



Alzheimer Scotland
Action on Dementia



Standards of Care for Dementia in Scotland

A guide for people with
dementia and their carers

Contents

Foreword.....	1
About this guide	2
About dementia care standards	2
The Standards of Care for Dementia in Scotland	3
Your right to a diagnosis	4
Your right to be regarded as a unique individual and to be treated with dignity and respect	6
Your right to have access to a range of treatment, care and support	8
Your right to be as independent as possible and to be included in your community.....	10
Your right to have carers who are well supported and educated about dementia.....	12
Your right to end of life care that respects your wishes.....	14
How you can use the standards to choose a care service.....	16
How you can use the standards to improve the quality of your care.....	17
Useful publications	18
Regulatory organisations.....	19
Organisations who can investigate complaints.....	19
Further help and information.....	20

Acknowledgements

Alzheimer Scotland is grateful to the Scottish Government for funding this publication which is a companion guide to the Scottish Government's *Standards of Care for Dementia in Scotland*. We are particularly grateful to the many people with dementia, their carers and professionals who helped in the development of the standards.

The standards are based on the Scottish Parliament's Cross Party Group on Alzheimer's *Charter of rights for people with dementia and their carers* and also what people with dementia have said is important to them. You can read, and register your support for, the *Charter of rights* at www.dementiarights.org.

Foreword

Alzheimer Scotland welcomes the Standards of Care for Dementia in Scotland and believes that the standards can play a significant role in improving the quality of care, support and treatment of people with dementia at every stage of the illness and in every setting.

We are pleased to have had opportunity to work in partnership with key stakeholders and to ensure that the views of our members, the people we represent, and the knowledge we have developed over many years working with, and campaigning for, people with dementia and their carers, have helped to inform the development of the standards.

While there are many good examples of care, support and treatment, we know from the experiences of people with dementia and those who care for them that, often, their human and other legal rights are not recognised or respected. People with dementia and their carers need dementia specific care, support and treatment from skilled health and social care staff working in the public, private or voluntary sectors, who understand their human and other legal rights and how to apply them in their day to day work.

The Standards of Care for Dementia and the Promoting Excellence Framework, both key developments of Scotland's National Dementia Strategy, are underpinned by the Charter of Rights for People with Dementia and their Carers. We welcome this human rights based approach to the standards which set out what people with dementia and their carers can expect when their human and other legal rights are fully respected. Alongside the Charter of Rights these standards can help empower people with dementia and their carers, and the health and social care staff who support them, to ensure that the necessary improvements in the quality of dementia care in Scotland are delivered.

Henry Simmons

Chief Executive
Alzheimer Scotland

About this guide

This guide to the *Standards of Care for Dementia in Scotland* is for people with dementia and their carers (family members, partners and friends).

It explains what your rights are and the quality of care, support and treatment you or the person you care for should receive to stay well, safe and listened to.

The guide also sets out how you can use the standards to ensure the services you receive meet the standards and what you can do if you are not happy with the standard of care, support and treatment provided.

These standards relate to everyone with a diagnosis of dementia in Scotland, regardless of where they live, their age, the support they receive or the severity of the illness. The standards apply wherever the service is being provided – whether it is in your own home and community, in a care home or hospital.

About dementia care standards

People with dementia have the same human and other legal rights as every other citizen to health, social care and other services to meet their needs. However, the nature of the illness often means they have difficulty protecting their own rights in the face of stigma and discrimination.

In June 2011, the Scottish Government launched the first *Standards of Care for Dementia in Scotland* as part of its action plan to improve dementia care and provide world class dementia services in Scotland. At the same time *Promoting Excellence, a skills and knowledge framework for all health and social care staff* was published, which will improve qualifications and training in relation to dementia.

