



**Health and
Social Care
Standards**
My support, my life.

Understanding and using the Health and Social Care Standards

A booklet for unpaid carers



Scottish Government
Riaghaltas na h-Alba
gov.scot

Any enquiries regarding this publication should
be sent to us at

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

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Introduction

The new Health and Social Care Standards (the Standards) set out what we should expect when using health, social care or social work services in Scotland. They seek to provide better outcomes for everyone; to ensure that individuals are treated with respect and dignity, and that the basic human rights we are all entitled to are upheld.

The new Standards have been written for both people experiencing and people providing care and support. They focus on people rather than policies, paperwork and property. Instead of setting out a list of inputs that all providers must meet, these Standards are much more outcome-focused and will help everyone focus on what really matters – the experience of the cared for person.

Who is this booklet for?

This booklet is to help unpaid carers to understand and use the new Health and Social Care Standards.

An unpaid carer is anyone of any age who cares, **unpaid**, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. This can be for any number of hours and does not need to be on a substantial or regular basis.

The term 'carer' is often used to refer to paid care workers, who are employed by the local authority or by independent agencies to provide care and support to people who need it. It is important to make this distinction: unpaid carers carry out a lot of the same tasks as paid care workers but also have the additional emotional impact of looking after a friend or family member. When the term carer is used in the Standards, this refers to unpaid carers.

Providing unpaid care to someone, especially without support or the chance for a break from caring, can have an impact on a person's financial situation, employment prospects and leisure opportunities, and physical and mental health. This means it is important that carers know where and how to access support for themselves as well as supporting the person they care for.

There is more information at the back of this booklet for carers to find out how to access support with their caring role.

What is this booklet about?

This booklet has been written to help carers understand how the Health and Social Care Standards relate to their caring role and to ensure that they are involved in planning and support. The Standards set out what people should expect when experiencing health, social care or social work services in Scotland. They seek to provide a better care experience for everyone; to ensure that individuals are treated with respect and dignity, and that the basic human rights we are all entitled to are upheld. This booklet explains what the Standards mean for unpaid carers and the people they look after.

You can find the Standards here: www.newcarestandards.scot

The Standards are underpinned by five principles:



The Standards are for everyone – especially including people who experience care and support and those that help to provide it.

What might the Standards mean for me as a carer?

Looking after someone can be challenging at times, and unpaid carers can use the Standards as a guide for finding high quality, suitable care when supporting the person they look after to choose a service. This applies whether the person is cared for in their home, in a residential care setting, or in hospital.

The Standards help carers to have clear expectations about what care and support should be available for the person they look after, and how they should both be involved.

For unpaid carers, the principle of Be included is very important. The person experiencing care should have as much direct control as possible. Carers are equal partners in care and experienced in the care they provide, and should, therefore, be involved in care and support planning and provision for the person they look after, where this is what that person wants.



The Standards most applicable to carers are listed below.

1.13	I am assessed by a qualified person, who involves other people and professionals as required.
2.12	If I am unable to make my own decisions at any time, the views of those who know my wishes, such as my carer, independent advocate, formal or informal representative, are sought and taken into account.
2.17	I am fully involved in developing and reviewing my personal plan, which is always available to me.
3.7	I experience a warm atmosphere because people have good working relationships.
3.13	I am treated as an individual by people who respect my needs, choices and wishes, and anyone making a decision about my future care and support knows me.
3.19	My care and support is consistent and stable because people work together well.
4.16	I am supported and cared for by people I know so that I experience consistency and continuity.
4.17	If I am supported and cared for by a team or more than one organisation, this is well coordinated so that I experience consistency and continuity.
4.18	I benefit from different organisations working together and sharing information about me promptly when appropriate, and I understand how my privacy and confidentiality are respected.
4.26	If I have a carer, their needs are assessed and support provided.

Examples of carer involvement and the Standards

The following case studies illustrate how the Health and Social Care Standards can be applied to carer involvement practices across a range of health and social care services.

1.13 I am assessed by a qualified person, who involves other people and professionals as required.

What does this mean for me? As a carer, you should be involved in the assessment of the person you look after. The adult carer support plan or young carer statement will capture information about the care and support needs of the person you look after and what you do as part of your caring role, such as practical support.

Lucy is 12 years old and lives with her mum, dad and brother, Aidan. Aidan is 17 and has cerebral palsy. Lucy's parents provide most of Aidan's practical care, but she helps with housework and spends a lot of time with him when he is at home, making sure he is happy and has everything he needs.

