered to you. Or you can pick a specific section that you are interested in and start reading from there. The glossary and sections on other support available will be useful for people who are new to SDS and are not sure about some of the words and phrases that are commonly used. There are also case studies throughout the guide that show how SDS can be used in practice.

## Other sources of support

- **The Scottish Government have produced Statutory Guidance** (<http://www.scotland.gov.uk/Publications/2014/04/5438>) on Care and Support. This is for Councils and Social Work Services but you may also find it useful to understand more about SDS.
- **Self-Directed Support Scotland (SDSS)** (<http://www.sdsscotland.org.uk>) is a national membership organisation which actively promotes Independent Living by supporting, working with and championing the aims of Self-directed Support disabled people's organisations. They raise awareness of SDS options amongst service providers and help them to deliver SDS options to service users.
- **Carers Trust Scotland** (<http://www.carers.org/scotland>) is the largest provider of comprehensive carers support services in Scotland, reaching around 40,000 adult carers and more than 3,500 young carers (aged up to 18) from all groups and communities, through a unique network of independent carers centres and young carers services (Network Partners) throughout Scotland. To find your nearest carers' centre or young carers service, go to **<http://www.carers.org/scotland>**.

# Support for carers

## Why do carers need self-directed support?

Carers need support because although caring is often very rewarding, it can also be very difficult at times. Carers can often have poor health due to their caring role, or they can feel very isolated and alone because their caring means they do not have the time or the money to do the things they want to do, such as work, enjoy hobbies, spend time with friends and family or go on holiday. To care safely and stay healthy, carers need information, support, respect and recognition from the professionals who are in contact with them and their families. Carers might also need specific support to be able to manage their work and caring roles, or to return to employment if they have given up work, or never worked, due to caring responsibilities.

Carers should be able to choose and control how they get their support in the same way as the people they look after. From April 2014, Councils will have to offer support to carers if a carer's assessment has been completed and it is found that they should get support. All of the options to get support that are available will also be available to carers.

Carers are able to get support from a carers' centre or carers' service whether or not the Council have offered you self-directed support. Any support you get through SDS will be in addition to getting information, advice and support from a carers' centre or any other kind of support organisation that the Council tells you about. However, carers' centres can help you and the person you look after to get in touch with the Council, have an assessment and decide what kind of support is right for them and for you. If you are interested in self-directed support and would like to know more about it, your local carers' centre will be able to help you. They can also work through this guide with you.

If you are caring for someone with a specific condition or illness, you might also be able to get support from an organisation or charity that provides information and advice about that condition. If you haven't done so already, try searching the internet for information about the condition or illness, or speak to your doctor, social worker or carers' centre.

## The supported person's pathway

The supported person's pathway shows the stages of planning for support. There are a number of steps in the pathway, but the step that you begin from will be different depending on your situation.

If you have not previously been getting any support but think that you might need support, you will start at the beginning – **Step 1**.

If you are currently getting support and want to change it, you will start at another stage. It will usually be at **review** stage, but you may need another **assessment** if your needs have changed since the last time you had one.

## Supporting the person you care for to get self-directed support

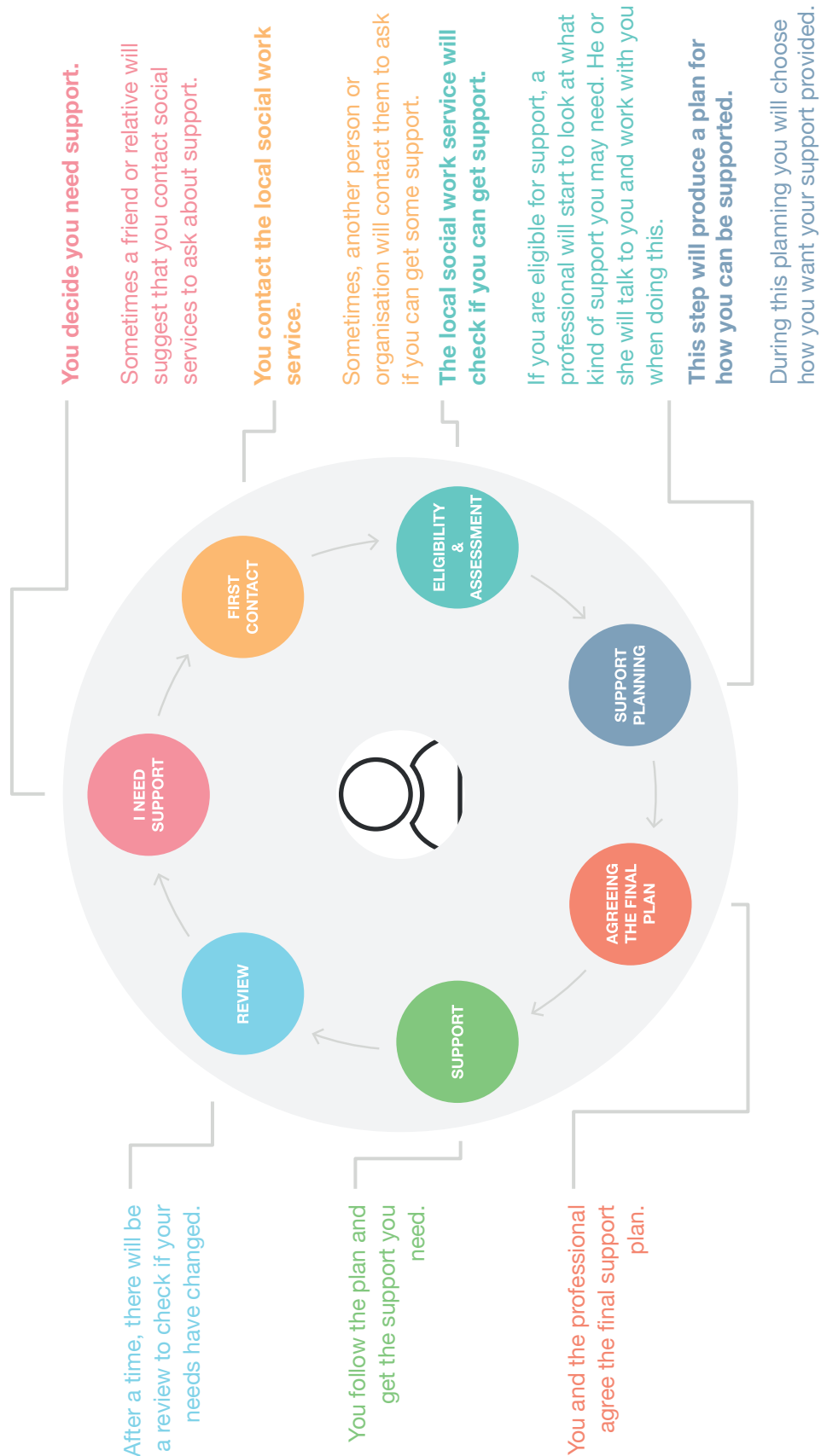
Carers who are involved in helping the person they look after to access self-directed support will be involved in many stages of the pathway, depending on how involved the person you are looking after wants you to be. The supported person's pathway shows how carers can help with support planning, and how the care you provide will complement the other support that is given.

