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# Standards of Care for Dementia in Scotland

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Action to support the change programme,  
Scotland's National Dementia Strategy

June 2011

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# 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 own rights.

There is still stigma and discrimination against people with dementia and they and their carers often feel, with some justification, that they are treated with less respect, dignity and understanding than other members of society.

These standards relate to everyone with a diagnosis of dementia in Scotland regardless of where they live, their age, the supports 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, especially general hospitals. For all the standards, we have given guidance about how they can be measured.

These standards have been developed to help people with dementia and their carers understand their rights, and how these rights can help make sure that they receive the support they need to stay well, safe and listened to.

The two main sources of information which underpins these standards are:

- 1 The Charter of Rights for People with Dementia and their Carers in Scotland. **(21)**
- 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*.

**(214)**

The framework outlines in detail the skills and knowledge health and social care staff should have depending on the role they play in supporting people with dementia.

We have identified organisations that have the main responsibility to make sure that each standard is met. However, the standards require many organisations to work together.

**(2)** Denotes link to signposts section

# WHAT THE STANDARDS MEAN FOR YOU

## **If you are a person with dementia or a carer**

The standards are based on your rights. You should use them to get the care, treatment and support you need. If you think the standards are not being met, there are a number of things you can do:

- You can quote the standards when making a complaint to the care provider.
- You can get help from independent advocacy or Citizens' Advice when making a complaint.
- You can ask an independent organisation for advice or, in some cases, to investigate.
- You can take your complaint further if you are not satisfied with the response. Whoever answers your complaint will tell you how to do this.
- You can get legal advice if you think the care provider has broken the law.

On page 44, you will find a list of organisations that may be able to help you.

## **If you are a care provider**

The standards let your staff who are providing services for people with dementia know what is expected of them and how to improve the quality of the service they provide. 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.

You should measure your care against the standards and look to improve if you are not meeting them. External visiting, scrutiny and improvement organisations will want to know how you assess your care against the standards.

### **If you manage or commission services for an NHS Board or local authority area**

These standards are intended to ensure that the quality of dementia care is in line with the Charter of Rights for People with Dementia and their Carers. You should use the standards to assess the services you manage or commission. Also, the standards should be reflected in your overall policy for helping people with dementia and their carers.

Initially, it will not be possible for you to assess all services against all the standards. You should examine the standards carefully and decide:

- Which standards might your services, as a whole, not meet?
- Which individual parts of your service are least likely to meet the standards?
- How should you target your actions to measure whether standards are being met?
- What action do you need to take so that your services improve if they fall below the standards?

External organisations and Scottish Ministers may ask for reports on what your services have done to meet the standards.

### **The role of external scrutiny and data collection**

Scrutiny and improvement organisations will use relevant standards when carrying out their work. This will include examination of self-reports from services and visits/inspections where there is greatest evidence that standards are not being met. Investigations and issues arising from complaints will also help to determine whether services are meeting the standards.

Some data is collected centrally by the Scottish Government. There are plans to increase the amount of routinely collected data.

All of this will help to build up a picture of what Scotland, as a whole, is doing to meet the standards, where we are doing well and where we need to improve. We will produce public reports on how the standards are improving the care of people with dementia.

By doing this, we can make sure that services in Scotland provide care that respects the rights of people with dementia and their carers.

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### MEASURING THE STANDARDS

Each standard is measurable. Because 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 blue column in the table of standards in the rest of this document gives examples of how each can be measured.

Here is the code used for measuring the standards.

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

**As a person with dementia...**

**I have the right to a diagnosis**

**I have the right to be regarded  
as a unique individual and to  
be treated with dignity  
and respect**

**I have the right to access  
a range of treatment, care  
and supports**

**I have the right to be as  
independent as possible  
and be included in  
my community**

**I have the right to have  
carers who are well  
supported and educated  
about dementia**

**I have the right to end  
of life care that  
respects my wishes**

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### I have the right to a diagnosis

The Charter of Rights for People with Dementia and their Carers in Scotland states... [▶1](#)

**People with dementia have the right to the highest attainable standards of physical and mental health.**

#### When this right is respected

##### People with dementia and their carers will

Receive a timely and accurate diagnosis and be provided with the information they need about their condition, treatments and support.

Receive the information and support they need to stay well and live with the challenges of dementia.

Be involved in decisions that are important to them now and in the future.

[▶](#) Denotes link to signposts section)

People with dementia will...

Reporting Code

Receive an accurate and timely diagnosis

Pre diagnosis

At time of diagnosis

**Wherever a person is living and whatever the stage of their illness, the individual has the right to a diagnosis...**

**NHS Boards will ensure that**

People worried about their memory have timely access to services for assessment, including those who may be seldom heard, e.g. homeless people, black and ethnic minority communities, people in remote areas, people with sensory impairment. (D15)

GP surgeries and hospitals have established pathways to diagnosis in place. This should include: referral to a service that specialises in the diagnosis of dementia when appropriate, identification of who is best placed to carry out specific roles in relation to diagnosis and pre and post diagnostic support. (D16)

**NHS Boards will ensure that**

GPs and hospitals can refer people with suspected dementia to services that specialise in the diagnosis of dementia. Services will have initial contact with the person within four weeks.

Services that specialise in the diagnosis of dementia can refer on to a neurologist, neuropsychiatrist or neuropsychologist if the diagnosis is complex.

D, P

C, P

D, P

P

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### People with dementia will...

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### Reporting Code

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#### At time of diagnosis continued

Before confirming a diagnosis of dementia, the practitioner will consider and record the effect the diagnosis may have on the person and their family and the degree of pre and post diagnosis psychological intervention that is likely to be required.

A, P

Careful consideration needs to be given to the most appropriate location for informing the diagnosis; for instance, whether in an out-patient clinic or at a person's own home. The length of the appointment needs to be sufficient to afford the person with dementia and their family time to consider what they want to know next.

A, P

Whether it is the GP, hospital doctor or a specialist service that considers the diagnosis, the assessment by skilled, confident and well trained staff using recognised diagnostic tools. **(17 and 14)**

A

There are clear referral processes for post diagnosis treatment and support for people recently diagnosed with dementia and contact details given of a service they can contact for further information and advice.

P

People diagnosed with dementia are included on the dementia register. **(15)**

A, P

## People with dementia will...

## Reporting Code

### Receive information about the illness and the supports and services available

**Everyone who receives a diagnosis of dementia is entitled to information about their illness and the local supports available to them, their family and people important to them.**

**NHS Boards and local authorities will ensure that**

The amount and type of information that is given will follow an assessment of the individual's needs and the needs of their family, including providing communication and language support if there are language, cultural or knowledge barriers.

If the person with dementia does not want to receive this information they should be offered the opportunity again at a future date.

Information provided is available in a variety of formats and aimed at maximising wellbeing and quality of life. It will include:

- Information about the condition, advice on managing symptoms and treatment available.
- Contact details for the Dementia Helpline and independent advocacy.
- Information on support available locally; this should cover information about local support services including post diagnostic support and counselling, either one-to-one or in groups.
- Specific information about continuing to drive following a diagnosis of dementia.

F, P

F, P

P

## Standards of Care for Dementia in Scotland

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### People with dementia will...

