



# Dementia, SDS and Promoting Individual Autonomy:

## A guide to self-directed support for people with dementia



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# Introduction

We are all entitled to have control over our own lives and to live as independently as possible. This is often referred to as “exercising autonomy” and applies to people with dementia as much as it does to anyone else. Having capacity to make decisions and being able to exercise legal capacity is important to making sure that this happens.

Self-directed support (SDS) is the main approach to delivering social care in Scotland. It is an important way in which people with dementia can make their own decisions and choices about how they live their life. “Social care” means services which provide support to improve your quality of life in the community and allow you to continue to live independently. Social care is also sometimes called “community care services” in legislation and practice.

## What will this guide do?

This guide will explain:

- ▶ What self-directed support is;
- ▶ How adults with dementia may access self-directed support and/or be assisted by carers and others to do this; and
- ▶ How self-directed support may interact with other legislation relevant to people with dementia.

## Who is this guide for?

This guide is relevant to:

- ▶ People with dementia who are eligible for social care support;
- ▶ The carers of adults with dementia; and
- ▶ Third sector and other health and social care professionals.

## Why is this guide necessary?

Exercising autonomy is an important part of our wellbeing. Human rights law makes it clear that it is essential to respect and support the autonomy of people with dementia. As self-directed support is a way in which this support can be provided, it is important to know when, why and how this operates. It is also important to know how you can access self-directed support and, where necessary, be supported to access and make choices about your support.

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## What this guide will not do

This guide provides general guidance only. It cannot be a complete guide to the law, and should not be treated as legal advice. If you need legal advice, you should contact a specialist legal adviser **as soon as possible**.

This guide has been written to reflect the law as it stands in October 2018. It does not represent the views of the author. It is also important to note that the law can and does change over time, as a result of developments in legislation, case-law and practice.

This guide will look at self-directed support for adults with dementia only (referred to as “people with dementia”). However, self-directed support is also available to children and other adults who are assessed as being entitled to it. Information about self-directed support for children and other adults may be available from some of the organisations mentioned in the Appendix to this guide.

# Introduction to Key Terms

## Capacity

Having capacity means being able to make a decision and have that decision respected by others.

You may **not** have capacity<sup>1</sup> if you have a physical or mental condition and even with support:

- ▶ Are unable to make a decision; or
- ▶ Do not understand the consequences of a decision you have made; or
- ▶ Do not remember a decision you have made; or
- ▶ Are unable to let others know about a decision you have made; or
- ▶ Are unable to carry out a decision you have made.

These decisions may be about everyday matters such as who you spend your time with; how you spend your time; or where and with who you live. They may also be about money and property matters, or about care and treatment for a physical or mental health condition.

It is important to realise that it is often possible to receive support (“supported decision-making”) to overcome difficulties in making and carrying out decisions. In this case, you will still have capacity and your decisions must be respected. Supported decision-making will be explained in more detail later in this guide.

It is also important to realise that capacity is not an all or nothing concept. You may not have capacity to make a decision about one thing but be perfectly capable of making a decision about something else. For this reason, capacity has to be looked at on a decision-by-decision basis: it is “decision-specific”.

## Exercising legal capacity

Exercising legal capacity means having the decisions you have made respected by others and under the law. This applies even where you have received support to make these decisions.

<sup>1</sup> For more information about how the law sees capacity in relation to persons with a mental illness, learning disability or dementia see section 1(6) Adults with Incapacity (Scotland) Act 2000 (see also note 23 below) and section 64(5) Mental Health (Care and Treatment) (Scotland) Act 2003. Both Acts’ Codes of Practice also give further details.

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## Autonomy

Having individual autonomy means having the freedom to make your own decisions, without these decisions being made or influenced by someone else. Where you are exercising legal capacity, you are demonstrating individual autonomy.

## Local authorities and health and social care partnerships

The law and guidance around self-directed support places duties on local authorities. However, following a process called “integration”, health and social care services are now delivered by new public bodies called health and social care partnerships, on behalf of local authorities. In practice, this means that social care services may be delivered in the name of your local council, your local health and social care partnership, or even your local health board.

Where the term “local authority” is used in this guide, this includes health and social care partnerships and health boards when they are delivering social care on behalf of the local authority.

# Human Rights

Human rights law supports people with dementia to have control over their own lives and to live as independently as possible.

The relevant human rights here are:

## European Convention on Human Rights (ECHR)

- ▶ The right to respect for private and family life/autonomy (Article 8)
- ▶ The right to freedom from inhuman or degrading treatment/respect for dignity (Article 3)
- ▶ The right to be able to enjoy your human rights without discrimination on the basis of, amongst other things, a disability (including dementia) (Article 14).

## United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

- ▶ The right to exercise your legal capacity on an equal basis with others and to have access to appropriate support in order to do this (Article 12)
- ▶ The right to live independently and be included in the community (Article 19)
- ▶ The right to be able to enjoy your human rights equally with others and without discrimination on the basis of a disability (including dementia) (Articles 3 and 5).