## Self-directed support for carers

If the carer is receiving support in their own right, they will follow all the stages in the pathway, as they are the person getting support. It may not be as straightforward, because supporting a carer might involve providing services to the person they're looking after rather than directly to them, but the general process is the same.

# The Person's Pathway

There are different steps to getting support. The steps are called the Person's Pathway. Here's how it might work for you.



## How do you know if you will be able to get support?

In order to get support, Councils need to know if you are eligible. All Councils have eligibility criteria, which is how they decide whether you need support from them or not.

During the assessment, the person doing it will talk to you about how you cope with your caring role, and how you will be able to cope and continue with caring if they do not give you any support, and what the risks would be to you and the person you're looking after.

There are usually four levels of eligibility that the Council identify based on the information you give them as part of the assessment:

- **Critical** – this means that there is a very high risk that the carer will not be able to begin caring for someone, or continue to care for someone, without having major problems in their own life, health or relationships, and they need to get support immediately.
- **Substantial** – this means that there is a risk that the carer will not be able to begin or continue caring for someone without experiencing some major problems in some parts of their life, and they need to get support very soon.
- **Moderate** – this means that there is some risk that the carer will not be able to begin or continue caring without moderate changes to some aspects of their life, and may need some support.
- **Low** – this means that there is a low risk to the carer and they will only have to change some parts of their life in order to begin or continue caring, and may need some low-level or preventative support put in place.

Each Council is different, but usually it is only people with critical or substantial needs who are given a full package of support, as they would be at risk if the Council did not provide a service to them.

People with **moderate** or **low** needs will be given information, advice, and details about other support that is available for them, but they may not receive any services from the Council directly. They will always give you information about the local carers' centre or carers' service, so that you can get some support from there if you are not doing so already. They may also give you information about other charities or support organisations in your local area, printed information or websites. Don't be afraid to ask for this kind of information – Councils have to provide this to you.

If your circumstances change in the future and you are finding it more difficult to cope with caring, or you are providing more care, or looking after more people, you may become eligible for support. You will be able to have another assessment done if your circumstances change so much that you think you might need more support.

The Council will also look at whether providing some support to you now will mean there is less need for support in the future. This is known as **preventative support**.

### Charging

The Social Care (Self Directed Support) Scotland Act 2013 introduces the right for carers not to be charged for any support they receive as a carer. Charges cannot be made for support provided to carers to continue in their caring role, whether directly provided by local authorities or commissioned by the local authority through voluntary organisations or private organisations.

This does not apply to services that are provided to the person who is being cared for. In this case, the normal charging for non-residential care services will still apply. In the case of short breaks, the elements of the break that are provided for the carer will not be charged.

More information is available at <https://professionals.carers.org/policy-and-legislation-scotland>

# Assessment

Everyone who gets support from the Council needs to have an assessment. An assessment is usually carried out by the Council's social work department and looks at the needs of the person who wants to get support – whether that is you as the carer, or the person you care for.

The assessment is a conversation between you and the Council to decide what kind of support you need and what you would like to do. During these conversations the Council will work with you to find out what your needs and outcomes are so that you can get support that is right for you. They will then need to agree what they are able to provide you with, based on your eligibility for support.

If you want the person you look after to be involved in these conversations, they can be. Other family members, or people like carer support workers, can also be involved if you like. But even when other people are involved, the assessment will first and foremost be about you and your outcomes and the support you want.

## **Carers' Assessments**

The law says that anyone who provides or intends to provide a substantial amount of care on a regular basis can have a carer's assessment. No definition of 'substantial' is given, but most people who want to see if they can get support with their caring role are likely to be able to get an assessment. Generally, if the amount of care you are providing is affecting your life and your opportunities to do what you want to do, you can have an assessment.

Even if the person you care for does not want to have an assessment and refuses to speak to a social worker, you can still have a carer's assessment.