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### Reporting Code

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**Have the opportunity to make plans for the future**

**The earlier a diagnosis is made, the more likely it is that the person with dementia will be able to make plans for their future and have their choices respected.**

**NHS Boards will ensure that**

At the time of diagnosis or shortly afterwards, the person with dementia and their family will be offered the opportunity to discuss the options that are available to them, most specifically with regard to health, welfare and money including benefits. This will include discussion of options such as appointing a welfare and/or financial power of attorney and making advance decisions about medical treatment. This will later be supplemented with clear written information, which will be provided at a time suitable to the person with dementia and their family. If the person with dementia declines to discuss these matters it needs to be offered to them again at a future date. (2a)

**A, F**

## Mr Smith's Diagnosis

**Mr Smith had noticed for a few months that he was forgetting things more than usual.**

His GP carried out a full physical, cognitive and mental health assessment, but on this occasion was not sure of the diagnosis so referred Mr Smith to the local specialist memory assessment service.

Mr Smith attended the clinic with his wife where he met with a Consultant Psychiatrist, underwent further mental testing and was given a diagnosis of Alzheimer's type dementia.

Before they left they were given written information about his diagnosis, what had been discussed about the proposed drug treatment and an appointment to return in a week's time to meet with a named member of the team to discuss the diagnosis further.

The next week they met with a nurse attached to the team to discuss the diagnosis and the post diagnostic support for Mr Smith and his wife that was available locally. Mr Smith was given a return appointment at the clinic for ongoing review of his medication and the nurse gave them contact details for a local support group for people with dementia.

Initially neither Mr Smith nor his wife wanted to think about making plans for the future as they did not feel ready to take this step. After meeting people at the support group they changed their minds and contacted the nurse from the memory assessment service who arranged to meet with them. At this meeting, the nurse explained the option of appointing Mrs Smith as her husband's welfare and financial power of attorney to them so that, if he did become unable to understand or make some decisions in the future, then he could rely on his wife to make those decisions on his behalf as she knew him better than anyone else.

This led onto discussions about other issues such as treatments for physical illness and also writing down the things that were really important to him. Not just the "big issues" such as medical care but the key information that he wanted people to know about him.

Following this discussion Mr and Mrs Smith spoke with their solicitor and made the necessary arrangements.

Two years later Mr Smith remains much as he was before his diagnosis. He receives regular reviews of his medication and continues to lead an active and busy life. He still drives his car, volunteers for his local church and goes on holiday. Neither he nor his wife have felt so far that they need any formal support from the local health or social services but have continued to attend the support group and know who to contact if the situation changes.

# Mr Young's Diagnosis

**Mr Young was admitted to a care home about three years ago. Until then, he had been living at home with his wife.**

Following his admission he began to have some problems with his memory and staff noticed a change in his behaviour. He was withdrawing from contact with other people and becoming increasingly bad tempered.

His wife was very upset about his behaviour; he could be very abusive towards her, which led her to visit less often. Staff in the care home started to accept this behaviour as "the way he was". He would often shout at them and lash out when they were attending to him.

He was physically very well so did not have any medical contact apart from his annual flu injection.

The nurse giving the flu injection asked the staff when Mr Young had been diagnosed with dementia. The staff said they were not sure about that so the nurse did some investigation and found that he had not been diagnosed with dementia; in fact, he had not come to the GP's attention at all.

## Since then

The GP visited and, following an examination, diagnosed Mr Young as having dementia. The GP referred Mr Young to the local community mental health team for advice on how to manage some of his behaviours. Mr Young was placed on the dementia register at the GP practice to ensure a review, at a minimum, annually.

Following assessment, the mental health nurse put in place a care plan to help staff who work with Mr Young, to understand why some of the behaviours were occurring and how to prevent them. The nurse was able to explain to Mrs Young the effect the dementia was having on his behaviour and she also referred Mrs Young to a local support group for carers, where she was able to talk to people who understood how she felt.

## I have the right to be regarded as a unique individual and to be treated with dignity and respect

The Charter of Rights for People with Dementia and their Carers in Scotland states... (▶1)

**People with dementia have the right, regardless of diagnosis, to the same civil and legal rights as everyone else.**

**People with dementia and their carers have the right to be able to enjoy human rights and fundamental freedoms in every part of their daily lives and wherever they are, including full respect for their dignity, beliefs, individual circumstances and privacy.**

**People with dementia and their carers have the right to have the full range of human rights respected, protected and fulfilled. In addition to those explicitly contained in the Human Rights Act 1998, these include:**

- the right to live in dignity and security and be free of exploitation, violence and physical, mental or sexual abuse
- economic, social and cultural rights including the right to an adequate standard of living including, social protection.

People with dementia and their carers have the right to be free from discrimination based on any grounds such as age, disability, gender, race, sexual orientation, and religious beliefs, social or other status.

**When this right is respected**

**People with dementia will**

Be valued and treated at all times as a person, with dignity and respect.

Be listened to, feel included and treated fairly.

Have their individual needs, preferences and aspirations met.

Receive information and the necessary support they need to continue to participate in decisions which affect them now and in the future.

And

Will not experience inhuman or degrading care or treatment. (▶3)

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### People with dementia will...

### Reporting Code

#### Be treated with dignity and respect.

#### Service providers will ensure that the actions of their staff and their policies and procedures demonstrate

An awareness of what the person with dementia and their family might be experiencing.

A, F

That the appropriate action is taken to ensure each person with dementia is treated with respect.

A, F

An understanding of different cultural, ethnic and other barriers to good communication (e.g. learning disability) and the steps taken to overcome these.

A, F

That the appropriate level of support is given to the person with dementia to access the food and drink the need to ensure a healthy diet.

A, F

That the person with dementia has access to their own personal belongings and memorabilia to personalise their physical environment.

E, S

That consideration is given to whether legal intervention is required to protect rights and provide safeguards if limits are being placed on the personal freedom of the person with dementia.

A, I

People with dementia will...

Reporting Code

Have their individual needs, preferences and aspirations met.

**Service providers will ensure that the actions of their staff and their policies and procedures demonstrate**

That care plans are person centred and strive to maintain the relationships, natural supports and routines important to the person with dementia.

A

That systems are in place to collect and share information from the person with dementia and/or their carer about their personal preferences, choices and expectations of the service.

A, F

Knowledge of whether the person with dementia has appointed someone as their welfare power of attorney or if there is a welfare guardian. (2a)

A

That the person with dementia retains as much choice in day-to-day activities as possible, e.g. what and when to eat, when to get up and go to bed, when to go outside.

A, F

That staff use a variety of communication aids to help communication, including the use of life story books, talking mats, digital stories, interpreters as appropriate and referral to speech and language therapy.

A

## Standards of Care for Dementia in Scotland

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### People with dementia will...

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### Reporting Code

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**Be listened to, feel included and treated fairly.**

**Service providers will ensure that the actions of their staff and their policies and procedures demonstrate that**

People with dementia have equitable access to services in the same way as any other person.