In Scotland, public bodies including local authorities must respect our ECHR rights. Where this does not happen then it is possible to apply to a court for these rights to be enforced.<sup>2</sup> UNCRPD rights cannot be enforced through a court but they are still very important, give weight to ECHR rights, and should be respected.<sup>3</sup> The Scottish Government has made a commitment to ensure that this happens in *A Fairer Scotland for Disabled People – Our Delivery Plan to 2021 for the United Nations Convention on the Rights of Persons with Disabilities*.<sup>4</sup>

<sup>2</sup> Sections 2, 3 and 6 Human Rights Act 1998 and section 57(2) Scotland Act 1998.

<sup>3</sup> Sections 35(1)(a) and 58(1) Scotland Act 1998.

<sup>4</sup> Scottish Government (2016) *A Fairer Scotland for Disabled People – Our Delivery Plan to 2021 for the United Nations Convention on the Rights of Persons with Disabilities* <<http://www.gov.scot/Resource/0051/00510948.pdf>>



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It is often sufficient to simply refer to your human rights in order to ensure that your choices are respected. Applying to a court to have your rights enforced is not always necessary and, hopefully, is a last resort.

For more information on challenging decisions about social care, including information about using human rights arguments, see [Challenging Social Care Decisions in Scotland: A legal guide by Tim Haddow](#) (MECOPP, 2018)

## **Human rights and social care: respecting autonomy and dignity**

The European Court of Human Rights has made it clear that respect for the autonomy of all persons, including persons with dementia, is important. You must only be prevented from exercising your capacity and making your own decisions on a decision-specific basis, meaning that the fact you may not be able to make certain decisions should not prevent you from making others that you are perfectly capable of making. In addition, even where you do lack capacity to make a decision the Court has emphasised that you may still have views about a particular matter and these views must be taken into account.

Article 8 ECHR gives you the right to make choices about how and where you live. This right may only be denied where the law allows it and it is a reasonable response to do this, for example, to prevent a crime or to protect your health.<sup>5</sup> It is important to remember that unreasonably restricting the right to choose where and how you live because you have dementia may be discrimination.<sup>6</sup>

The European Court of Human Rights and the UK courts tend to allow public bodies a wide discretion about how they provide social care.<sup>7</sup> However, European Court of Human Rights case law has made it clear that if you have dementia and are refused support that is essential for you to enjoy your private and family life then this may not respect your Article 8 rights.<sup>8</sup>

A failure to provide social care where you are in extreme need or providing you with very poor services may also not respect your right to dignity (Article 3 ECHR).<sup>9</sup>

<sup>5</sup> Article 8(2) ECHR.

<sup>6</sup> *Glor v Switzerland* (Application No 13444/04), judgment of 30 April 2009.

<sup>7</sup> See, for example, *Stec v United Kingdom* (2006) ECHR 393, *McDonald v United Kingdom* (2014) ECHR 4241/12 and *Watt v Lothian Health Board* 2015 CSOH 117.

<sup>8</sup> *Botta v Italy* (1998) 26 EHRR 241 and *Senteges v Netherlands* (2004) 7 CCL 400.

<sup>9</sup> *Price v United Kingdom* (2003) 34 EHRR 53 and *Stanev v Bulgaria* (2012) ECHR 46.

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The above ECHR rights are reinforced by the UNCRPD rights mentioned above. These UNCRPD rights strongly promote autonomy, and an enabling approach towards persons with disabilities (which includes people with dementia). The Committee on the Rights of Persons with Disabilities, which monitors how well UNCRPD rights are respected in different countries, has made it clear that people with dementia must be able to exercise their autonomy (including legal capacity) on an equal basis with others and to receive proper support to do this.<sup>10</sup> The same Committee has also made it clear that this is important for independent living<sup>11</sup> and that social care is a tool for effective independent living.<sup>12</sup> Such social care must be assessed on the basis of an adult with dementia's needs and circumstances and the person with dementia must control and allocate that social care support.

## **Human rights and social care: equality and non-discrimination under the Equality Act 2010**

It is clear from both the ECHR and UNCRPD that people with dementia are entitled to enjoy their rights on an equal basis with others and without discrimination. The fact that a person has dementia is no reason to say they have reduced human rights. It is therefore discrimination to deny a person with dementia services and support simply because they have a diagnosis of dementia.

If you have dementia and a local authority fails to provide you with appropriate support then it may be possible to argue that this is discrimination under the Equality Act 2010.<sup>13</sup>

<sup>10</sup> UN Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014) Article 12: Equal recognition before the law. Geneva: UN Committee on the Rights of Persons with Disabilities. CRPD/C/GC/1. 11 May 2014.

<sup>11</sup> UN Committee on the Rights of Persons with Disabilities, General Comment No. 5(2017) on living independently and being included in the community. CRPD/C/GC/5. 27 October 2017.

<sup>12</sup> Paragraphs 16 and 17, UN Committee on the Rights of Persons with Disabilities, General Comment No. 5(2017) (above).

<sup>13</sup> Sections 6 and 29 Equality Act 2010.