A carer can have a carers' assessment whether they live with the person they're looking after or not, whether they are caring full time or whether they are working and caring at the same time. If you share caring responsibilities with another person, you can both have a carers' assessment as long as you are both providing substantial amounts of care on a regular basis. A carer's assessment can take place before you start caring (for example, if the person you are looking after is in hospital but will be leaving hospital soon) or at any point afterwards.

## **How to get a carer's assessment**

The best way to get a carer's assessment is to email or write to the social work services department at your Council. You can also phone them to ask for a carer's assessment, but it is a good idea to follow this up in writing. You will be able to choose where the assessment takes place – at home, at the Council offices, or the carer's centre.

## **What will the assessment be like?**

Every assessment will be different. An assessment should be unique to you and your individual circumstances.

The assessment will usually be carried out by a social worker, or sometimes it might be carried out by a carer support worker at your local carers centre. If the person you look after is in hospital or has recently left hospital, it might be carried out by someone at the hospital.

In some parts of Scotland, the local Council works with the local carers' centre to carry out carers' assessments, and the assessments are done by staff from the carers' centre. Your social work department will explain who will carry out the assessment.



The assessment will normally be a face to face meeting. However, some Councils will ask carers to complete a self-assessment questionnaire before the meeting.

You can have a friend or family member, or someone like a carer support worker, with you during the assessment if you wish. The person who you care for can also be there, if you like. Having someone with you should be discussed when the meeting is being arranged.

A self-assessment questionnaire is a form you fill in yourself. It is ideal if you need information, advice or simple adaptations or pieces of equipment. If the self-assessment shows that the carer's needs are more complex, a full carers' assessment should take place as soon as possible.

As part of the carer's assessment, you will be asked about:

- how being a carer affects you
- your own health
- your own feelings about caring and how much care you want to do or are able to do
- how your caring affects work, studying, leisure time, living arrangements and any other commitments such as looking after children
- any help you need to care for someone

By the end of the assessment, the Council will have a better idea of what kind of support you need, and you can discuss any support you think you need with them. You will be given the opportunity to say how you want to receive your support and how much control you want to have over the support you get.

The person who does your assessment will help you identify what is important to you, what needs to change, and how to make this change happen.

### Young Carers

Young carers can also have assessments in the same way as adult carers have a carer's assessment. Assessments for young carers can be more likely to identify a need for support to the person they are looking after, as well as support given directly to the young carer.

Assessments for young carers will usually involve the young carer's parent or guardian, if they are able to take part. Throughout the assessment, the parent or guardian must work with the Council to ensure that the support will contribute to the child's wellbeing by keeping them:

<b>Safe:</b>	protected from abuse, neglect or harm
<b>Healthy:</b>	experiencing good physical and mental health, and supported to make healthy safe choices
<b>Achieving:</b>	receiving support and guidance in their learning, boosting their skills, confidence and self-esteem
<b>Nurtured:</b>	having a nurturing and stimulating place to live and grow
<b>Active:</b>	offered opportunities to take part in a wide range of activities – helping them to build a fulfilling and happy future
<b>Respected:</b>	to be given a voice and involved in the decisions that affect their well-being
<b>Responsible:</b>	taking an active role within their schools and communities
<b>Included:</b>	receiving help and guidance to overcome problems and to help them be accepted as full members of the communities in which they live and learn

## **Assessments for the person you are caring for**

If you are caring for someone, they may have an assessment of their own needs. You will usually be involved in this assessment as their carer, as any support that is provided to the person who is being looked after will have to fit in with the care that you are willing or able to provide, or the kind of care that the person wants to get from you as their carer. There may be specific questions for carers on the assessment, or there may be the opportunity to have a carers' assessment at the same time.

For example, a lot of people do not want their family or friends to give them personal care, such as helping them wash or use the toilet. They would prefer care workers or a personal assistant to do this kind of care. Other people might want their carer to give them personal care because they feel more comfortable having someone they know doing this for them, but want someone else to help with household work like cleaning, cooking and washing clothes. Or they might want the carer to drive them to places they want to go, such as college or a day centre. Carers have to be involved in this kind of planning so that they know what they are needed to do, and whether they'll be able to do it or not.

The assessment will take place in more or less the same way as a carer's assessment – it will be done by a social worker, other family or support workers can be involved, and the assessment will be a conversation about needs and outcomes.

## **Outcomes**

Before and during the assessment, you will hear a lot about outcomes, or outcomes-based planning. Outcomes are the things that matter to you, and the results of getting support. So when planning support, people decide what they want to happen and then work out what kind of support will be best to make this happen.

Focusing on outcomes means that people are supported to identify:

- what is important to you in your life
- why these things are important
- how to go about achieving these things
- who will be involved, including you, other people in your life and community, and services

## **Outcomes for carers**

Outcomes for carers are identified in the same way as outcomes for people who are being looked after. The outcomes might be to remain in employment, be able to keep up with a specific hobby or interest despite having a caring responsibility, to gain more confidence, or to have a regular break from caring.

You might already have an idea what your outcomes are, or you might not. An important part of the assessment is to work together with the Council and others to discover and agree what your outcomes are.

This guide isn't a substitute for a conversation with a qualified social worker or other support organisation, but it can help you to start thinking about what outcomes are important to you.

## **Support for you and support for the person you care for**

As the carer's assessment can also affect the assessment of the person who is looked after, some of your needs as a carer may be included in the support plan of the person you're caring for. Help may be provided for them instead of directly to you, but it will still help you to care.