**F, P**

People with dementia should know how to make a complaint about services and receive support and assistance (e.g. from independent advocacy) to make a complaint

**E, F**

**Receive information and the necessary support they need to continue to participate in decisions which effect them now and in the future.**

**Service providers will ensure that the actions of their staff and their policies and procedures demonstrate that**

Staff understand that an individual's capacity can fluctuate depending upon particular circumstances and that they do not make assumptions about capacity to be involved in decision making.

**F, I**

Staff give people with dementia the opportunity to be involved in making decisions and choices, and the person is afforded adequate time and information is given in a variety of formats.

**F, I**

People with dementia are given the assistance they need to register and exercise their right to vote where they retain the capacity to do so.

**F, P**

## Treating Anna as an unique individual

### Anna was admitted to a care home for a period of respite care as her husband was unwell.

Anna was diagnosed with dementia about five years ago. Anna is Polish and came to live in Scotland with her husband after the Second World War.

Her husband, Alexander, was worried about how she would settle into the care home; her use of English was reducing and she was reverting back to using her Polish language, particularly if she was worried or stressed.

Anna's social worker spoke to the manager of the care home and they took some steps to make it easier for Anna during her stay there.

Alexander was asked to provide some family photographs and the care home had these copied and laminated and placed around her room in the care home. They also asked her husband to make sure she brought a number of personal mementos with her, and her favourite snacks.

The social worker spoke to Alexander and asked him to write down some common Polish phrases and words that Anna would understand. The social worker gave these to the care home manager who copied them and gave them to the care home staff.

The care home manager spent a lot of time before the admission speaking to Alexander to find out about what Anna liked to do and her preferences for what she liked to eat and when she liked to get out of bed etc, ensuring that a care plan was in place on the day of her admission.

Anna found the first night in the care home very difficult; she was disorientated and frightened but was reassured by the staff who knew just what to say and what to do to help her settle in.

The admission went well and Anna went home two weeks later to her husband who had enjoyed a good rest and took up the offer of regular respite admission to the care home.

# Not treating Robert with dignity and respect

**Robert was diagnosed with Parkinson's disease and dementia about three years ago. He now lives in an NHS continuing care ward because he has specialist nursing care needs and sometimes displays behaviours such as shouting, swearing and hitting out at people.**

Sometimes, Robert tried to leave and get on the local bus. He recently managed to get on the bus and staff had to persuade him to return to the ward.

Staff were worried about him getting lost so they decided to use an electronic tagging device to alert them when he leaves. He was given a tag to wear like a watch, which sets off an alarm if he goes beyond the front door.

One day, another visitor saw Robert leave the ward, then heard a very loud alarm shrieking and observed nurses running out of the ward. The visitor was told not to worry about the noise, that it was just Robert's alarm.

Later, the visitor noticed Robert walking around the ward with just his underpants and a T-shirt on. The visitor asked the staff if they could help Robert to get dressed but the staff said they just leave him to do this as they were too frightened to intervene in case he hit them.

The visitor made a complaint to the hospital manager about how Robert was being treated. He felt staff were not treating Robert with dignity or respecting his human rights, reasoning that:

- The alarm used was stigmatising, it identified Robert as having particular needs.
- Staff gave him (the visitor) private information about Robert that the visitor neither asked for nor needed.
- Staff were placing limits on Robert's personal freedom and it was not clear under what authority they were doing that.
- Robert's personal dignity was not being respected by allowing him to walk around semi-dressed in front of strangers in the ward; the visitor thought that neither he nor anyone else would like to think this is how they would be treated in similar circumstances.

- Staff were too frightened to intervene, which meant it was likely they did not have the appropriate training or expertise to care for Robert, a situation which required urgent review.

The hospital manager arranged an immediate multi-disciplinary review of the care and treatment Robert was receiving. Some of the issues covered in this review included:

- Assessing the need to use mental health and/or incapacity legislation.
- Deciding whether the use of the alarm system was appropriate.
- Considering whether the ward team, with support and training from the mental health team, could meet Robert's needs and respect his dignity.
- Considering whether Robert would receive better care and treatment elsewhere.

Following this, the hospital manager contacted independent advocacy services to arrange an advocacy worker to come and meet with Robert.

## I have the right to access a range of treatment, care and supports

The Charter of Rights for People with Dementia and their Carers in Scotland states... [▶1](#)

**People with dementia and their carers have the right to full participation in care needs assessment, planning, deciding and arranging care, support and treatment.**

**People with dementia have the right to access appropriate levels of care providing protection, rehabilitation and encouragement.**

**People with dementia have the right to the highest attainable standard of physical and mental health.**

**When this right is respected**

**People with dementia and their carers will**

Feel listened to, participate in decision making and have a say in how support and treatment is provided.

Receive the support and treatment that they need to stay well and lead a fulfilling life on a timely and coordinated basis.

And

Will not experience inhuman or degrading treatment. [▶3](#)

[▶](#) Denotes link to signposts section)

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### People with dementia and their carers will...

### Reporting Code

**Have access to independent advocacy services.**

**All service providers will ensure that**

Wherever the person with dementia is; at home, attending a day service, in hospital or in a care home, they will know about the purpose and availability of local independent advocacy services and be given any necessary support to contact and use advocacy services.

Advocacy services will be publicised in a way that the person with dementia and/or their carer can understand and be given the necessary support to enable them to contact advocacy services.

**Local authorities and NHS Boards will ensure**

The availability of independent advocacy in their area. (4)

A, F

E

P

People with dementia and their carers will...

Reporting Code

Be able to easily obtain information and advice about supports and care services that are available locally in order to make informed choices.

**Local authorities and NHS Boards will ensure that**

Information on supports and services is advertised locally in a variety of formats and includes who to contact for more information. Information should also be provided about eligibility criteria, service prioritisation, and assessment and care management processes.

D, F

People with dementia and their carers are given information about self directed support, such as direct payments, and are given assistance to access this.

D, F

Receive a good quality, timely and integrated assessment.

**Local authorities and NHS Boards will ensure that**

When an assessment for support and care is carried out, it will be outcome focused. This means focusing on what it is the person with dementia and their carer(s) want to achieve. (36)

A, D

The person with dementia and their carer will have an active and ongoing role in the assessment process to find out the amount and type of care and support needed and what can be achieved in partnership with services. They will be given a choice as to how, and by whom their support is provided.

A, F

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### People with dementia and their carers will...

### Reporting Code

**Receive a good quality, timely  
and integrated assessment.  
Continued**

Assessment will include looking at the supports that are already available and the relationships important to the person with dementia that must be maintained.

**A, F**

Life story and personal preferences will be recorded and taken fully into consideration during the assessment process.

**A, F**

Assessment processes include consideration of the person with dementia's capacity to make their own decisions and referral processes are in place for further assessment if required.

**A, F**

All agencies involved will co-operate with the assessment process to ensure that the person with dementia and their carer know who to contact and that a single care plan is put in place.

**A, F**

The person with dementia and their carer can receive a copy of their assessment and have the opportunity to challenge it if they wish to.

**A, F**

Carers are made aware of their entitlement to an assessment of their needs. (5)

**D, F**

Procedures are in place to ensure staff have the time, resources and skills necessary to undertake quality assessments and to engage with the person with dementia and their carer on an ongoing basis.