If you want a copy of the full *Standards of Care for Dementia in Scotland*, please contact David Berry, Scottish Government on 0131 244 3098; email: David.Berry@scotland.gsi.gov.uk

Standards for dementia care are needed because:

- staff who plan, arrange or provide services for people with dementia need to know what is expected of them and how they can improve services. This includes the NHS, local authorities, voluntary and private sector providers of health and social care services
- all staff who give direct support to people with dementia require an understanding of the human rights of people with dementia and how the standards should be applied, wherever they happen to work
- people with dementia and their carers need to know what quality of care to expect from those who provide health, social care and other services.

The Standards of Care for Dementia in Scotland

The standards are based on the Scottish Parliament's Cross Party Group on Alzheimer's *Charter of rights for people with dementia and their carers*, and also what people with dementia have said is important to them. There are six standards, each one expressed as a statement of your rights.

The standards say that as a person with dementia or a carer you have a right to:

- a diagnosis
- be regarded as a unique individual and to be treated with dignity and respect
- access a range of treatments, care and supports
- be as independent as possible and to be included in your community
- have carers who are well supported and educated about dementia
- end of life care that respects your wishes.

Your right to a diagnosis

If you are worried about your memory or have been feeling confused, you are entitled to a timely assessment and diagnosis. You are also entitled to take someone with you to all medical appointments.

There are many causes of memory loss or confusion such as a chest or urinary infection, depression, or the side effects of medication. These are all treatable and it is important that they are ruled out before considering a diagnosis of dementia.

Following a diagnosis, you should be offered time and professional support to talk about how you feel. You should be given information about the illness and any treatments as well as the supports available (emotional and practical) to help you live well with your diagnosis.

The earlier a diagnosis is made, the more likely it is that you will be able to make plans for your future and have your choices respected.

If the diagnosis is given later in the illness and you are no longer able to make all decisions for yourself, your carer should be given full information to enable him/her to make the best possible decisions for you.

When this right is respected

- your GP will listen to you, take your symptoms seriously, investigate and treat them accordingly, or refer you to a specialist
- you will be given a timely diagnosis of dementia (if you are referred to a specialist, you should be contacted within four weeks of the referral to arrange an appointment)
- you will be given your diagnosis and have it explained to you in a sensitive manner
- you will be given information, at a time that is right for you, about the treatments and supports available, in a form you can understand
- you will have access to appropriate health and social care services, including counselling
- you will be involved and supported to make decisions about the support, care and treatment you want now and in the future
- you will be offered information about the types of financial and legal support available to help you plan for future welfare and financial decisions (such as arranging a will or powers of attorney).

Your right to be regarded as a unique individual and to be treated with dignity and respect

Being treated as an individual is about being accepted for the person you are. This means having the things that are important to you considered by those who care for you so you can live as fulfilling a life as possible.

You have the right to be treated with dignity and respect at all times and to be free from any kind of discrimination or harm.

When this right is respected

- you will feel valued as an individual, and treated with dignity and respect
- you will be supported to exercise freedom of choice about how you live your life, without putting yourself or others at risk of harm
- you will be listened to and feel included in all decisions affecting you
- any assessment of your needs will take account of your preferences and the things that are important to you
- you will have access to a range of treatments, care and support that help you to continue doing the things that matter to you
- you will be helped to keep up relationships and connections with people who are important to you, whether you live at home, in a care home, or are in hospital
- your privacy, confidentiality and your right to enjoy your own possessions will be respected
- you will be free from any type of harm, neglect, inhumane or degrading treatment, including inappropriate use of restraints.

Your right to have access to a range of treatment, care and support

You should be given the help you need to stay well, to use the abilities you already have, and to develop new interests if that is what you would like to do. This means that you should be given the opportunity to be as involved as possible in all decisions which affect your life.

If you need help to have your voice heard, you should be offered support from an independent advocacy service.