# Self-Directed Support

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## What is self-directed support and who is entitled to it?

People with dementia may receive social care support and services under the Social Care (Self-directed Support) (Scotland) Act 2013. This is called “self-directed support”.

If you have dementia, and are assessed as having social care needs, the Social Care (Self-directed Support) (Scotland) Act gives you four options about how such care is delivered. As mentioned, it is an important way in which you can make your own decisions and choices about how you lead your life.

These options for how social care is delivered are:

1. A direct payment; or
2. You choose the support you need, and the local authority or another organisation arranges the support; or
3. The local authority arranges the support; or
4. A combination of any of the above.

For more information on self-directed support and how it is assessed see [Factsheet: A Guide to Self-directed Support](#) (MECOPP, 2017).

## Self-directed support principles

The Social Care (Self-directed Support) (Scotland) Act 2013 sets out some important principles that must be applied by local authorities carrying out social care assessment and providing social care support. These principles very much reflect the human rights principles mentioned above and include a duty on the local authority to:

- ▶ **Involvement:** Involve you as much as you want in the assessment of your needs for support and services and how these are provided.
- ▶ **Assistance:** Provide any assistance reasonably required to help you to express your views and make informed choices.
- ▶ **Participation and dignity:** Take reasonable steps to respect your right to dignity and to take part in the community in which you live.
- ▶ **Collaboration:** To work with you when assessing your social care needs.

## Assistance in making and communicating decisions about self-directed support

The self-directed support legislation recognises that some people, including some people with dementia, may find it difficult to make and/or communicate decisions about their social care support.

The local authority must provide any assistance that is reasonably required to enable you to make a decision about the type of social care you would like.<sup>14</sup>

Where the local authority gives you the opportunity to choose one of the self-directed support options it must provide you with:<sup>15</sup>

- ▶ An explanation about each of the options
- ▶ Information about how to manage support
- ▶ Information about persons (including persons who are not employed by the local authority) who can provide:
  - Assistance or information to help make decisions about the options
  - Information about how to manage support
- ▶ Where the local authority considers it appropriate, information about independent advocates.

This information must be provided in writing and, if necessary, in another format to meet your needs. This could include providing information in large print, braille, or in another language.

Where you do not have a guardian or welfare or continuing attorney, and there is no relevant intervention order in place (see p16), then the local authority must take reasonable steps to enable you to choose the services or support that you want to receive. This includes identifying persons who are able to assist you. If you agree, then such persons should be involved in assisting you to make decisions and communications about the social care assessment and self-directed support options.<sup>16</sup>

The next section of this guide will look at some of the ways in which support for making or communicating decisions about social care may be provided to people with dementia.

<sup>14</sup> Social Care (Self-directed Support) (Scotland) Act 2013, section 1(3).

<sup>15</sup> Social Care (Self-directed Support) (Scotland) Act 2013, section 9.

<sup>16</sup> Social Care (Self-directed Support) (Scotland) Act 2013, section 6.

## Supported Decision-Making

### What is “supported decision-making” and why is it relevant to self-directed support?

As mentioned above, sometimes people with dementia may need support to make decisions and to make sure that those decisions are respected under the law. Article 12 UNCRPD<sup>17</sup> requires that appropriate support for the exercise of legal capacity must be made available to do this. This is so that what you would like to happen (the UNCRPD refers to this as your “will and preferences”), is respected in the same way as for everyone else. This support is often referred to as “supported decision-making”.

Supported decision-making should be provided to assist you to make your own decisions and have these respected. As above, the self-directed support legislation specifically requires support to be provided to help you make and communicate decisions about social care support. Where you have a guardian or an attorney, or where there is an intervention order, then the guardian, attorney or intervener should also provide or help you access the necessary support for decision-making. They should make sure that what you want to happen is reflected in all decisions made that concern you (see p16 below for more information about this).

Supported decision-making can come in many forms and to be effective must meet your particular needs. It may also involve more than one type of support and may or may not be formally recognised under the law. What is essential is that the support ensures that your wishes and feelings are genuinely at the centre of all decisions that concern you, including decisions about your care and support.

### Types of supported decision-making

One or more of the following types of supported decision-making might be used to ensure that you are able to express your views about self-directed support and have such views respected.

#### A trusted person or persons and “circles of support”

In the context of self-directed support this might include individuals or “circles of support”. These individuals or “circles of support” might include unpaid carers, family members, partners, friends, neighbours, community organisations, professionals (including health and social care professionals), guardians or attorneys.

<sup>17</sup> Articles 12(3) and 12(4) UNCRPD.

## Example

Jean is 84 years old and has a diagnosis of vascular dementia. Her husband Peter died last year. Since then, she has lived alone. It is becoming clear to Jean and her family that she needs some extra help to continue living safely in her own home.

Jean has very strong views about how she would like to live her life – she enjoys living in her own home, and values her independence. She has a routine that works well for her, and enjoys attending a local line dancing class on a Thursday and church on a Sunday. She is very clear in these views. However, Jean now finds it difficult to keep track of complex information and to make more complicated decisions, especially about money.