**D, F**

People with dementia and their carers will...

Reporting Code

Experience a person-centred approach to support and care.

**Local authorities, NHS Boards will ensure that**

Access to a wide range of quality support and care services is available, including practical help, support at home, personal care, day opportunities and day care services, short breaks and flexible respite, care homes, counselling services, peer support and specialist housing.

The person with dementia and their carer are supported to make decisions that put them in control of the care and support they receive.

Regular reviews are held to ensure outcomes are being achieved and changes made to the support provided if, for example, the person's needs have changed or extra support is available at times of transition (e.g. returning from hospital, moving to a care home, bereavement).

If there is evidence that the person with dementia is at risk of harm, exploitation or abuse there are local procedures in place to protect them and the staff take account of the person's views about risk. (6)

D, P

F

A

A, D

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### People with dementia and their carers will...

### Reporting Code

Receive treatment that is in line with the law.

#### NHS Boards will ensure that

Systems are in place to ensure that capacity to consent to treatment is considered and appropriate documentation in place where necessary. (2b)

A

Wherever they are living, people with dementia will have access to the full range of primary and specialist healthcare, including assessment and management of sensory impairment.

P

Receive treatment that is likely to be of benefit, including a range of non-drug based treatments.

#### NHS Boards will ensure that

Referral for specialist dementia assessment to a team specialising in the management of dementia is available wherever the person with dementia is living.

F, D

Assessment for the use of nationally recognised and approved drug treatments for dementia is carried out using an approved assessment tool and approved treatment prescribed and reviewed where clinically indicated. (17 and 19)

C, D

High quality pharmaceutical care and safe medicines management systems are available to people with dementia in all settings.

D, E

## People with dementia and their carers will...

## Reporting Code

**Receive treatment that is likely to be of benefit, including a range of non-drug based treatments. Continued**

If symptoms develop that cause distress or lead to behaviour that challenges, there will be an integrated assessment to establish the cause and a care plan developed to manage this. (▶17)

**A, D**

When psychoactive medication (including anti-depressants and tranquilisers) and in particular anti-psychotic medication is prescribed for people with dementia the prescribing doctor will need to be satisfied that there will be a clear benefit for the person with dementia and no reasonable alternative. The doctor will set a date to review its continued use and put in place a plan to ensure that carers and staff are aware of any potential side effects and where to report any concerns they have.

**A, D**

A range of non-drug based interventions are available and include evidence based therapies, such as group based or individual cognitive stimulation, individual reality orientation therapy, art therapy, therapeutic activities and physical exercise programmes. (▶19)

**A, D**

If behavioural or psychiatric symptoms are ongoing and distressing, referral is available to a psychologist or suitably qualified therapist for assessment and tailored intervention.

**P**

## Standards of Care for Dementia in Scotland

Action to support the change programme,  
Scotland's National Dementia Strategy

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### People with dementia and their carers will...

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### Reporting Code

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**Receive good quality care if admitted to a general hospital, accident and emergency department, or attend an out-patient department.**

#### **NHS Boards will ensure that**

Systems are in place so staff can easily identify someone with dementia, who may need extra support

**E, P**

Each general hospital has access for advice and/or assessment to a liaison service specialising in the diagnosis and management of dementia.

**F, P**

Systems are in place to request and record key personal information about people with dementia and ensure that this information is shared with staff who are in direct contact with them.

**A**

Guidelines on the management of delirium are available to all staff who provide care to acutely unwell people.

**F, P**

Systems are in place to monitor the number of moves people with dementia are subject to when in hospital.

**D**

Regular audit of the physical environment using the dementia design checklist and that appropriate action is taken to meet any deficits. (20)

**E**

Along with local authority partners, discharge planning arrangements will consider a range of care and support options. Robust procedures are in place to review decisions taken to transfer someone with dementia who previously lived at home to a care home. (21)

**A**

## Support and care for Marion

**Al cares for his wife Marion who has dementia; they live in a city centre. Marion has been assessed as needing 1 hour and 45 minutes of personal care each day.**

Having previously received support from private sector agencies, arranged by the social work department, Al now uses a direct payment to employ a personal assistant for Marion.

Al was unhappy with the inconsistency of carers and the standard of service provided by the first private sector agency he experienced. He asked the social work department to use a different agency, a request which took three months to implement.

'Carers would regularly cut visits short and blatantly cut corners. The agency regularly sent different care workers, which meant spending time showing them where things were and what was required.' Al

Whilst the new agency was good for the first few weeks, they soon resorted to similar bad practices as the first agency. Al made complaints about the service but felt they had no impact, his view being that the care workers knew they had the backing of the system.

Al found out about direct payments by chance at a welfare rights talk given at an Alzheimer Scotland carer support group. Once he applied for a direct payment, things moved fast with the support of his social worker and all other staff members involved in the process.

They initially received a direct payment at the lowest hourly rate; however, Al felt they needed a carer with an awareness of Marion's illness. He asked his social worker for a higher rate, so that he could employ someone who better understood dementia. This request was approved by the social work department once they received a supportive letter from Marion's consultant.

Al initially found it difficult to find an appropriate person to employ; he wanted someone who would be working for them only so they were not "slotting you in" with other clients. He feels the nature of dementia makes flexibility essential, and having

someone who is not fully booked for the day means they can provide the extra help they may need at any time. Al's daughter helped with the advertising and selection of a personal assistant, and they found their current carer after a few attempts. Al feels it is important to build a good relationship with the carer so they start to feel like one of the family.

Their personal assistant has accompanied them on a trip to London to visit family. Although Al could only pay the normal daily hours, their carer appreciated the opportunity to explore London. When staying in their daughter's holiday home in Spain, Al used the direct payment to pay a local person to help with Marion's personal care.

\*This example has been reproduced with permission of Alzheimer Scotland – let's get personal, personalisation and dementia.

# A poor care experience for Mr Walker

**Mr Walker was diagnosed with dementia about five years ago; he lives with his wife at home with no formal supports.**

He needed to be admitted to a general hospital for some physical investigations and was told he would need to be there for a day from 7am to 7pm.

His wife accompanied him to the ward and stayed with him for the first hour. Before leaving, she told a member of the nursing staff about his illness and how this affected his short term memory.

For the first hour on the ward Mr Walker was quite content reading his newspapers; he remembered quite clearly where he was and why.

During the course of the morning he was separately interviewed by a member of the nursing staff, the ward doctor, the anaesthetist, the pharmacist and the physiotherapist. All of them asked him very similar questions and Mr Walker quickly became tired.

At lunchtime, a tray of food was left near his bed so Mr Walker ate this as he was very hungry and thought this was for him. A member of staff found him eating this and seemed annoyed with him, she told him he was supposed to be fasting before his procedure and now it would have to be delayed until the early evening.

Mr Walker was becoming increasingly disorientated. From his bedside he could see the hustle and bustle of activity in the ward but no one spoke to him. He could not see where the nearest toilet was and could not work out how to use the combined telephone/television/radio unit beside his bed. He was becoming very frustrated and had great difficulty finding his way around the ward.

By the time his wife visited in the evening she found him very upset. He could not remember where he was or why he was there and he was insisting on leaving with her.