When this right is respected

- you will be listened to, and as involved as possible, in any assessment or review of your needs and decisions about your treatment, care and support
- you will get information and advice about the available options so you and your carer can make informed choices
- you will be given a copy of your assessment or review, time to think about it, and the chance to discuss anything you disagree with or are unsure about
- you will have the opportunity to meet locally with other people with dementia to share experiences and receive mutual support
- you will be given an immediate assessment, and treatment or support to manage any distressing symptoms you develop
- you will be offered care and treatment, including non drug treatments such as exercise and other therapies, to help improve your sense of wellbeing
- you will be supported to have a high standard of nutrition and hygiene
- you will receive any extra support you need when visiting a hospital accident and emergency unit or out-patient clinic
- you will be cared for in an environment which minimises any distress or confusion for you, especially in hospital, and you should not be moved, within or between hospitals, unless necessary.

Your right to be as independent as possible and to be included in your community

You should have the same opportunity as everyone else to live as full a life as possible within your community. This means being able to keep up relationships with the people who are important to you and to do the things you enjoy. This might be going for a walk, going to your local swimming pool, place of worship or cinema.

You should be given the help you need to make sure that you have equal access to all of the leisure, recreational and cultural activities within and beyond your own local community.

When this right is respected

- you will receive, and be as involved as possible in an assessment of your everyday needs
- you will have access to a range of supports to enable you to remain at home for as long as possible, including personal care, day opportunities, breaks from home, recreational, and other services appropriate to your needs at all stages of the illness
- you will be given the opportunity to be fully involved in planning, deciding and arranging your support, care and treatment
- you will be given as much choice and control as you wish over how your support needs are met to help you lead a fulfilling and meaningful life
- you will be given information about self directed support¹ options for funding and organising the supports you need to live your life
- you will be helped to live a normal life in your community, balancing your safety and your right to take risks, so that you can maintain your usual interests, activities, social contacts and spiritual life as long as possible
- you will have equal access to all of the services and amenities in your community.

¹ Self directed support is a way of helping you to live as independently as possible by giving you more flexibility, choice and control over how your support is arranged and provided. It allows you to choose how the money available is used to meet your needs rather than have the social work department arrange and pay for your services.

Your right to have carers who are well supported and educated about dementia

Your family, partner or friends who care for you should be fully supported in their caring role. This means that they should be offered information and support so that they can stay well and continue to live their normal lives as far as possible, while providing you with the help you need.

This also means you have a right to be cared for and supported by paid professional health and social care staff who understand the complexity of the illness and how it affects each person and their relationships differently.

You should be supported by staff who understand how best to communicate with you and involve you, and those who are close to you, in making decisions about your care, support and treatment.

When this right is respected

- you will receive services from health and social care staff who are educated in dementia and the rights of people with dementia and those who care for them

As a carer you have a right:

- to receive information about available services to help support you in your caring role, including financial, emotional and practical support
- to be offered an assessment of your own needs in supporting the person you care for which takes account of your health, social wellbeing and financial needs
- to have your views listened to and taken into account in the assessment, planning and review of the support, care and treatment of the person you care for
- to be respected by professionals as a person in your own right
- to be offered information about dementia and dementia care training
- to have access to a range of flexible options for breaks from caring
- to have the opportunity to meet locally with other carers to share experiences and receive mutual support.

Your right to end of life care that respects your wishes

You should have the opportunity to say what will be important to you towards the end of your life.

This means that when you are involved in planning and deciding on how your needs are met you should be given the chance to look ahead and make advanced decisions such as preparing an advanced statement² or advanced directive³.

Towards the end of your life you should be cared for in a way that respects your wishes and beliefs.

² An advanced statement allows you write down, in advance, the kind of care and treatment you would want for yourself in the event of you being unable to choose or express your wishes. This might include your preferences about particular drugs or being cared for in a particular way.

³ An advanced directive, sometimes called a living will, is a term often used to describe your written instructions for refusing a specific treatment or treatments in certain circumstances. The sorts of treatments usually covered by an advanced directive include artificial feeding, mechanical ventilation, antibiotic therapy and resuscitation.