Jean's allocated Social Worker, Yvonne, carries out an assessment and agrees that Jean needs some support. Yvonne also thinks that Jean would benefit from having some assistance to make decisions about her support.

Yvonne knows that Jean has a daughter, Margaret, who lives in Wales but who visits regularly. Yvonne has also met Jean's neighbour, Frieda, who sees Jean almost every day and goes to her line dancing class with her. Jean also tells Yvonne that one of the elders from her Church, Fiona, has been a great support since her husband died.

Yvonne asks Jean whether she would be comfortable with Margaret, Frieda, and Fiona helping her to make decisions about her support. Jean agrees, and Yvonne arranges a meeting during one of Margaret's regular visits. Together, Jean and her "circle of support" (Margaret, Frieda, and Fiona) discuss the four options for self-directed support with Yvonne and Jean decides that option 2 will work best for her. They then help Jean to choose a support provider and decide how the support package will fit together so that the support worker's visits fit in with Jean's routine and don't clash with any of the social activities that she enjoys.

Jean knows that she would have found it difficult to understand the four self-directed support options without assistance, and would definitely have found it hard to keep track of all the information she was given about support providers and their services. Thanks to the support of the people who understand her and her routine, she has been able to choose support that suits her and allows her to continue doing the things she enjoys.

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## Peer support

This might include your friends or other individual or groups with similar lived experience of dementia and/or accessing self-directed support.

## Advocacy

The Scottish Independent Advocacy Alliance says that, “Independent Advocacy is a way to help people have a stronger voice and to have as much control as possible over their own lives. Independent Advocacy organisations are separate from organisations that provide other types of services. An independent advocate will not make decisions on behalf of the person/group they are supporting. The independent advocate helps the person/group to get the information they need to make real choices about their circumstances and supports the person/group to put their choices across to others. An independent advocate may speak on behalf of people who are unable to do so for themselves.”<sup>18</sup>

The Scottish Independent Advocacy Alliance has made it clear that independent advocacy must be directed by the person concerned and assist them to have control over their own lives.

The Scottish Government<sup>19</sup> states that one of the main themes of independent advocacy is to speak up for people who are not being heard, help them to express their own views and make their own decisions.<sup>20</sup>

Anyone with dementia is entitled to independent advocacy. This will be discussed in more detail on p21. The self-directed support legislation requires local authorities to provide information about independent advocacy to people accessing self-directed support where it considers that this is appropriate.<sup>21</sup>

If you have dementia you might personally ask an advocate to help you (this is referred to as “instructed advocacy”). Where, despite significant attempts, it is not possible to ascertain what you want or what you would prefer, an advocate may be asked to help you (this is referred to as “non-instructed advocacy” because you have not personally appointed the advocate). However, it is important that non-instructed advocacy always provides a best interpretation of what you would want to happen.

Advocacy might also be collective. This is where a group of people with similar experiences or interests to your own represent their and your will and preferences.

<sup>18</sup> <https://www.siaa.org.uk/us/independent-advocacy/>

<sup>19</sup> Scottish Government (2013) *Independent Advocacy: Guide for Commissioners*, page 5  
<http://www.gov.scot/Resource/0044/00441045.pdf>

<sup>20</sup> The other main theme is safeguarding individuals who are at risk.

<sup>21</sup> Social Care (Self-directed Support)(Scotland) Act 2013, section 9(2)(d).

## Assistance with, and clear, communication

It is essential that information is presented clearly either orally, in writing or by pictures. It must be presented in a way that is understandable to you and, depending on your particular needs, includes sign language, translation or interpretation, speech and language therapy, and other means of communication. As above, the self-directed support legislation requires certain information to be provided in writing, and in other formats where necessary.<sup>22</sup>

## Technological support

This might include iPads, Talking Mats and other forms of technology. Making a record of your decisions and decision-making processes may also help you with decision-making in the future.

## Advance planning

You may wish to make arrangements in advance, in writing or recorded in another way, so that everyone is clear about what you want to happen if later you are unable to express your wishes. You are, however, entitled to change your mind. It is therefore important that before anyone relies on your wishes in any advance planning arrangement they make absolutely sure that you, through words or actions, still hold these views.

- ▶ **Anticipatory care plans** are one example of advance planning in the context of self-directed support. These care plans may, for example, set out the type of support you would like after a diagnosis of dementia.
- ▶ **Powers of attorney** are another potential type of advance planning. When you have capacity you may grant powers to another person to manage your financial (continuing) or welfare affairs, or to an organisation to manage your financial (continuing) affairs. Financial powers in a power of attorney can come into effect before or after you lose capacity. Welfare powers only come into effect after you lose capacity. The Adults with Incapacity (Scotland) Act 2000 regulates the making and use of powers of attorney.

When granting the power of attorney you can decide:

- Who the attorney or attorneys will be.
- Whether or not the attorney can use their financial powers before you lose capacity.
- Exactly how, and by whom, your lack of capacity will be decided.
- The powers that the attorney will have.