For example, if you are having difficulties lifting the person you look after, you could be provided with lifting equipment and training on how to lift someone safely. The equipment will be mentioned in the support plan of the person who is looked after, but the lifting equipment will help you to provide care.

If you don't want this information to be written in the support plan of the person you are looking after, then you can ask for your own separate carers' plan.

## **Who can help with planning support?**

There are independent organisations such as advocacy organisations that can help you decide what kind of support you want and what your outcomes should be. Family and friends may also be able to support you.

Carers and the people they care for are often involved in the assessment and support planning process for each other.

Advocacy is a way to help people have a stronger voice and to have as much control as possible over their own lives.

An independent advocate will not make decisions behalf of the person they are supporting. The independent advocate helps the person to get the information they need to make real choices about their circumstances and supports the person to put their choices across to others. An independent advocate may speak on behalf of people who are unable to do so for themselves.

# Self-Directed Support Options

Everyone who needs support will be offered the same four options for how the support will be given to them. This is how you can choose your own support.

This part of the guide explains what each of these options are. The Council will give you a more detailed description of each of the options and including how they apply to your own individual circumstances. Your carers' centre or carer support worker will also be able to help you think about the options.

**Option 1** is usually called a direct payment. This is a cash payment that will be paid into your bank account and used to pay for the services required. This money can be used to employ support workers or buy services from organisations. **If you want to have a lot of control over the service you get, Option 1 is for you.**

**Option 2** is when the money is held by the Council or another organisation, but you are in charge of how the money is spent. This is sometimes called an individual budget or an individual service fund. **If you want to have some choice in what kind of service you get but do not want to arrange the service yourself, Option 2 is for you.**

**Option 3** is when the individual budget is held by the Council and they arrange the support for you. **If you do not want to choose your own support and are happy with everything being organised and provided by the Council, Option 3 is for you.**

**Option 4** is a mix of any of the above options. **If you want to choose some of your support but have other parts arranged for you, Option 4 is for you.**

## Children and young people

Most of the information in this guide is also applicable to young carers and children and young people who are being cared for. However, there are other things that also need to be considered for children and young people who are getting support.

Where there is a concern for a child's wellbeing, such as because they are a young carer, have a disability or long term condition, or a difficult family life, a Child's Plan must be prepared. The principles of Getting It Right For Every Child (GIRFEC) means that every child or young person who gets support from more than one organisation (such as the NHS, the Council, and their school) will have one plan that sets out all their support.

GIRFEC is a Scottish Government approach to supporting children and their families. It makes sure that everyone who is involved in supporting the family works together to make sure that the family are supported in the best possible way.

This means that as young carers and young people who are cared for get older, and move from children's services to adult services, they will be able to have more responsibility for their own support, become more independent and have more of a say in their future.

If you are a young carer, the parent or guardian of a young carer, or caring for a child or young person, the Council will let you know if a Child's Plan is being prepared, and you will have a chance to talk about the kind of support you want for yourself or for the child that you look after. It will be very similar to an assessment (see page x for information about assessments) in that it will be like a conversation about needs, risks and outcomes.

Children who are aged under 16 are not able to get self-directed support in their own right. A parent or guardian can manage the support on a child's behalf, if they are able to do so. There is more information for each specific option in the sections of this guide that look at self-directed support options.

# Option 1: direct payments

This is the option where the person getting support has the most control and choice over the kind of support they get. Direct payments are cash payments from the Council for people who have been assessed as needing help and support from social work services, but who want to choose how and when they get this kind of support. They can be given to people with a disability or support needs who would like to arrange and pay for their own support services, as well as to carers who have been assessed as needing support and would like to arrange and pay for this themselves.

Once a support plan has been worked out and an individual budget decided upon, the Council will pay the amount of money into your bank account. You can then use this money to buy the services you have decided to use. You have to keep track of how the money is spent by saving receipts and invoices.

In most cases, the person receiving a direct payment has to be able to consent to getting it and must be capable of managing it – this is known as having capacity. However, if you are looking after someone who is not able to manage a direct payment themselves, they may still be able to have a direct payment as long as they get help from someone else to manage the payment. In cases like this, as a carer, you may be asked to take on the management of a direct payment for the person you look after.

## *Siobhan's Story*

Siobhan looks after her mum, who is 82 and suffers from osteoarthritis and has recently been diagnosed with Alzheimer's disease. She was getting a daily visit from a care worker for a small amount of personal care and housework support, but over time her support needs increased and after reassessment the number of visits was increased to an hourly visit three times a day. The number of different care workers attending increased, up to around 30 different staff members over a one month period. This made it difficult to establish any kind of rapport or continuity between Siobhan, her mum and the care workers.

Some staff were not very good at properly meeting Siobhan's mum's needs and wishes, and she developed anxiety and fear of the care workers visiting and finally began to refuse care. Siobhan had to be present when the care workers attended in order to reassure her mum, which was not the best use of anyone's time as the care workers were supposed to give Siobhan a break from caring.

After receiving some support and advice from her local carers' centre, Siobhan's mum now receives a direct payment which is managed by Siobhan's brother Eamonn. The direct payment is used to employ Siobhan to provide care for their mother. Eamonn has continuing power of attorney, which means he looks after the money on behalf of their mum. Siobhan can be employed to look after her mother because she has no responsibility for her mum's money and because the care that she now provides is over and above what she does as an unpaid carer. The direct payment works very well, both Siobhan and her mum are happy and her mum's health has improved since Siobhan has been providing care.