His wife spoke to the staff on duty and found out that the nurse she spoke to in the morning had made an entry in Mr Walker's notes that he had dementia but had not told anyone else about this, nor had she highlighted any assistance he might need in his care plan. As Mr Walker looked physically very well and initially came across as articulate and settled, the staff had made an assumption that he did not require any extra explanation or reassurance about what was happening, so had left him alone to wait for his procedure.

Mrs Walker felt she had no option but to take her husband home. Mr Walker was in no longer a fit state to go for a medical procedure then spend the night there.

Unfortunately, it would be at least six weeks before he could return for the procedure and he worried about going back to the hospital.

## I have the right to be as independent as possible and be included in my community

The Charter of Rights for People with Dementia and their Carers in Scotland states... [▶1](#))

**People with dementia and their carers have the right to live as independently as possible with access to recreational, leisure and cultural life in their community.**

**People with dementia have the right to help to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.**

**People with dementia and their carers have the right to access opportunities for community education and lifelong learning.**

**When this right is respected**

**People with dementia will**

Feel safe, secure and live as independently as possible.

Preserve the relationships important to them.

Feel involved and included in their community wherever they live.

[▶](#) Denotes link to signposts section)

## Standards of Care for Dementia in Scotland

Action to support the change programme,  
Scotland's National Dementia Strategy

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### People with dementia will...

### Reporting Code

**Be supported to remain as independent as possible.**

**NHS Boards, local authorities and other service providers will ensure that**

A range of local supports and services are available to enable people with dementia to remain in their own home or current care environment for as long as practicable. This should include – practical help, support at home, personal care, specialist dementia day care services, short breaks, flexible respite and access to telecare and assistive technology.

**A, D**

There is access to self directed support, including direct payments and other types of assistance, to enable a person with dementia and their carer to direct and determine their own support package.

**A, D**

People with dementia will have access to sight and hearing tests and have the aids they need.

**A**

Services provided are committed to promoting independence and providing personalised services that enhance and maintain existing supports available to people with dementia and their carers.

**A**

People with dementia will...

Reporting Code

**Be supported to remain as independent as possible.**  
**Continued**

The care provided shows a balance between their duty of care and the right of people with dementia who retain capacity to make decisions for themselves and to take risks in their own lives.

A

The principles of the Adults With Incapacity (Scotland) Act 2000 are used to inform decision making when taking decisions on behalf of a person with dementia who lacks capacity to make that decision. (2)

A, I

Risk assessment and management processes include analysis of the potential benefits of an activity.

A, I

Adaptations and reasonable adjustments are made to the physical environment in buildings where people with dementia are likely to attend to make the design of any building as dementia friendly as possible. (20)

E

## Standards of Care for Dementia in Scotland

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### People with dementia will...

### Reporting Code

**Have the opportunity to be included in community life and meaningful activities as they wish.**

#### **All service providers will**

Give people with dementia the support they need, wherever they are living, to continue to be involved in their ordinary activities such as; exercise, involvement in music, dance, social events and religious activity and to become involved in new activities and experiences.

**A, F**

Assess the mobility needs of the person with dementia and give assistance as necessary.

**A**

Encourage and support the person with dementia to maintain the family and social relationships important to them.

**A, F**

Help minimise social exclusion and develop new relationships by establishing and maintaining strong positive engagement with local community and voluntary groups such as befrienders, volunteers, schools, churches, nurseries.

**A, F**

Support people with dementia who may wish to volunteer in their own local communities (e.g. at day centres, peer support groups and churches).

**A, F**

## Mrs Brown: Being involved

### Some of the good practice introduced in an NHS continuing care setting to keep people who have more severe dementia involved and active.

Mrs Brown has severe dementia and physical disabilities following a stroke. She has some movement in one arm and will often lie there waving it in an apparent random fashion. Prior to her stroke she had difficulty in finding the right words to express how she was feeling; described by staff as “hard to reach”. She often sits with her eyes open staring blankly or with eyes tight shut.

The occupational therapist (OT) decided to use a projector on the ceiling or curtain (depending on where her gaze was) projecting a “lava lamp” effect in time with some music known to be liked by her. Mrs Brown will track the movement of the shapes with her eyes, and her random arm movement will slow and sometimes cease entirely. At other times, it is noted that her arm will either follow the direction of the projection or, if the music has a beat, will start to move in time to the music. At times, it appears as though she is conducting the music and can spend 10 minutes at a time absolutely engaged. She will end the session by shutting her eyes or looking away.

Other things used by the OT included, colour changing balls (battery operated). Mrs Brown will reach out and allow objects to be placed in her hand. She then clearly focuses on the object, exploring it and being thoroughly absorbed by it.

Mrs Brown used to work in makeup and the OT will bring a large blusher brush or powder puff in. Mrs Brown will allow these to be placed in her hand and if one moves close to her, she will move her arm very purposefully and pat and stroke the OT's face with the item. This affords a real connection between the staff and Mrs Brown.

# Isobel: Losing independence and her community

**Isobel lived alone in her own home, a first-floor flat in a large city. She was diagnosed with dementia about two years ago but it had little real impact on her daily life; her routines and contacts with her friends and neighbours continued as normal.**

About six months ago she was burgled while she was out at bingo and this had a really devastating effect on her. Following that, she began to leave the flat in the early hours of the morning and was returned to her home by the local police who found her walking along the road dressed in her nightdress and slippers. Some of the neighbours were concerned about her and that she may be targeted by local youths and be burgled again.

A social worker was allocated to visit Isobel and assess the situation. Isobel was offered a range of home supports, including home help and a community alarm, but she refused to consider these; she saw this as interference and she was a fiercely independent woman. A case conference was hastily arranged as Isobel had again gone walking late at night; Isobel refused to attend as she did not see what all the fuss was about.

At the case conference a decision was taken that Isobel should be admitted to a care home for respite care, given the

level of risk if she remained at home. The GP, who knew her very well, asked if alternatives could be considered and thought that some telecare systems that alerted a warden if she left late at night might be useful. It was decided though to go ahead with the move as it was thought the risk was so great that she needed to be moved immediately and, in any event, she had already refused offers of assistance.

When Isobel was told about this she was horrified and was adamant that she would not move. The social worker made an application for an interim welfare guardianship order to give her the power to insist that Isobel move to the care home and she moved there two days later. Isobel thought she had no choice but to move when all the "official" paperwork was produced. The care home was located about 10 miles away but was quite remote and meant she would need to take two buses and a walk up a long drive to visit her friends and vice versa. As most of her friends were over 80 years of age this made it unlikely that they could visit regularly.

Unfortunately, Isobel suffered a fall shortly after her admission to the care home and fractured her hip. She took a long time to regain her mobility and by then had lost many of her housekeeping and social skills. Her last social worker had moved on to another post and because of her fall there was no plan put in place to try and get her back to her home, so she remained in the care home on a permanent basis.

In Isobel's case, so much more could have been done to keep her at home. The risk assessment concentrated only on the current risks and not on the benefits to her of remaining in her own home. A decision to move her to a care home was taken at a time of crisis in her life, the recent burglary had affected her greatly and she needed time and support to recover. Isobel also had no support to help her oppose the move; she had no family and no independent advocacy worker.