<sup>22</sup> Social Care (Self-directed Support)(Scotland) Act 2013, section 9.



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There are virtually no limitations on who you can appoint as your attorney or what powers they grant. The only restrictions imposed are to protect your autonomy. For example, a solicitor acting for you when granting the power of attorney must be satisfied that this is your own and no one else's decision.

The Adults with Incapacity (Scotland) Act 2000 Code of Practice encourages those granting a power of attorney to have detailed discussions with those they intend to appoint to make sure that they are fully aware of their likes, dislikes and values. See p16 below for more information about the role of attorneys and self-directed support.

Further information about types of supported decision-making and how it works can be found in [Mental Welfare Commission for Scotland Supported Decision-Making: Good Practice Guide \(2016\)](#).

## **How can supported decision-making help a person with dementia make choices about self-directed support?**

Self-directed support allows people who are eligible for social care support to make important choices and decisions about how they lead their lives. If a person with dementia is eligible for self-directed support, it is important that choices about how they use such support are made by them.

If you have dementia you may be able to access and make choices about self-directed support on your own. It may, however, be that you require support to make decisions about self-directed support. You may be able to seek, access and use such supported decision-making yourself or with the support of your carers, guardians or attorneys.

If you are unable to access self-directed support on your own, then your carers, guardians and attorneys may need to assist you to access self-directed support and to make decisions about it. Carers, guardians and attorneys may also need to seek and access other forms of supported decision-making to help you access and make decisions about self-directed support.

As mentioned above, supported decision-making comes in many forms and to be effective must meet your particular needs. Importantly, the person providing the support must not seek to influence the decision so that it is made only or mostly for their benefit. It is essential that the support maximises your ability to ensure that what you want is at the centre of all decisions that concern you.

# Self-Directed Support and the Adults with Incapacity (Scotland) Act 2000

The Adults with Incapacity (Scotland) Act 2000, amongst other things, authorises the granting of guardianship and intervention orders and regulates their use. It also regulates the use of powers of attorney.

A carer may have powers as a guardian or attorney to act for a person with dementia who lacks capacity. If this is the case, then they must exercise these powers with the Adults with Incapacity Act and human rights principles in mind at all times. This also applies to situations involving self-directed support.

Importantly, these principles mean not making decisions on behalf of the adult where the adult is able to make such decisions. Capacity is not an all or nothing concept.<sup>23</sup> A person may have capacity to make decisions about some things but not others. They may therefore be able to make decisions about self-directed support when they cannot make decisions about other matters.

It also means that any decision taken by a guardian or attorney about self-directed support must take the person's wishes and feelings into account, be for their benefit and be the least restrictive option for that person.

## If self-directed support is being sought for an adult with incapacity, carers, professionals, guardians and attorneys must check:

### 1. Does the adult lack capacity to make decisions about self-directed support?

It is essential to first check whether or not the person with dementia is able to make their own decision and, where necessary, to support them to do this. It is only where it is impossible for the person to make their own decisions about self-directed support, even with support, that the powers under a guardianship or power of attorney should be considered.

<sup>23</sup> An "incapable adult" is defined in section 1(6) of the Adults with Incapacity (Scotland) Act 2000 as being a person who is:

"...incapable of—

- (a) acting; or
- (b) making decisions; or
- (c) communicating decisions; or
- (d) understanding decisions; or
- (e) retaining the memory of decisions,

as mentioned in any provision of this Act, by reason of mental disorder or of inability to communicate because of physical disability;.."

Importantly, the Act also states that a person is not "incapable" if they simply cannot communicate at all or well but that these problems with communication can be overcome by human or mechanical assistance.

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## 2. Does the guardian or attorney have the power to act in relation to self-directed support?

If the person lacks capacity to make decisions about self-directed support then anyone who has powers to act under a guardianship or power of attorney must:

- ▶ First, make sure that they actually have a specific power to act. If anyone with powers to act under a guardianship or power of attorney is unsure whether or not they are able to act on behalf of the person in relation to self-directed support they should seek legal advice. It may also be advisable to apply to the Sheriff Court for guidance.
- ▶ Always make sure that the person's wishes and feelings are reflected in the decisions taken. Any means of communication appropriate to the person can be used to ascertain their wishes and feelings. It also means encouraging and supporting the person to make their own decisions wherever possible and to give effect to these decisions.

## Support for decision-making relating to self-directed support

See p11 of this guide for suggestions of the types of supported decision-making that may be used. This support may be provided by the carer, professional, guardian or attorney themselves or by one or more other means. It should be remembered that local authorities are under a duty<sup>24</sup> to provide an explanation of and information on the self-directed support options that are available to the adult (see p10 of this guide).

*Note: The Scottish Government is currently considering proposals for reform of the Adults with Incapacity (Scotland) Act. The changes that will be made to the Act are not yet known. However, it is possible to safely assume that, in line with international human rights requirements, these will further reinforce the exercise of autonomy of persons with mental disabilities and support for this.*

<sup>24</sup> Section 9 Social Care (Self-directed Support) (Scotland) Act 2013.