## **Being an employer**

A lot of people use their direct payment to employ a care worker or personal assistant (PA). This is a very flexible way of getting support, and can be particularly suitable for people with unpaid carers, as they can make sure that the support given by the PA is complementary to the support that is given by them. For example, the PA might come to spend time with the person when the carer is at work during the day, or they might come every evening to make the dinner so that the carer can spend some time doing something else.

The amount of money that the Council give to buy support will be the same amount each week, but if more or less support is needed on different days (for example, if a family member is coming to stay for the weekend, and they'll be able to do some of the PA's work, like cooking), then the PA could work fewer hours on that day and make them up at another time.

If you use an agency, they will let you know if you can 'bank' hours in this way. If you directly employ a PA, you can discuss with them how this will work in practice.

As well as paying your PA a regular wage and keeping a note of the hours they work, you will need to make sure that you do all the things an employer needs to do, such as pay the correct amount of tax and National Insurance. Organisations such as SPAEN can help people with the responsibilities of being an employer such as employment contracts, holiday and sick pay, and payroll services.

When choosing this kind of support, or helping the person you look after to choose their support, it is important to think about the tasks you expect the staff to do and the way in which you would like them done. You will also need to think about what will happen if you want to stop having a PA in the future, or what will happen if your PA is ill, goes on holiday or wants to leave. There are organisations who can help you make these decisions and who can provide emergency replacements if your PA is ill or goes on holiday.

If you would prefer not to have the responsibility of being an employer, you can use a direct payment to buy support from an agency. You will still be able to have a personal assistant or a dedicated care worker, but the paperwork will be reduced as the PA will be employed by the agency and they will take care of all the official matters.

## **Carers and Option 1**

Carers can either receive direct payments for their own support as a carer, or they can manage the direct payment on behalf of the person they care for. They might also do both. Most people who receive direct payments will be able to manage them if they have sufficient understanding and memory, but if they lack capacity then the carer, or someone else acting on the person's behalf, may have to manage the direct payment for them. In this situation, if you are also receiving a direct payment for your own support as a carer, the money will have to be kept in a separate bank account.

Power of Attorney (PoA) is a written document that says someone can make decisions on behalf of someone else. Carers often have PoA for the people they're looking after when the person is no longer able to make decisions or communicate by themselves.

Continuing power of attorney is a power over someone's property or money, if they are not able to handle things by themselves or make decisions.

Welfare power of attorney is a power over someone's personal health and care needs, if they are not able to decide this for themselves.

A guardianship order is a court appointment which authorises a person to take action or make decisions on behalf of an adult with incapacity.

Carers who receive direct payments in order to buy support for themselves are expected to account for the money in exactly the same way as anyone else who receives direct payments. The money will be paid into a specific bank account and you will have to keep records of how the money is spent. The Council will regularly check that the money has been spent on meeting your outcomes.

In order to manage a direct payment on behalf of someone who is over 16, you will need to have guardianship or power of attorney. For more information about this, you should speak to your local carers' centre or look at the back of this guide for information from the Office of the Public Guardian.

### **Young carers and young people**

Children under 16 cannot receive direct payments in their own right, but they can be paid to their parents or guardians who will manage them on their behalf. If the young person is caring for their parent or guardian, the parent or guardian can still manage the direct payment for the young person as long as they are capable of doing so.

Young people aged 16 and over are able to have direct payments for themselves as young carers and also manage direct payments for the person they are caring for.

### **When are direct payments not allowed?**

Sometimes you or the person you look after will not be able to have a direct payment. You will not be able to have a direct payment if having one would put your safety at risk. The Council will tell you if you or the person you look after will not be able to get a direct payment, and they will always explain why they think you would not be safe and make sure you understand. There is more information for each specific option in the sections of this guide that look at self-directed support options.

### **Sharing a budget**

A group of people who receive direct payments can 'pool' this money to buy support for shared activities. This can be useful if the cost of the service cannot be paid for just with one budget, and can also help build relationships and friendships amongst groups. It also works well for activities such as art, music and other activities that build skills, as these are activities that can be better in a group.

### **Direct payments for equipment and adaptations**

If you or the person you look after needs equipment or minor adaptations in order to meet your outcomes, you could use a direct payment to buy the equipment you need, rather than get it provided for you. This means you can buy equipment from a different company that the one used by the Council, or you can use the money to buy a more expensive piece of equipment and make up the difference yourself. If the equipment needs maintenance, you should also receive direct payments to cover the cost of the maintenance.



## ***Gillian's Story***

Gillian, who lives in a small rural town, cares for her two sons who have a learning disability. When she first heard about SDS she wasn't keen, thinking it sounded like social care services were passing the workload to carers for the organising and managing of a person's support. However as time went on and she learned more about SDS, she started to think it may be a possibility for her family. With the support of the local carers' centre she started the process for her older son. She received good support from her son's Care Co-ordinator who was enthusiastic and keen to work on the support plan with both of them. After the Council gave the go-ahead to the support plan, she was delighted but also apprehensive.

With support and guidance from the carers' centre, she set up meetings with various care agencies and support providers to see what they could offer, and eventually decided on a local service provider as the best one for her son. As she is in control of the budget it means they have freedom to plan and arrange things for her son at a time to suit him. Some of the activities he has taken part in wouldn't have been possible without having the right SDS option. Other family members and staff at the carers' centre have noticed that both Gillian and her son's confidence has increased.

Gillian pools some of the money with other parent carers to provide services to all of their children. This means they can use their money to purchase more and different types of support that they wouldn't be able to do by themselves, such as group activities for all the children.

