

STANDARD OF CARE FOR DEMENTIA IN SCOTLAND

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THERE IS STILL STIGMA AND DISCRIMINATION AGAINST PEOPLE WITH DEMENTIA. THEY AND THEIR CARERS OFTEN FEEL THAT THEY ARE TREATED WITH LESS RESPECT, DIGNITY AND UNDERSTANDING THAN OTHER MEMBERS OF SOCIETY.

**Charter of Rights
for people with
dementia and their
carers in Scotland
Read the charter**

INTRODUCTION

People with dementia retain the same rights as anyone else in society but the nature of their illness means that they often have great difficulty in protecting **their rights**. Standards of care have been developed to help people with dementia and their carers understand their rights, and how these rights can **ensure** that they receive the support they need to stay well, safe and listened to. The 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 their illness. This includes younger people, people with a learning disability and people with rare types of dementia. They apply to people living in their own homes, care homes or hospitals.

TWO SOURCES OF INFORMATION UNDERPINNING STANDARDS

- (1) The Charter of Rights for People with Dementia and their Carers in Scotland.
- (2) What people with dementia and their carers in Scotland have identified as being important to them and what they want from services.

To ensure continuous improvement, the standards should be used in conjunction with *Promoting Excellence: A framework for health and social care staff working with people with dementia and their carers*, which outlines the skills and knowledge health and social care staff should have depending on the role they play in supporting people with dementia.

WHAT THE STANDARDS MEAN

The standards are based on rights of people with dementia or carers, and they should be used to get the care, treatment and support required. If standards are not being met, then one of the following should be done:

- Quote the standards when making a complaint to the care provider
- Obtain help from independent advocacy or Citizens' Advice when making a complaint
- Consult an independent organization for advice or, in some cases, to Investigate
- If response is not satisfactory, then complaints can be taken further, the person answering the complaint will advise on how to do this
- Obtain legal advice if care provider has broken the law

Health and social care providers from the statutory, private and voluntary sectors have equal responsibility for meeting the standards. In their day-to-day work, staff need to be aware of the standards and do their best to provide the care that the standards aim for. The standards should be used to assess the services managed or commissioned. Therefore, the standards should be reflected in overall policies, for helping people with dementia and their carers.

EXTERNAL SCRUTINY AND DATA COLLECTION

In order to build a picture of what Scotland is doing to meet the standards, scrutiny and improvement organisations will examine self-reports from services, visits and inspections, where there is greatest evidence that standards are not being met. Investigations and issues arising from complaints will help determine whether services are meeting the standards.

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MEASURING THE CODE

Each standard is measurable but since the standards are based on outcomes for people with dementia, there is no one measurement that can be used across all the standards. Each standard has been given at least one way it can be measured, but in many cases there will be more than one. *The table on the left illustrates*

Code	Internal reporting	External reporting
A Audit	Self audit of case files/records.	<p>The Scottish Government will:</p> <ul style="list-style-type: none"> • Collect benchmarking data. • Give national guidance on priorities for measuring services against standards. • Collate information for an overall report on the implementation of the standards. <p>External visiting, scrutiny and improvement organisations will:</p> <ul style="list-style-type: none"> • Examine self-reports against standards (including compliance with existing care standards and compliance with care pathways) and other information available to them. • Conduct visits and inspections on the basis of greatest risk that standards are not being met. • Report to the Scottish Government on their overall findings.
C Care Pathway	Self assessment of compliance with/ variation from recognised care pathway.	
D Data	Use of data that is already collected (or soon will be) from other sources (e.g. via benchmarking data).	
E Environment	Carrying out environmental audits, walking around and checking.	
F Feedback	Seeking views of people with dementia, carers and staff using a variety of methods. Reviews of complaints and comments.	
I Individual	Production of individual case reports to demonstrate examples of compliance with the standard.	
P Policy and Planning	Can demonstrate compliance by way of internal policies, protocols and service description.	
S Standards	Self report on compliance with national care standards.	

the code used to measure the standards.

Adapted from <http://www.scotland.gov.uk/Publications/2011/05/31085414>.

RIGHTS OF PEOPLE WITH DEMENTIA UNDER THE STANDARDS

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

THE FUTURE

The Scottish Government is set to produce public reports on how the standards are improving the care of people with dementia, and there are plans to increase the amount of routinely collected data. This will help to identify areas that have been improved as well as those that need improving, and make sure that services in Scotland provide care that respects the rights of people with dementia and their carers.