## Example

Naveed is 80 years old. He has been diagnosed with Parkinson's disease dementia. Over the last few years, he has found it increasingly difficult to remember information and make decisions. He also now finds it difficult to communicate verbally, as he struggles to find words. As a result of Parkinson's disease, his mobility is affected and he now spends most of the day in his chair watching TV. Naveed has a daughter, Laila, who lives nearby. Naveed granted power of attorney to Laila shortly after he was diagnosed with dementia.

Naveed has had a package of care for a few years. The package has been arranged by the Local Authority, and care assistants who work for a local care company call in first thing in the morning and in the evening to help Naveed with personal care. However, it is clear to everyone involved that Naveed's needs have increased and that he now needs more help during the day, especially with food preparation, eating meals, and taking his medication regularly.

Naveed's Social Worker arranges a review of the care package. Naveed's GP, who knows him well, confirms that he does not think Naveed would be able to participate in discussions about his care package and that he lacks capacity to make decisions about his care and support. Laila and the Social Worker check the terms of the power of attorney document, which states that Laila can make decisions about care and support on Naveed's behalf. The power of attorney also allows Laila to manage Naveed's finances, and specifically states that Laila can manage a direct payment on Naveed's behalf.

The Social Worker explains the four options for self-directed support to Laila and Naveed. Naveed lived in Pakistan until he was in his 60s, and has always been a practising Muslim. Laila is concerned that the current care provider may not understand the cultural and religious considerations that apply, particularly around preparing food. Laila knows that the daughter of a neighbour is a very good cook, and is looking for work that fits around caring for her young family. Her name is Mina. However, Laila also knows that her father would not be at all comfortable with receiving personal care from someone he knows, especially not a young woman.

Laila thinks it would work well if she uses a direct payment to employ Mina for a few hours during the day, but the care provider continues to call in twice a day to provide personal care. Laila explains this plan to her father. Naveed doesn't really understand about the self-directed support options, but he remembers Mina and remembers that she is a good cook like her mother. He nods to show that he is happy for Mina to help him during the day. He also nods when Laila asks him if he is happy with the current care provider helping him with personal care. Laila and the Social Worker arrange the package of care under self-directed support option 4.

Although Naveed has not been able to make decisions about his own care and support, or manage his own direct payment, Laila has taken care to think about the wishes and feelings that her father has expressed in the past, particularly around religious and cultural issues. She has also taken steps to seek her father's views on the proposed care package, although ultimately she has made the decisions on her father's behalf as his attorney.

# Self-Directed Support and the Mental Health (Care and Treatment) (Scotland) Act 2003

The Mental Health (Care and Treatment) Act 2003 applies to people who have a “mental disorder”. The term “mental disorder” includes dementia.

## Ensuring the most appropriate and least restrictive care and treatment environment

A person with dementia may be subject to a Compulsory Treatment Order under the Mental Health (Care and Treatment) Act. If they are living in the community they may also be eligible for self-directed support.

This is relevant to how restrictive the care and treatment authorised under the Mental Health (Care and Treatment) Act is. It may influence decisions about whether the care and treatment takes place in hospital or in the community. It may also influence whether or not compulsory care and treatment authorised under the Act is actually required.

The Mental Health (Care and Treatment) Act and human rights principles require that a person with dementia’s autonomy and ability to live independently is respected as much as possible. The Act requires that decisions about care and treatment: take into account the person’s present and past wishes and feelings (as far as it is possible to tell what these are); will be the minimum restriction on the person’s freedom; and provide maximum benefit to the person in their particular circumstances. The Act also requires that the person’s abilities, background and characteristics be taken into account. This includes their age, sex, sexual orientation, religious persuasion, racial origin, cultural and linguistic background and membership of any ethnic group.

## If self-directed support is being sought for a person with a mental disorder (including dementia), carers, professionals, guardians or attorneys must check:

### 1. Does the person with a mental disorder have capacity to make decisions about self-directed support?

It is essential to first check whether or not the person is able to make decisions for themselves and, where necessary, to support them to do this. As mentioned above, capacity is not an all or nothing concept. A person with

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a mental disorder may not have capacity<sup>25</sup> to make decisions about aspects of their care and treatment for their mental disorder but still be able to make decisions about self-directed support.

## **2. Does someone else have the legal authority to make decisions on the person's behalf?**

If the person is not able to make decisions about self-directed support, even with support, then only an attorney or guardian with the appropriate powers can make these decisions on their behalf. See p16 above for more information about when and how attorneys and guardians can make such decisions.

## **Support for decision-making in relation to self-directed support**

When considering available support for the person with dementia note that under section 259 of the Mental Health (Care and Treatment) Act every person with a mental disorder (including every person with dementia) is entitled to receive independent advocacy whether or not they are actually receiving care and treatment under the Act.

It is also important to remember that a local authority has a duty<sup>26</sup> to provide an explanation of and information on the self-directed support options that are available to the adult (see p10 of this guide).

See p11 above for possible types of supported decision-making. This support may be provided by the carer, professional, an attorney or a guardian themselves or in one or more ways.