She is now considering different options for her younger son's support as her older son's support is going so well for the family.

## ***Isobel's Story***

Isobel looks after her sister Mary, who is in her 80s and needs help to go shopping and do housework. Isobel still works part time and sometimes struggles to fit in caring for her sister around her work & other commitments. Mary likes to go to the supermarket during the day because there is a better selection of products than in the evening, but if Isobel is working then sometimes she won't be able to go until the evening.

Isobel receives a direct payment and uses this to buy a tablet computer. With input from Mary, she can do online shopping and arrange for it to be delivered straight to Mary at a time that suits her. Isobel and Mary still go to the supermarket together when they can manage it, but being able to do online shopping is really convenient when time is short.

# Option 2: individual budgets

This option is for people who do not want the responsibility of managing a direct payment but would still like to have some choice and control over the support they get.

The individual budget is worked out by the Council following the assessment. The Council then tell you how much money is available to spend, and you can then decide where you want to spend this money. The Council will make arrangements to pay the support provider that you choose.

The main difference from Option 1 is that you don't physically receive the money and therefore there is less responsibility. You won't have to set up a separate bank account and in most cases you won't have to show how the money has been spent, because this will all have been agreed beforehand. You still have choice over your support provider and it is possible to have the same control and continuity as with a direct payment.

The Council will have a list of local providers in your area that you can choose from, but this list is unlikely to include every organisation in your area who can provide support. Local support organisations may also be able to give you information on other providers. There are also some online search engines that will let you search for support providers in your area.

## **Carers and Option 2**

Carers can help the person they look after to choose what kind of support they get, and they can also get support under Option 2 in their own right.

### ***Case Study #1***

A carer wants to have a regular break from caring. The local authority provide her with a short break voucher as a form of 'virtual break' which she uses to buy a short break that meets her outcomes from a support provider. The organisation providing the break is paid by the local authority, and the carer can use her own money to top up the value of the voucher.

### ***Case Study #2***

A carer looks after her daughter with who has been given a budget for personal care in the morning and evening. During the week when the carer has to get ready for work, the care workers come in to get her daughter ready for school. At the weekend, she is able to provide this personal care herself as she does not have to get ready for work. The money that is saved by not needing the care workers at the weekends can be used to buy something else from the agency, like help with housework or some help with shopping, so that the carer can spend more time with her daughter at the weekend.

## *Emily's Story*

Emily looks after her father, Angus, who is getting older and more frail and needs a bit of help around the house. She does the more heavy-duty housework such as vacuuming and mowing the lawn, as well as going to the supermarket and running errands.

Angus has a stroke and is taken into hospital. He is in hospital for three weeks and during this time Emily has a carer's assessment, organised by the hospital discharge team and the social worker from the Council. It establishes that although Emily was able to support Angus before the hospitalisation, the care required when he leaves hospital will be more than what she was doing before, including personal care, and she will need some support because of this. It is also not known how long the more substantial care will be needed for, as recovery following a stroke can be quite variable.

Emily will not be able to cope with this level of caring and uncertainty as she works full time and has two teenage children. She does not want to provide personal care for Angus, and he would prefer to receive this kind of support from paid care workers. She is still able to visit regularly, and helps with the housework when she visits, as well as picking up shopping, running errands and supporting him when the occupational therapist and physiotherapist visit.

Angus has an assessment himself and is offered support from the local authority, and after talking with Emily about how the support will fit in with the care she can provide, he decides to take support through Option 2, asking the Council to arrange support from a private care agency who can come and help him with showering, dressing and cooking at times that suit him. The care agency is flexible and will come along in the mornings and evenings to provide personal care and help with making meals. The care workers have shorter visits at weekends and on days when Emily is not at work, as she is able to help Angus with meals then and so the care workers only have to help him wash and dress.

A key safe is installed as well to make it easier for the care workers to access the property. It also means that other family members, such as Angus' other children and his grandchildren, can visit if Emily is not available.

# Option 3: arranged support

This is the option for people who want to have their support arranged for them. The individual budget is worked out by the Council following the assessment, and then the Council will arrange all the support that is needed.

The person getting the support is still involved in planning the kind of support they want, but all of the detail of planning the support, and all of the arranging and payment is done by the Council. The support that the Council arranges can be provided from their own social work department, from another agency, or any sort of service provider that will provide the services that are needed.

Taking Option 3 does not mean that you have given up all control over your support. The Council will still work with you to find support that is right for you. It just means that you let the Council recommend support and, if you're happy with what they offer, arrange it for you.

## **Carers and option 3**

Carers can help the person they look after to choose what kind of support they get, and they can also get support under Option 3 in their own right.

### ***Charlie's Story***

Charlie is 22 and, along with his mum, looks after his dad who experiences severe depression, anxiety and periods of obsessive-compulsive behaviour. Charlie sometimes struggles to understand why his dad finds it difficult to socialise, work or participate in family life, and often resents having to do things when his dad's not able to help out.

Charlie has recently moved back in with his parents after graduating from university, as he has not been able to find full-time work and is currently working evenings and weekends in a supermarket. The next time Charlie's dad has an appointment with the community mental health team, he mentions that Charlie is living in the family home and is given a leaflet about the young adult carer service at the local carers' centre. Charlie visits the centre and speaks to a young adult carer support worker, gets a chance to meet other young adult carers and has a chance to explore options for finding work in the future. Charlie also gets a chance to speak to carer support workers about how he sees his caring role in the long term and makes sure that if he ever needs any extra support as a carer, the young adult carer service will help him to speak to his parents and to the Council to make sure he is not taking on more of a caring role than he is happy with.