When this right is respected

- you will be involved in planning your end of life care, including preparing an advance directive to ensure your wishes are recorded and respected; this could include who you want to be with you and where you would prefer to be
- you will always be cared for with dignity and in privacy
- you will have immediate access to pain relief and other symptom control
- you will be offered the spiritual or emotional support you need
- you will have access to specialist care and treatment, including palliative care, at home, in a care home or in hospital
- you will not experience inhumane or degrading treatment at the end of your life.

How you can use the standards to choose a care service

The standards are based on your rights and complement the existing national care standards.

You can use the standards to get the care, treatment and support you need, including when you are choosing a service provider. Here are some simple suggestions to help you choose the right service provider for you:

- before you meet with a service provider, think about what you want from the service and what questions you would like to ask
- ask the manager about how the service you get will meet the standards
- speak to the manager about what is important to you and ask how the service can meet your needs in the way that you want
- ask to meet the staff who will be working with you so that you can talk to them
- think about having a few weeks' trial period to allow you time to see if the service meets both your expectations and the quality of care demanded by the standards
- ask to see the Care Inspectorate inspection reports for your local authority's social work department and any registered care service you are thinking about choosing (you can also get these online at www.scswis.com)
- if you are admitted to hospital you may not get to choose where you go, but you can still talk to the staff caring for you about how the care you get will meet the standards.

How you can use the standards to improve the quality of your care

If you think the care, support or treatment you are receiving does not meet the standards, there are a number of things you can do:

- keep a written record of times when you think the standards have not been met (note down what and when it happened, the names of staff involved and what response you got when you raised your concerns)
- speak to the manager in charge of the service to try and resolve the matter informally (ask someone such as a friend, family member or an independent advocacy worker to help if you don't feel comfortable speaking to your service provider on your own)
- if your service was arranged by your local authority social work department, you can speak to your care manager about your concerns
- if you are not satisfied after speaking to the manager in charge, you can make a formal complaint (the NHS, local authority social work departments and registered care services all have complaints procedures and should tell you how to use them)
- quote the standards when speaking to the manager of the service or when making a complaint
- take your complaint directly to the public organisation responsible for regulating and inspecting the service (see page 19). You don't need to speak or complain to your service provider first if you don't want to
- get legal advice if you think the care provider has broken the law
- get help from Alzheimer Scotland and other specialist advice organisations (see page 20).

Useful publications

NHS Health Scotland

- Coping with dementia – a practical handbook for carers
- Facing dementia – how to live well with your diagnosis
- Understanding dementia – a guide for young carers
- Worried about your memory?

Available from your local Health Promotion or Health Education Department – Find local addresses in your phone book under the local NHS Board. Single copies also available free to carers and people with dementia in Scotland from Alzheimer Scotland. Call the Dementia Helpline on **0808 808 3000** or contact your local Alzheimer Scotland service.

Alzheimer Scotland

- Getting help from your doctor: a guide for people worried about their memory, people with dementia and their carers
- A positive choice: choosing long- stay care for a person with dementia
- Information sheets, single copies free:
- Community care and assessments
- Self-directed support (including direct payments)
- Making decisions about future treatment (including advance statements)
- Solicitors specialising in adults with incapacity/mental health

Available by phoning the Dementia Helpline on 0808 808 3000 or to download from Alzheimer Scotland's website (www.alzscot.org).

Regulatory organisations

Healthcare Improvement Scotland

Edinburgh Office; Elliott House,
8–10 Hillside Crescent, Edinburgh, EH7 5EA.

Tel: 0131 623 4300

Glasgow Office; Delta House,
50 West Nile Street, Glasgow, G1 2NP.

Tel: 0141 225 6999

Website: www.healthcareimprovementscotland.org

Works to improve the quality of NHS and independent health care and deals with complaints about independent health care providers.

Care Inspectorate

Compass House, 11 Riverside Drive, Dundee, DD1 4NY.