As Aidan is nearly 18 he is preparing to transition from children's services to adult services, and his care and support needs are being reviewed as part of this. It is important for Lucy to be involved in the assessment as it is likely she will provide more care and support to him as she gets older. Her parents and the health and care professionals make sure she is given opportunities to talk about her caring role and how she supports Aidan. Lucy also has her own young carer statement, which focuses on making sure her own needs and personal outcomes are discussed, that she understands the support which is to be provided to her as a young carer, and who to contact if there are any concerns about the intensity of her caring role.

2.12 If I am unable to make my own decisions at any time, the views of those who know my wishes, such as my carer, independent advocate, formal or informal representative, are sought and taken into account.

What does this mean for me? It means that your role as a carer is valued by health and social care professionals, and your knowledge and experience is considered in the care needs of the person you look after. When the person you look after is unable to make their own decisions, your views are sought and taken into account as soon as possible.

Jason cares for his adult son, Calum, who has bipolar disorder. An advance statement has been prepared, which is actioned if Calum's condition deteriorates and he refuses to attend medical appointments or take medication. The advance statement makes clear that Jason can make decisions about Calum's care and support, including if medication needs to be altered or admission to hospital is required. Calum agrees with the content of this advance statement, which was prepared at a time when he was well. If Calum's mental health seems to be deteriorating but he still has capacity to make decisions, Jason can still provide valuable information to health and care professionals and Calum is encouraged to keep Jason involved in discussions about care and treatment. The advance statement is regularly reviewed with input from both Calum and Jason.

2.17 I am fully involved in developing and reviewing my personal plan, which is always available to me.

What does this mean for me? It means that you are properly involved in any plan to support you as a carer (an adult carer support plan or young carer statement).

It also means that the person you look after is involved in decisions about their support planning. You also have the right to have your own views taken into account, as well as the level of care that you are willing and able to provide. If your own decisions about the care and support you are able to provide do not quite fit with the decisions made by the person you look after, health and care professionals should help you to come to a solution.

George is 22 and has autism. He wants to move away from home and into supported accommodation; up until this point he has been living with his parents, who have provided fluctuating levels of care since he reached adulthood. George's parents are a little bit worried about him leaving home and moving into supported accommodation, as they like that he lives at home with them, but George is keen to move out as he is getting older and wants to be more independent. After discussing options, meeting with potential support services and talking about how his parents can still support him if he lives away from home, George is able to move to a shared flat with other young people who have additional needs. His parents are still involved in many aspects of his care, such as taking him food shopping and providing emotional support, and there is a personal assistant based at the flat who also helps George to live independently.

3.7 I experience a warm atmosphere because people have good working relationships.

What does this mean for me? This means that the services who are providing care to the person you look after are compassionate, confident and work together well, which is reflected in the way that you are involved and supported.

Alf and Morag are kinship carers for their niece, Isla, who has a range of severe and complex health problems. Isla is in and out of hospital quite frequently but has a complex care package with services provided by the local authority, NHS and a children's hospice. The kinship care arrangement has been in place for almost a year and staff at all the services who work with Isla have given Alf and Morag the right information and support they need to look after her, taking time to explain things when this is needed. The complexity of Isla's care package requires strong working relationships between different sectors and services.



3.13 I am treated as an individual by people who respect my needs, choices and wishes, and anyone making a decision about my future care and support knows me.

What does this mean for me? This means that anyone supporting you or the person you look after listens to you and treats you both with respect. It also means that anyone making decisions about future support for you or the person you look after should try to understand what is important to you both as individuals.

Emily looks after her mother, Irene, who has Alzheimer's disease. Irene lives in a care home and was recently admitted to hospital with a chest infection and dehydration. The chest infection and dehydration were treated and Irene was medically fit to leave hospital, but her illness is progressing and a discharge assessment concluded that the current support was no longer suitable as her needs were too complex for the level of care her care home can offer.

The hospital social worker met with Emily and Irene to discuss the way forward. A residential care service that can provide a higher level of care is available, but Irene is happy in the care home she currently lives in and does not want to move.

There was a lot of discussion with Emily, Irene and the staff at the care home who have been looking after her before the hospital admission. Both Emily and Irene's views are taken into consideration when discussing the best way forward. Emily would like her mother to move to another care home as she is concerned that as Irene's condition gets more serious she will need more support, but Emily also recognises the good relationship both she and Irene have with the staff at the current home. The option for specialist dementia care to be provided in the current residential home is raised by the hospital social worker, and both Emily and Irene agree that it would be a good idea to try this and see if it works well.

3.19 My care and support is consistent and stable because people work together well.

What does this mean for me? This means that if you have a concern about the care of the person you look after, you can speak to any organisation also involved in providing care, and work together with them and the person you care for to reach a solution. It also means that different services should work well with each other to ensure that the care and support is consistent.