## I have the right to have carers who are well supported and educated about dementia

The Charter of Rights for People with Dementia and their Carers in Scotland states... [▶1](#))

**People with dementia have the right to health and social care services provided by professionals and staff who have had appropriate training on dementia and human rights to ensure the highest quality of service.**

**People with dementia and their carers have the right to be provided with accessible information and the support they require in order to enable them to exercise their right to participate in decisions which affect them.**

### When this right is respected

Carers will feel valued and properly supported in their role and will know where to get help if needed.

All health and social care staff will know about and promote the interests of people with dementia.

[▶](#) Denotes link to signposts section)

## Standards of Care for Dementia in Scotland

Action to support the change programme,  
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### Reporting Code

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#### Carers will be recognised and valued as partners in care and be supported in their role

##### All service providers will ensure that

Carers are involved in the assessment, planning and review of support, care and treatment for the person with dementia.

A, F

Carers are given the opportunity to continue with, or adapt, their caring role if either the circumstances of the person with dementia or their own circumstances change.

A, F

##### Local Authorities and NHS Boards will ensure that

Carers of people who have recently been diagnosed with dementia are given access to educational resources about dementia. (22)

A, F

Carers are given information about the right to request a carer's assessment and that up-to-date information on carers' support in their local area is available. (7)

F

The carer support plan will include assessment of the financial, emotional and practical support that is required.

F

Psychological support including peer support is available locally for carers of people with dementia.

A

Supports available to carers include the provision of short breaks and flexible respite.

A, P

## Reporting Code

### Paid care staff

#### All service providers will ensure that

Health and social care staff have the knowledge and skills they need in relation to their role in supporting people with dementia. (14)

A

Carers of people with dementia are invited to contribute to staff training and development.

F, P

Staff receive the appropriate levels of supervision and opportunities to reflect on their practice.

A, F

# Support for a carer

**Joan and her husband George moved from Glasgow to a small country town shortly after their retirement. Joan continued to work part time in the local supermarket to supplement their income.**

George was diagnosed with dementia soon after their move and was put in touch with Claire, a community psychiatric nurse (CPN), who visited every month. Joan felt isolated; she had not had the chance yet to make new friends as she was so busy working and looking after George. The CPN put Joan in touch with a local carers support group and referred her to a local counselling service.

Other carers she met told her all about the support that was available locally and what Joan found most helpful was the support of her local community. She was comforted by knowing that people were looking out for her and George. One evening at a meeting of the support group a social worker came along to talk about direct payments and how carers could claim and use these.

With some support from the social worker, Joan used these payments to employ a personal assistant for George a few hours a week, so she could manage her hours at work. It also allowed her to arrange occasional overnight care, so that Joan could visit her friends in Glasgow to catch up and relax.

## A lack of support for Jim

Following a lengthy period of time, Alice was diagnosed with a rare type of dementia.

The diagnosis took a long time to be made because other psychiatric and physical illnesses needed first to be excluded.

When the diagnosis was eventually confirmed by a neuropsychiatrist, there was no further information given about support, information or guidance, just a follow up appointment in three months time. Her husband, Jim, described leaving the consultation with his world in absolute tatters and a feeling that he had been left completely alone to deal with it. Jim spent a lot of time on the internet trying to find out more information, much of which he found frightening and conflicting. Jim said he spent the next three months in a daze.

The next appointment only confirmed the diagnosis, but there was a promise made to refer him to the community mental health team for support and advice. When Alice and Jim eventually met with the Consultant Psychiatrist it had been more than six months since diagnosis and they had a 20-minute time slot to ask all the questions and explain the worries they had.

Jim was keen to speak to the doctor or nurse on his own; he did not want Alice to hear his worries about how quickly she was deteriorating but he wasn't given this opportunity.

As well as being the carer for Alice, Jim also had to carry on working full time and support his children, who were finding it difficult to cope too.

Eventually, through a family friend, Jim got in touch with some other carers and he was surprised when he heard about the good support they were receiving from a Community Psychiatric Nurse and the social work department. Jim was angry about the lack of consistency in service provision. He had to seek out and make a fuss to get these services, rather than be helped and supported.

Jim thinks this happened because Alice was younger than most people with dementia and so didn't fit into "the tick box" that services used to decide the care and support that people with dementia and their carers needed. Jim says that he and Alice are individuals who don't fit into the typical picture of dementia and instead of services adapting to their needs, they are expected to adapt to what the service wants to deliver.

# I have the right to end of life care that respects my wishes

**The Charter of Rights for People with Dementia and their Carers in Scotland states... (▶1)**

**People with dementia have the right to the highest attainable standard of physical and mental health.**

**People with dementia and their carers have the right to full participation in care needs assessment, planning, deciding and arranging care, support and treatment, including advanced decision making.**

**When this right is respected**

**People with dementia will**

Have access to the full range of palliative care services and good quality compassionate care towards the end of life.

Receive the support they need to die with dignity and in the place of their choosing wherever possible.  
Receive care towards the end of life that respects their previously expressed wishes.

And

Will not experience inhuman or degrading treatment at the end of their life. (▶3)

People with dementia will...

Reporting Code

Have access to a full range of palliative care services.

**People with dementia have the same right of access to palliative care services as anyone else.**

**NHS Boards will ensure that**

The person with dementia is given the opportunity, if they wish; to consider an anticipatory care plan and advance care planning that will be reviewed at least annually. (23)

A, D

The anticipatory care plan and any other advance planning made will be recorded in the primary care record and shared with those providing care.

A, D

Assessment and review of palliative care needs using recognised assessment tools will include physical, social, emotional and spiritual needs.

A, D

Any care plan will be person centred, taking into account the needs, wishes and preferences of the person with dementia and their carer.

A, D

People with dementia will be included on the palliative care register where clinically indicated and appropriate.

A, D

## Standards of Care for Dementia in Scotland

Action to support the change programme,  
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### People with dementia will...

### Reporting Code

**Have access to a full range of palliative care services.**  
**Continued**

Referral for specialist palliative care services will be made, if required, wherever the person with dementia is living.

A, D

Staff across all care settings know how to get specialist advice and assistance if required.

A, F

**Receive end of life care that respects their wishes.**

#### **Towards the end of life**

People with dementia and their carers may need support from a variety of NHS and local authority services to continue living at home and to die there if that is their wish.

#### **NHS Boards, local authorities and other care providers will ensure that**

Specialist palliative care services are provided in a variety of settings, including hospitals, care homes and people's own home and that the person with dementia is not moved from their home in the last few days of life unless absolutely necessary.

A, F

Specialist multidisciplinary assessment and advice is available if required including dietary and specialist swallowing assessment.

F, P

## People with dementia will...

## Reporting Code

### Receive end of life care that respects their wishes. Continued

Staff caring for the person with dementia know about any advance planning that has been made, including if a decision has been made about resuscitation and active management of symptoms. (24)

A, F

If a decision has been made not to resuscitate, this will be in accordance with national guidelines. (24)

A, F

Pain relief is available, pain is well controlled and staff use observational pain assessment tools.

A, F

Encouragement and support is given to family and friends to continue to be involved in planning and delivering care.