<sup>25</sup> The "capacity" test under the Mental Health (Care and Treatment) (Scotland) Act 2003 is where the person has "significantly impaired decision making ability" because of the mental disorder (section 64(5)(d)).

<sup>26</sup> Section 9 Social Care (Self-directed Support) (Scotland) Act 2013.

## Example

Mary is 75 years old. She is a widow. She has two daughters, Mercy and Grace. Mercy lives in Birmingham, and Grace lives in London. Mary has recently been diagnosed with dementia.

Mary has been forgetting to take her medication, and has also left the oven on a couple of times. Mary knows that it is no-longer safe for her to live alone.

A case conference is organised, which is attended by Mary, her daughters, her GP, her consultant psychiatrist, her social worker and her Community Psychiatric Nurse. Mercy and Grace both want Mary to live with them, and quite a heated argument breaks out about who is better placed to look after Mary. Mary doesn't like to see her daughters argue, and becomes upset. She finds the whole case conference, with so many professionals talking about her, quite intimidating.

The Social Worker feels that Mary has not been able to express her views at the case conference, so it is agreed that another case conference will take place in a few weeks' time. In the meantime, the Social Worker will make a referral to a local independent advocacy organisation, so that Mary has the opportunity to be supported by an advocacy worker at the next case conference.

A few days later, Mary meets with Kristina. Kristina is an independent advocate. Kristina and Mary have a long discussion about where Mary would like to live. Mary accepts that she cannot continue to live in her own home, and admits that she has been very lonely since her husband died. However, Mary is very clear that she doesn't want to live in England with either of her daughters. She wants to live in a local care home, where she would have support but still be able to remain active in her local community and see her friends.

At the next case conference, Kristina supports Mary to tell her family and the professionals what she would like to do. Mary feels much more confident with Kristina's support. At the end of the case conference, it is agreed that the Social Worker will support Mary to find a place in one of the local care homes. Mary's daughters are a bit put out that their mother doesn't want to live with either of them, but Mary is just pleased they've stopped arguing!



# Self-Directed Support and the Adult Support and Protection (Scotland) Act 2007

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Whilst self-directed support promotes independent living, it is also important that this does not increase the risk of harm to people with dementia.

## Ensuring that self-directed support enhances independent living and does not place people with dementia at risk

The Adult Support and Protection (Scotland) Act 2007 contains principles that support independent living but also allow for public bodies, through a range of options, to intervene to protect an “adult at risk” where necessary.

The Adult Support and Protection Act defines “an adult at risk” as an adult who is unable to safeguard their own well-being, property, rights or other interests and is at risk of harm because their disability, mental disorder, illness or physical or mental infirmity makes them more vulnerable to being harmed than other adults. It applies to individuals with or without capacity to make decisions and may apply to people with dementia. A person with dementia may be at risk of harm because another person’s conduct is, or is likely to, cause them harm or the person themselves is causing, or is likely to cause, self-harm.

The Adult Support and Protection Act’s principles require that any intervention to protect an “adult at risk” must provide benefit to the adult and be least restrictive to the adult’s freedom. The person’s wishes and feelings must also be taken into account. These principles must be taken into account when decisions about self-directed support are being made. Where a person with dementia chooses one of the options for self-directed support the local authority has a responsibility to assess risk, inquire, investigate or, where necessary, intervene to protect them as well as to support their choices.

## Support for decision-making in relation to self-directed support

When supporting a person with dementia to make decisions about self-directed support it is therefore vital that carers, guardians, attorneys and professionals also ensure that the supported decision-making they provide, or help the person to access, does not expose the person to actual or potential harm.

Suggested methods of supported decision-making can be found at p11 of this guide. Importantly, the person or body providing the support must not influence the decision made so that it is only or mostly to their own benefit. It is essential that the support maximises the person's ability to exercise their legal capacity so that their rights, will and preferences are at the centre of all decisions concerning self-directed support.

### Example

Dominic was seriously injured in a car accident 20 years ago. Since then, he has used a wheelchair to get around. He has received a direct payment for a number of years, which he used to employ a personal assistant. Recently, Dominic has become increasingly forgetful. He has been struggling to complete tasks he used to find easy, like making coffee and loading the washing machine. He has become confused about when his PA will arrive, and has started phoning him in the middle of the night to ask why he isn't at work. His GP thinks he probably has dementia, and has referred him for further tests.

Dominic recently got chatting to two young men in a local bar, and they have started visiting him at home a couple of times a week. They ask lots of questions about whether Dominic has any family, and seem very interested in how much money he made in this career as a stockbroker. As it happens, Dominic has no close family so he is pleased to have these young men to talk to. He also has quite a lot of money, so when one of the men starts to mention money trouble Dominic is happy to help him out by lending him some money.

Unfortunately, as Dominic becomes more forgetful and confused, his relationship with his PA breaks down and he hands in his resignation. Dominic tells his new friends about this, and they suggest that Dominic could employ one of them as his PA. They tell Dominic that it would be easier if he just took the cash out of his bank account and paid the new PA "cash in hand".