Tel: 0845 600 9527

Email: enquiries@careinspectorate.com

Website: www.scswis.com

Regulates the quality of social work and registered care services. It can investigate complaints against registered care providers.

Organisations who can investigate complaints

Office of the Public Guardian (OPG)

Hadrian House, Callendar Business Park,
Callendar Road, Falkirk, FK1 1XR.

Tel: 01324 678300

Email: opg@scotcourts.gov.uk

Website: www.publicguardian-scotland.gov.uk

Can investigate concerns where the property or financial affairs of an adult with incapacity seem to be at risk.

Scottish Public Service Ombudsman (SPSO)

4 Melville Street, Edinburgh, EH3 7NS.

Tel: 0800 377 7330

Email: ask@spsso.org.uk

Website: www.spsso.org.uk

Considers complaints about organisations providing public services in Scotland, normally only once you have been through the complaint procedure of the organisation concerned.

Local authorities

Your local authority can investigate complaints about a service it provides or arranges for you. You can find contact details for all Scottish local authorities here www.direct.gov.uk/en/D11/Directories/DevolvedAdministrations/DG_4003604 or check your local phone book.

Further help and information

Alzheimer Scotland

22 Drumsheugh Gardens, Edinburgh EH3 7RN.

Tel: 0131 243 1453; **Email:** alzheimer@alzscot.org **Website:** www.alzscot.org

24 hour Dementia Helpline 0808 808 3000 – freephone

Email: helpline@alzscot.org

Provides specialist information and support for people with dementia and their carers in Scotland.

Care Information Scotland

Helpline: 08456 001 001; **Website:** www.careinfoscotland.co.uk

Provides care information for older people.

Citizens Advice Bureau (CAB)

The address of your local CAB can be found in the phone book or from Citizens Advice Scotland, **Tel:** 0131 550 1000; **Website:** www.cas.org.uk

Provides general advice and has a specific project called the Independent Advice and Support Service (IASS) to help people make complaints about the NHS.

Equality and Human Rights Commission (EHRC)

The Optima Building, 58 Robertson Street, Glasgow, G2 8DU.

Helpline: 0845 604 5510; **Email:** scotland@equalityhumanrights.com

Website: www.equalityhumanrights.com/scotland

Works to eliminate discrimination and promote human rights.

Law Society of Scotland

26 Drumsheugh Gardens, Edinburgh, EH3 7YR.

Tel: 0131 226 7411; **Email:** lawscot@lawscot.org.uk; **Website:** www.lawscot.org.uk

Can help you find a solicitor.

Mental Welfare Commission for Scotland

Thistle House, 91 Haymarket Terrace, Edinburgh, EH12 5HE.

Freephone: 0800 389 6809; **Email:** enquiries@mwscot.org.uk;

Website: www.mwscot.org.uk

Safeguards the rights and welfare of people with dementia and others and can investigate when you do not receive the right care.

Scottish Human Rights Commission (SHRC)

4 Melville Street, Edinburgh, EH3 7NS.

Tel: 0131 240 2989; **Email:** hello@scottishhumanrights.com

Website: www.scottishhumanrights.com

Promotes and protects the human rights of everyone in Scotland.

Scottish Independent Advocacy Alliance (SIAA)

Melrose House, 69A George Street, Edinburgh EH2 2JG.

Tel: 0131 260 5380; **Email:** enquiry@siaa.org.uk; **Website:** www.siaa.org.uk

Can provide details of local independent advocacy in all parts of Scotland.

You can download a copy of this guide, including a large print version, from our website at www.alzscot.org.

This guide to the *Standards of Care for Dementia in Scotland* is for people with dementia and their carers (family members, partners and friends).

It explains:

- what your rights are
- the quality of care, support and treatment you or the person you care for should receive to stay well, safe and listened to
- how you can use the standards to ensure the services you receive meet the standards
- what you can do if you are not happy with the standard of care, support and treatment provided.

© Alzheimer Scotland
April 2012



www.alzscot.org

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