A, F

Staff respect the faith and cultural preferences of the person with dementia and should enquire into matters if the information is not already available.

A, F

In the last days and hours of life, the care given should be guided by the Liverpool care pathway. (25)

A, F

Staff are able to provide bereavement support at the time of death including guidance about what to do next and where family and friends can receive ongoing bereavement support service, if required.

A, F

# Planning ahead

**Mr Smith was diagnosed with dementia around the time of his retirement. In addition, he had various physical complaints that worried him, including heart disease and high blood pressure.**

Shortly after his diagnosis he met with a Community Psychiatric Nurse (CPN) from the local community mental health team to discuss thinking ahead and making plans for the future.

During this initial meeting they discussed the things that Mr Smith and his wife and family might want to think about, such as appointing his wife as his welfare and financial power of attorney and thinking about the care and treatment he would want in the future.

Some months later he shared with his CPN that he was worried about his death; he did not fear death itself but worried that he might not be in control of what was happening, which was his biggest fear. He had seen his own father die in pain and distress and did not want to put his family through the same thing.

The CPN contacted the GP practice and arranged a meeting with the practice

nurse, who knew Mr and Mrs Smith well, to discuss advance care planning. They discussed things that the couple might want to consider, including the medical treatment Mr Smith would and wouldn't want if he became physically very unwell.

Mr Smith prepared a statement of wishes relating to his future care, which was signed and witnessed and a copy placed in his medical notes. The practice nurse also prepared an anticipatory care plan, which included details of his illness and the care he would want to receive in the event of his health deteriorating rapidly. She gave a copy to Mr and Mrs Smith and also placed a copy in the practice notes. Mr Smith was placed on the practice's palliative care register. This meant that the anticipatory care plan formed part of a palliative care summary. Mr Smith's consented to the transfer of information collected by his GP practice to a central information store, making this available to Out of

Hours services, NHS 24 and Accident and Emergency services.

Over the next 12 months, Mr Smith's physical and mental health deteriorated rapidly. He was admitted briefly to a cardiology unit to try and stabilise his heart condition but he found his stay there to be confusing and distressing. He was offered major surgery for his heart condition but was no longer able to make decisions about his health care so his wife, as his welfare power of attorney, declined the treatment as it seemed to be of little benefit to him. Mrs Smith was sure that her husband would not want any further invasive treatment.

With limited life expectancy it was decided that, in keeping with his previously expressed wishes, he should remain at home if possible and the necessary community care support arrangements were put in place to make sure this happened, and to provide support for Mrs Smith.

## A lack of planning

**Mr Andrew was admitted to an NHS continuing mental health care ward two years ago; he had complex care needs, was physically frail and had dementia.**

His physical condition had been deteriorating for some weeks; he was taking little food or fluid and had been confined to bed for a few days.

During the night he was found to have a very high temperature and seemed to be in pain, so the nurse asked the on call doctor to attend. The doctor examined him and found he had a severe chest infection and dehydration. There was no plan in the care file about how this was to be managed and Mr Andrew was unable to express his views. The doctor arranged for admission to the local general hospital for fluids and antibiotics through a drip.

He was admitted via Accident and Emergency to an acute admission ward and his family were informed of his admission.

Mr Andrew was distressed to be somewhere he did not know with people who did not know him. He became increasingly distressed and noisy and other patients were showing obvious annoyance at the level of disturbance.

He was examined by a senior doctor who decided to stop giving active treatment and to focus instead on keeping him comfortable over the next few days.

Mr Andrew was visited by his family who found him very noisy and distressed and asked that he be given pain relief as they thought his distress was caused by pain and discomfort. He responded well to the pain relief.

His family were upset that they were not involved in, or informed of, the decision to withdraw treatment and to put in place a do not attempt resuscitation order.

They did not disagree with the decisions, but were upset that there had been no plan in place to manage his expected physical deterioration or their views sought about how this should be managed. They felt his transfer to the general hospital had been unnecessary and distressing for him.

Arrangements were made to transfer Mr Andrew back to the NHS continuing care ward the next day but, unfortunately, he died that night.

## Standards of Care for Dementia in Scotland

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### SIGNPOSTS

#### ➤1 **Charter of Rights for People with Dementia and their Carers in Scotland. 2009**

The rights contained within the charter are based on internationally agreed human rights and are intended to promote the respect, protection and fulfilment of all human rights of people with dementia and their carers as guaranteed in the European Convention of Human Rights and the Universal Declaration of Human Rights, The International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights and the Convention on the Rights of Persons with disabilities. <http://www.dementiarights.org/>

#### **Supporting legislation**

(All legislation available from <http://www.legislation.gov.uk/>)

#### ➤2 **The Adults With Incapacity (Scotland) Act 2000**

The general principles of the Act include ensuring that the present and past wishes of the adult (so far as they can be ascertained by any means of communication) are taken into account when determining if an intervention under the Act should be made.

➤2a **Part 2** of the Act gives a competent adult the right to appoint a person to make decisions on their behalf relating to general welfare and/or their finances in the event they lose capacity (a power of attorney).

➤2b **Part 5.** Some people with dementia may not always be able to give a valid consent for any proposed treatment. The law in Scotland recognizes this and has put in place procedures and safeguards to protect

people. People with dementia, as with everyone else, must have their capacity to consent to medical treatment assessed by anyone proposing to prescribe medication or carry out any other medical treatment or intervention. If they have capacity to consent then it is up to the person with dementia to either give their consent or not. If the person with dementia cannot give valid consent then the view of any proxy decision maker (a welfare power of attorney or welfare guardian) should be sought. A certificate of incapacity must be completed under Section 47 of the Adults with Incapacity Act (Scotland) Act 2000 when someone lacks capacity to consent. This certificate authorises treatment and ensures treatment is given lawfully.

#### ➤3 **The Human Rights Act 1998**

affects the way that public bodies such as hospitals and local authorities treat people when carrying out their functions. It adopts the articles of the European Convention of Human Rights giving them a legal basis in the UK.

These articles include

- The right not to be treated in an inhuman or degrading way (Article 3)
- The right to freedom and liberty (article 5)
- The right to respect for private and family life, home and correspondence (Article 8)

#### ➤4 **The Mental Health (Care and Treatment) (Scotland) Act 2003**

Section 259 states that every person with a mental disorder (this includes people with dementia) shall have a right of access to independent advocacy.