# Option 4: a mix of options

This option is different from the other options as it's not a specific way of arranging support – it is being supported by a mix of Options 1, 2 and 3. So you can arrange some of your support yourself, and have some other parts of your support arranged for you by the local authority.

## ***Henry & David's Story***

David looks after his partner Henry, who has epilepsy and mobility difficulties and uses a wheelchair. Henry needs someone to be with him in case he has a seizure – usually David is with him but David works part time and a care worker from the Council comes in every day to sit with Henry and make sure he is OK.

Henry can transfer from his wheelchair to a special armchair but not to the sofa as it is too difficult. As well as having support arranged by the Council, a direct payment is provided so that David and Henry can buy a replacement sofa that is more supportive and that Henry can use as well as the armchair. This means they can sit together in the living room and spend time together.

## ***Sarah, Alex & Robert's Story***

Sarah and Alex look after their son Robert, who is in his 20s and has a learning disability. The Council arranged for Robert to go to a day centre when he was younger and this worked well at the start, but as he gets older his needs have changed. With the help of his parents he decides to reduce the time he spends at the day centre and starts to use another agency that helps young adults with independent living. The agency workers support him to go to clubs and other social activities of his choosing.

## ***Adam's Story***

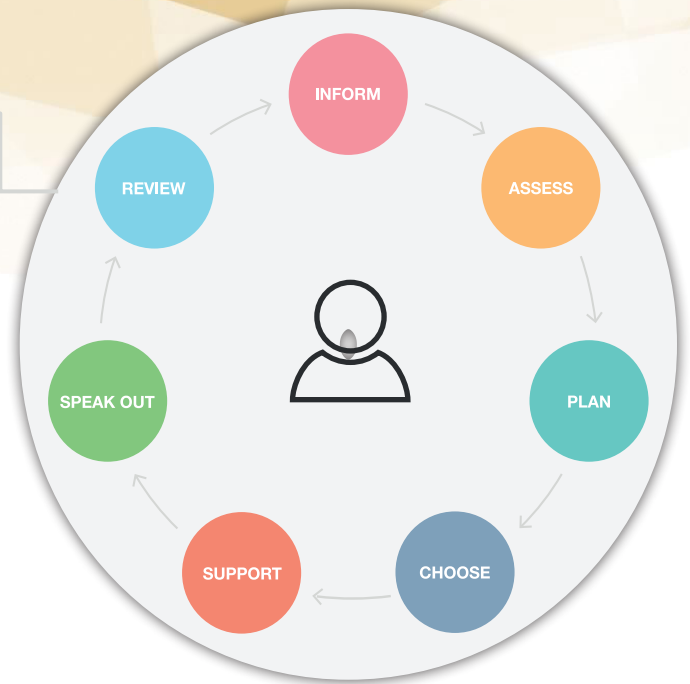
Adam is 14 years old and lives at home with his mother Sheena. Sheena has a diagnosis of multiple sclerosis (MS) which affects her mobility and ability to carry out some tasks like cooking, ironing, washing, shopping and dispensing her own medication. Adam has been her main carer for the last 3 years. The family have no other family support and Adam is determined to continue to support his Mum at home and undertakes a number of the daily household chores that Sheena is unable to manage. He takes responsibility to cook their meals when Sheena's health is poor and also helps Sheena with taking her medication. Sheena has been assessed for her own needs and receives daily support from the local homecare team to assist with her personal care needs as she is determined that this is not an area that Adam should support her with. She also receives a weekly shopping service and attends a local club for people with physical disabilities once a week with transport arranged by the local authority. Due to the complexities of his Mum's needs, Adam has been assessed as a young carer with needs in his own right. It is felt Adam needs time away from his caring role and the opportunity to explore his feelings around the impact his caring role has on his family life.

Adam uses a mixture of options. He receives a small budget to help him purchase a computer that helps him stay connected to friends through social media. The Council also pays for Adam to keep up with his music lessons twice a month. He still likes to attend the local young carers group on a monthly basis, as he has close friendships with other young carers and enjoys sharing experiences and having fun. Adam also helps by mentoring some of the younger carers that attend this group. He takes this responsibility seriously and likes that he can support others in this way.

# Review

After a time, there will be a review to check if your needs have changed.

Reviews are co-produced between professionals and supported people.



It is the responsibility of the Council to make sure the support you receive is meeting your needs and that you are on course to achieve your agreed outcomes. The Council must review the support that you get at least once a year. If your circumstances change, you can ask for a review to be done as soon as possible.

A review is not as formal as a full assessment, but it will take into account the original assessment that you had and any other changes to your circumstances.

If you are caring for someone and their support is being reviewed, this will also look at whether the care you are providing has changed or is going to change in the future so that the support they get can complement this.

# Complaining, advice and information

If you aren't happy with your care assessment or anything else the Council has done, you can use their standard complaints procedure.

If you are not happy with the outcome of your complaint, you may be able to go to the **Scottish Public Services Ombudsman** (<http://www.spsso.org.uk>).

If you are not happy with the services you get from a provider that isn't the Council, you can complain directly to them. If they are registered with the Care Inspectorate, a complaint can be made to the **Care Inspectorate** ([http://www.scswis.com/index.php?option=com\\_content&view=article&id=7569&Itemid=369](http://www.scswis.com/index.php?option=com_content&view=article&id=7569&Itemid=369)).

If you aren't happy with the service provided by a self-employed individual, you will have to speak to them directly. The **Scottish Personal Assistant Employers' Network** (SPAEN - <http://www.spaen.co.uk>) and other local support services can provide information and advice about this.