Sarah is looking after her brother, Dean, who has Parkinson's disease. She noticed that the dosette boxes delivered by the pharmacy were sometimes unused and medication was not being taken at the right times or in the right order. She is unable to support Dean to take all his medication as she only visits him once a day. With her brother's agreement, Sarah spoke to the home care service about what could be done to support correct medication, as care workers were delivering meals at lunch time and could support Dean to take medication when they visited. After a review, the home care service visits increased to twice daily to support taking medication in the morning as well as delivering meals. The home care service is also aware that Dean's condition might be deteriorating, especially if his medication has not been consistent, and makes sure the care workers speak to Dean regularly about how he's feeling and note any concerns. Sarah continues to visit Dean each evening and makes sure that he takes his last daily dose of medication.

4.16 I am supported and cared for by people I know so that I experience consistency and continuity.

4.17 If I am supported and cared for by a team or more than one organisation, this is well coordinated so that I experience consistency and continuity.

What does this mean for me? This means that you should be aware of, and involved in, the provision of services to the person you look after, and the care you provide will fit in with the care provided by services.

Ali cares for her dad, Norman, who is 84 and suffers from osteoarthritis and high blood pressure. He was getting a daily visit from a care worker for a small amount of personal care and household work, but over time his support needs increased. After reassessment, the number of visits was increased to an hourly visit three times a day. The number of different care workers who came to the house increased, which made it difficult to establish any kind of rapport or continuity between Norman, Ali and the care workers.

After some discussion with the local authority, Norman now receives a direct payment which is used to employ one care worker who can visit multiple times a day. This is also reassuring for Ali as she also has a good relationship with her dad's care worker and is able to contact them directly if there are any issues.

4.18 I benefit from different organisations working together and sharing information about me promptly when appropriate, and I understand how my privacy and confidentiality are respected.

What does this mean for me? This means that services supporting the person you care for should share information with each other, and with you, if the person you look after agrees to this information being shared. There must be a clear explanation of privacy and confidentiality, and you are made aware if the person you look after does not want information to be shared with you.

Kevin's wife Claire has an eating disorder and has been admitted to a psychiatric ward. Their relationship has been difficult in the weeks before admission due to her illness, and she is adamant that Kevin isn't told about any medication she is given or what food she is eating. If Kevin visits at mealtimes Claire refuses to see him. This is difficult for Kevin who is trying to support and care for her. The staff on the ward discuss this with Kevin and encourage him to visit outwith mealtimes, so that Claire's privacy about her own care and treatment is respected but Kevin can also spend time with his wife regularly. The staff on the ward also continue to encourage Claire to involve Kevin in her support and treatment, so that when she leaves hospital he will be able to look after her with the appropriate information.

4.26 If I have a carer, their needs are assessed and support provided.

What does this mean for me? As a carer, you are entitled to an adult carer support plan or young carer statement as soon as you intend to provide care for someone. Your needs will be assessed and, if you meet local eligibility criteria, you will be provided with support. If you do not meet the eligibility criteria, you may still be provided with support to meet other needs identified in your adult carer support plan or young carer statement. This support might include information and advice as well as support available in your local community, such as a carers' centre.

Kara is looking after her young daughter, Holly, who has learning and mobility difficulties. Holly is due to start school later in the year and after working part time whilst she has been at nursery, Kara is keen to take up more hours at work. She has an adult carer support plan and it is decided that a personal assistant will be found who can support Holly with the morning routine, take her to and collect her from school, and support her to attend an after-school club. This support for Holly is also support for Kara as it means she can take up longer hours at work without worrying about always having to be available.

Carer involvement and the Carers (Scotland) Act 2016

The Standards do not replace or remove the need for services to comply with existing legislation. Health and social care services will continue to follow the existing legislation and best practice for their service or sector, in addition to applying the Standards.

The Carers (Scotland) Act became law in Scotland on 1 April 2018. This Act extends and enhances the rights of carers to support. The Act also strengthens the principle of carer involvement in the development and delivery of services by amending existing legislation and adding to it. Carer involvement is set out in several parts of the Act:

- Carers must be involved in strategic planning of carer services in their local area
- Carers must be involved in their own assessment and support planning
- Carers must be involved before the cared-for person is discharged from hospital
- The views of carers and carer representatives must be considered by local authorities when preparing and reviewing short breaks services statements
- Carers must be involved in assessing the needs of the person they look after, and in decisions about whether and how to provide services to them.

This aspect of carer involvement is key when thinking about how the Standards apply to carers.

Carers (Scotland) Act 2016 – www.legislation.gov.uk/asp/2016/9/contents

Carers' Charter – www.gov.scot/Publications/2018/03/4874/

Scottish Government – carerspolicy@gov.scot

Why is carer involvement important?