After a few weeks, the Local Authority notice that the way in which Dominic spends his direct payment has changed. A Social Worker visits him, but he just says that he has all the help he needs and doesn't want anyone else interfering. The Social Worker notes that Dominic, who has always been a very well-dressed gentleman, is wearing a dirty jumper and looks

unkempt. As the Social Worker is leaving, the new PA arrives. He seems unwilling to give his name, evasive about why he is there, and he is wearing a shiny new watch.

The Social Worker is concerned, and an Adult Support and Protection investigation is opened. A referral is made to an independent advocacy organisation. Dominic meets with an independent advocate, Katie, who supports him to attend the case conference. At the case conference, Dominic is able to explain that, whilst he was initially pleased to have new friends, he is no-longer sure that they have his best interests at heart. He explains that he now feels he cannot say no when they ask for money, as they know that he receives a direct payment every month. It is agreed at the case conference that Dominic's care will now be provided by a local care provider, under self-directed support option 2, so that he is not placed at risk by receiving a direct payment. Dominic also accepts that he needs someone to help him manage his finances, to protect him from further exploitation, so he appoints his solicitor as his financial attorney. Once the young men realise that Dominic is no-longer alone for most of the day, and no-longer has ready access to large sums of cash, they soon leave him alone.

## About This Guide

This Guide has been commissioned by MECOPP and the Life Changes Trust as part of MECOPP's 3 R's Project, a self-directed support legal rights project.

MECOPP is an Edinburgh based charity supporting Black and Minority Ethnic carers and carers from other marginalised communities access health, social work and social care services. For more information, see: <http://www.mecopp.org.uk/>

The Life Changes Trust is an independent Scottish charity, established in April 2013 with a £50 million endowment from the Big Lottery Fund. The Life Changes Trust was created to drive real and meaningful improvement in the lives of young people with experience of being in care and people affected by dementia. For more information, see: <https://www.lifechangestrust.org.uk/>

MECOPP's 3 R's Project aims to increase knowledge of existing rights and entitlements under self-directed support, human rights and equalities legislation as well as to build the capacity of third sector organisations supporting individuals to access self-directed support. This guide is part of that work.

MECOPP's 3 R's Project is jointly funded by the Life Changes Trust and the Baring Foundation (see <https://baringfoundation.org.uk/>).

### About the author

This guide has been produced by Professor Jill Stavert, in partnership with MECOPP. Professor Stavert is the Founder and Director of the Centre for Mental Health and Capacity Law at Edinburgh Napier University. Her areas of research and expertise are international, European and national human rights and mental health and mental capacity law, and she works with a number of public and voluntary sector organisations and bodies and regulatory bodies in the field of mental health, mental capacity and/or human rights.

### Feedback on this guide

MECOPP welcomes feedback and comments on this guide.

Any feedback should be sent to: The 3 R's Project, MECOPP, Maritime House, 8 The Shore, Edinburgh EH6 6QN or by email to [info@mecopp.org.uk](mailto:info@mecopp.org.uk).

## Appendix: Useful Resources

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### **iHub Anticipatory Care Planning Toolkit**

iHub Anticipatory Care Planning Toolkit

### **MECOPP**

#### **Self-Directed Support Resources**

[http://www.mecopp.org.uk/resources-3\\_r\\_s\\_project\\_resources.php?section\\_id=401](http://www.mecopp.org.uk/resources-3_r_s_project_resources.php?section_id=401)

### **Mental Welfare Commission for Scotland**

#### **Good Practice Guides**

Supported Decision-Making (2016)

Working with Independent Advocates (2017)

Working with an Interpreter (2018)

Rights in Mind (2017)

*Booklet and other resources*

### **Scottish Independent Advocacy Alliance**

#### **Homepage**

<https://www.siaa.org.uk/>

#### **About Advocacy (2016)**

<https://www.siaa.org.uk/wp-content/uploads/2016/09/SIAA-Autumn-magazine-2016-V2.pdf>

#### **Advocating for Human Rights (2017)**

[https://www.siaa.org.uk/wp-content/uploads/2017/09/SIAA\\_Advocating\\_Human\\_Rights\\_Guide.pdf](https://www.siaa.org.uk/wp-content/uploads/2017/09/SIAA_Advocating_Human_Rights_Guide.pdf)

### **Scottish Government**

#### **Statutory guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013 (2014)**

<http://www.gov.scot/Publications/2014/04/5438>

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### **Self Directed Support: My Support My Choice website**

<http://guidance.selfdirectedsupportscotland.org.uk/>

*Information about self-directed support for people who use social care services and health and for social care professionals.*

### **Local Self-Directed Support Information and Support**

#### **Self Directed Support Scotland homepage**

<https://www.sdsinfo.org.uk/>

### **Local Support for Carers**

**Care Information Scotland has compiled a list of links for local carers centres:**

<http://www.careinfoscotland.scot/topics/support-for-carers/carers-centres/>

# Notes

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**The Baring  
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