If you want to know more about guardianship or power of attorney, then the **Office of the Public Guardian** (<http://www.publicguardian-scotland.gov.uk>) can give you further information.

## Advice and information

Your local council might be able to give you details of local organisations that can provide help, information and advice. Your local carers' centre will also be able to give you information about support that is available to carers.

## National Carer Organisations

**Carers Trust Scotland** (<http://www.carers.org.uk/scotland>)

Carers Trust Scotland is the largest provider of comprehensive carers support services in Scotland, reaching around 40,000 adult carers and more than 3,500 young carers (aged up to 18) from all groups and communities, through a unique network of independent carers centres and young carers services (Network Partners) throughout Scotland.

**Carers Scotland** (<http://www.carersuk.org/scotland>)

Carers Scotland supports carers and provides information and advice about caring, influences policy through our research based on carers' real life experiences, and campaigns to make life better for carers.

**Coalition of Carers in Scotland** (<http://www.carersnet.org/>)

The Coalition is a network of over 80 autonomous local carer-led groups, centres and projects. Members of the Coalition meet quarterly to share information and debate issues.

**Crossroads Caring Scotland** (<http://www.crossroads-scotland.co.uk/>)

Crossroads Caring Scotland support carers in Scotland through the provision of respite care and other forms of practical support.

**Shared Care Scotland** (<http://sharedcarescotland.org.uk/>)

Shared Care Scotland is a national charity that works to improve the quality, choice and availability of short break (respite care) provision across Scotland, for the benefit of carers and the people they care for. Their website has a Short Breaks Directory that can help you find a short break for you and/or the person you look after.

**Minority Ethnic Carers of Older People Project** (MECOPP - <http://www.mecopp.org.uk/>)

MECOPP supports Black and Minority Ethnic carers to access support and services appropriate to their caring situation.

## **Other organisations**

### **Self-directed Support Scotland**

(SDSS) is a national membership organisation which actively promotes Independent Living by supporting, working with and championing the aims of Self-directed Support disabled people's organisations. They raise awareness of SDS options amongst service providers and help them to deliver SDS options to service users

Email: [info@sdsscotland.org.uk](mailto:info@sdsscotland.org.uk)

Tel: 0131 516 4195

### **Scottish Personal Assistant Employers Network (SPAEN)**

The Scottish Personal Assistant Employers Network (SPAEN) is a Scotland wide network for people seeking to become or already employing their own personal assistants to meet their assessed health & social care needs.

Email: [info@spaen.co.uk](mailto:info@spaen.co.uk)

Tel: 01698 250280

### **Office of the Public Guardian (Scotland):**

The OPG (Scotland) supervises the actions of those appointed through the Adults with Incapacity (Scotland) Act to manage the property and financial affairs of adults who lack the capacity to carry out these functions for themselves. It also provides a wide range of advice and guidance on these matters.

Email: [opg@scotcourts.gov.uk](mailto:opg@scotcourts.gov.uk)

Tel: 01324 678300



# Appendix: Glossary

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If you are not familiar with self-directed support, a lot of words and phrases that are used in this guide may be new to you. The glossary gives a definition of these words and phrases.

**Assessment:** The process of working out what your needs are and how you would like them to be met. It should involve you, a professional (such as a social worker) and other people such as other family members.

Carers have a carers assessment, which is an assessment carried out to identify the needs of a carer. People with support needs have an assessment of their own, which can be called a community care assessment or an assessment of care needs.

**Capacity:** This is when people who are aged 16 or over are legally capable of making personal decisions for themselves and of managing their own affairs. People who cannot do this because of an illness, disability or condition do not have capacity.

**Direct payment:** Your direct payment is money that is paid to you, usually into a separate bank account in your name, to pay for your support needs. You manage this money and it must be spent on services that meet your support needs.

**Eligibility criteria:** The council's rules on who can get support. The rules are based on the level of risk to a person if they do not get support, or the risk to a carer if they do not get support to help them to care.

**Guardianship:** A guardianship order is a court appointment which authorises a person to take action or make decisions on behalf of an adult with incapacity.

**Individual budget:** Money that is allocated to you by your local council to pay for care or support to meet your assessed needs. The way the budget has been decided should be clearly explained by the professional working with you. You should be given the chance to agree the budget before the support plan is put into action.

**Outcomes:** 'Outcomes' means the benefits or positive changes you should experience as a result of the support provided to you. Your outcomes will be decided by you, and will reflect what matters most to you and what you want to change.

**Personal assistant:** A person who provides support to you who you directly employ through a direct payment (Option 1).

**Power of attorney:** Power of Attorney (PoA) is a written document that says someone can make decisions on behalf of someone else. Carers often have PoA for the people they're looking after when the person is no longer able to make decisions or communicate by themselves.

Continuing power of attorney is a power to look after someone's property or money, if they are not able to handle things by themselves or make decisions.

Welfare power of attorney is a power to make decisions about someone's personal health and care needs, if they are not able to decide this for themselves.

**Service provider or support provider:** A service provider is an agency, voluntary organisation or local authority that provides or arranges your support services. It could be:

- An organisation that provides staff and other support to you (sometimes people call these care providers or care agencies).
- A personal assistant that you employ to support you
- The council or the NHS
- Or any organisation that provides a service that could help you

**Support plan:** A document that identifies how an individual's support needs will be met. A support plan is drawn up following the assessment process between the council and the individual.



This guide has been produced in partnership by the following organisations:



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