Carer involvement is important as carers have a unique role in the life of the person they care for. They also have essential knowledge to contribute to the planning and delivery of care and services for that person. The involvement of the carer in the assessment and support of the cared for person, such as when someone leaves hospital, ensures that their knowledge and experience as a carer is properly valued.

Equal partners in care means that providers of health and social care services should listen to and involve carers in the planning and decision-making processes, as well as involving the person they care for. This creates an environment of mutual respect, as any decision made will have an impact on their caring role.

Carer involvement in service planning and delivery is not a new idea but there has been some variation in how different services have involved carers. The benefit of seeing carers as equal partners in care was recognised in Scotland's Carers Strategy 2010-2015, providing opportunities for services to recognise the role of carers and how the cared-for person's service experience could also be improved by involving carers in planning these services. The Health and Social Care Standards are a way to ensure that carer involvement is at the heart of high quality care and support services.

There are several resources aimed at health and social care professionals to ensure they are knowledgeable about carer involvement processes and are aware of the benefits of carers being equal partners in care:

EPiC (Equal Partners in Care) is a national framework developed by NHS Education for Scotland and Scottish Social Services Council. This is supported by a learning and development toolkit for the health and social care workforce

www.knowledge.scot.nhs.uk/home/portals-and-topics/equal-partners-in-care/epic-elearning.aspx

Best Practice Standards for Carer Engagement have been developed by the Coalition of Carers in Scotland (COCIS) to help planners and commissioners of services improve their practice. The standards were developed jointly with carers and carer organisations, with support from the Scottish Government's carer policy unit and the Scottish Health Council.

www.carersnet.org/policy-legislation/best-practice-standards-for-carer-engagement

The National Standards for Community Engagement are good-practice principles designed to support and inform the process of community engagement, and improve what happens as a result. They have been used to support community engagement, and user involvement, in Scotland in areas such as community planning and health and social care.

www.scdc.org.uk/what/national-standards

Advocacy

Carers may also play a role in representing the person they look after in relation to the care services they experience.

Advocacy for unpaid carers is important to ensure they can represent their own views and the views of the person they look after effectively. Working with health and social care professionals can be challenging if there are conflicting viewpoints or if the situation is stressful, and advocacy can be very useful for carers who need support to express their views, or those of the person they care for.

Information and advice about advocacy for carers must be included as part of each local authority's information and advice service for carers.

Carers Scotland has developed a Self-Advocacy Toolkit - a group of integrated resources to help carers get their voices heard:
www.carersuk.org/scotland/training-resources/self-advocacy-toolkit-scotland

The Scottish Government has published Guidance for Unpaid Carer Advocacy in Scotland: www.gov.scot/Publications/2016/03/5362

More information



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Care Inspectorate

0345 600 9527

enquiries@careinspectorate.com

www.careinspectorate.com



**Healthcare
Improvement
Scotland**

Healthcare Improvement Scotland

0131 623 4300

comments.his@nhs.net

www.healthcareimprovementscotland.org



Carers Trust Scotland

0300 123 2008

scotland@carers.org

www.carers.org/scotland



**carers
SCOTLAND**

Carers Scotland

0141 445 3070

info@carerscotland.org

www.carerscotland.org



Organisation name	Address	Contact details
Carers Scotland	The Cottage 21 Pearce Street Glasgow G51 3UT	0141 445 3070 www.carerscotland.org info@carerscotland.org
Carers Trust Scotland	Skypark 3 Suite 1/2, 14/18 Elliot Place Glasgow G3 8EP	0300 123 2008 www.carers.org/scotland scotland@carers.org
Coalition of Carers in Scotland	PO Box 21624 Stirling FK7 1EF	01786 850 247 www.carersnet.org coalition@carersnet.org
Crossroads Caring Scotland	Crossroads Caring Scotland 24 George Square Glasgow G2 1EG	0141 352 9757 www.crossroads-scotland.co.uk info@crossroads-scotland.co.uk
MECOPP (Minority Ethnic Carers of Older People Project)	172 Leith Walk Edinburgh EH6 5EA	0131 467 2994 www.mecopp.org.uk info@mecopp.org.uk
Scottish Young Carers Services Alliance	Scottish Young Carers Services Alliance c/o Carers Trust Scotland Skypark 3 Suite 1/2, 14/18 Elliot Place Glasgow G3 8EP	0300 123 2008 www.carers.org/scotland scotland@carers.org
Shared Care Scotland	Unit 2 Dunfermline Business Centre Izatt Avenue Dunfermline Fife KY11 3BZ	01383 622462 www.sharedcarescotland.org.uk office@sharedcarescotland.com



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