- 5 **The Community Care and Health (Scotland) Act 2002**  
provides local authorities with the duty to assess the community care needs of anyone that requests it, but also to deliver a package of care in order to meet those needs.
- 6 **The Adult Support and Protection (Scotland) Act 2007**  
gives powers for local authorities to investigate circumstances where an adult at risk may be at risk of harm and creates duties for other public bodies to share information when an adult may be at risk of harm.
- 7 **The Carers (Recognition and Services) Act 1995 & Community Care & Health (Scotland) Act 2002.**  
These acts set out the local authority powers and duties. Guidance to the 2002 Act states that local authority assessments should consider what support is necessary to sustain the carer's role and should meet the needs of both the cared for person and the carer, as far as possible and appropriate.
- 8 **The Public Services Reform (Scotland) Act 2010**  
**Part 5** establishes Social Care and Social Work Improvement Scotland (SCSWIS) with scrutiny functions in relation to care services and social work services.  
**Part 6** establishes Healthcare Scotland (HIS) with scrutiny and other functions in relation to NHS and independent healthcare services.
- 9 **The NHS and Community Care Act 1990** gives local authorities the lead responsibility for planning and coordination of community care services and duties for community care assessments.
- 10 **The Equality Act 2010** brings together nine separate pieces of legislation into one single Act simplifying the law and strengthening it in important ways to help tackle discrimination and inequality. From 1 October 2010, the Equality Act replaced most of the Disability Discrimination Act (DDA).
- 11 **The Community Care (Direct Payments) Act 1996** regulates the provision of welfare services and community care more generally. It requires local authorities to promote the welfare of persons in need in their area, and to assess need and provide services in order to do this. There are specific provisions relating to nursing and residential care.
- 12 **Regulation of Care (Scotland) Act 2001**
- 13 **National Health Service (Scotland) Act 1978**  
There is no specific legislation covering palliative care in Scotland. It is covered under general duties within this Act. Those with palliative care needs may also be eligible for a range of social or community care services to support them in day-to-day living.

## Standards of Care for Dementia in Scotland

Action to support the change programme,  
Scotland's National Dementia Strategy

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### Existing Standards and Best Practice Guidance

- 14 **Promoting Excellence: A framework for health and social care staff working with people with dementia, and their families and carers.** Scottish Government (June 2011)
- 15 **HEAT Target 4. Improvement in the early diagnosis and management of patients with dementia,** Scottish Government (2008). <http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/DFMH/antidepressantprescribing>
- 16 **Standards for Integrated Care Pathways for Mental Health** NHS Quality Improvement Scotland (2008). Timely diagnosis, standard 10, 14, and 21 <http://www.icp toolkit.org/>
- 17 **SIGN 86 management of patients with dementia. A national clinical guideline.** Scottish Intercollegiate Guidelines Network (2006 reviewed 2009). <http://www.sign.ac.uk/guidelines/fulltext/86/index.html>
- 18 **Working with independent advocates.** The Mental Welfare Commission for Scotland (2009). [www.mwscot.org.uk](http://www.mwscot.org.uk)
- 19 **Standards for integrated care pathways for mental health.** NHS Quality Improvement Scotland (2008).  
– Standard 15, Suitability for psychological and/or psychosocial interventions  
– Standard 16, Person centred care  
– Standard 17, Single care plan  
– Standard 18, Recording medication decisions  
– Standard 20, Inpatient admission and discharge  
– Standard 21, Measure of needs and outcome  
– Standard 27, Treatment for cognitive impairment  
– Standard 28, Matched intervention  
– Standard 29, End of Life <http://www.icp toolkit.org/>
- 20 **Design for People with Dementia: Audit Tool.** The University of Stirling: Dementia Services Development Centre (2008). <http://www.dementiashop.co.uk/?q=node/142>
- 21 **CEL 6, NHS Continuing Healthcare.** Scottish Government (2008) [http://www.sehd.scot.nhs.uk/mels/cel2008\\_06.pdf](http://www.sehd.scot.nhs.uk/mels/cel2008_06.pdf)
- 22 **Coping with dementia: a practical guide.** NHS Health Scotland, (2009). [www.healthscotland.com](http://www.healthscotland.com)
- 23 **Living and Dying Well: A national action plan for palliative and end of life care in Scotland.** Scottish Government (2008). [www.scotland.gov.uk/publications](http://www.scotland.gov.uk/publications)
- 24 **Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) – Integrated Adult Policy.** NHS Scotland (2010). <http://www.scotland.gov.uk/Publications/2010/05/24095633/0>
- 25 **Liverpool Care Pathway for the Dying Patient.** Marie Curie Palliative Care Institute Liverpool (2010) <http://www.mcpcil.org.uk/liverpool-care-pathway/index.htm>
- 26 **Facing dementia.** Health Scotland (2008). A booklet for those who are either worried about dementia or who have been diagnosed with dementia. It provides reassurance and suggests practical steps to improve or maintain dignity and the quality of life as far as possible <http://www.healthscotland.com/documents/15.aspx>

- 27 **National care standards.**  
Scottish Government (2010).  
– Care homes for people with mental health problems  
– Care Homes for Older People  
– Housing Support Services  
– Support services:  
– Care at Home  
– Nurse agencies  
<http://www.scotland.gov.uk/Topics/Health/care/17652/National-Care-Standards-1-1>
- 28 **National care standards; Care Homes for Older People.**  
Scottish Government (2010). **Standard 19** is about support and care in dying and death. It states that people living in care home can be confident that the home's staff will be sensitive and supportive during the difficult times when someone dies.
- 28 *continued* **Standard 14** is about keeping well. It states that people who live in care homes should be confident that the care home staff will know their healthcare needs and meet them in a way that suits them best.  
<http://www.scotland.gov.uk/Topics/Health/care/17652/National-Care-Standards-1-1>
- 29 **Dementia: ethical issues.**  
Nuffield Council on Bioethics (2009).  
<http://www.nuffieldbioethics.org/dementia>
- 30 **Let's get personal- personalisation and dementia.**  
Alzheimer Scotland (2010).  
<http://www.alzscot.org>
- 31 **Caring Together: The Carers Strategy for Scotland 2010 – 2015.** Scottish Government (2010). <http://www.scotland.gov.uk/Publications/2010/07/23153304/0>
- 32 **Decisions relating to cardiopulmonary resuscitation.**  
British Medical Association, Resuscitation Council (UK) and Royal College of Nursing (2007).  
<http://www.resus.org.uk/pages/dnar.pdf>
- 33 **Making good care better: National practice statements for general palliative care in adult care homes in Scotland.**  
Scottish Partnership for Palliative Care (2006). [www.palliativecarescotland.org.uk/publications](http://www.palliativecarescotland.org.uk/publications)
- 34 **Gold Standards Framework** provides a framework in primary and community care for effective person centred planning during last 12 months of life. [www.gsfs.scot.nhs.uk/](http://www.gsfs.scot.nhs.uk/)
- 35 **Standards for Integrated care pathways for mental health.**  
NHS Quality Improvement Scotland (2007). Standard 29, End of life care. <http://www.icptoolkit.org/>
- 36 **Talking Points: A personal outcome approach**  
Joint Improvement Team (2006)  
<http://www.jitscotland.org.uk>

## GLOSSARY

**Advocacy:** independent advocacy is a way to help people have a stronger voice and to have as much control as possible over their own lives. It empowers people who need a stronger voice by enabling them to express their own needs, secure their rights and make their own decisions.

**Advance care planning:** promotes discussion between people diagnosed with dementia, those close to them and those who provide care with respect to their future health, personal or practical aspects of care.

**Anticipatory care plan** is the document produced in relation to advance care planning.

**Antipsychotic drug:** a drug used to alleviate the symptoms of a psychotic illness.

**Care planning:** planning to provide services and supports to meet the outcomes a person wants to achieve, in order to meet their assessed need.

**Carer:** someone who spends a significant proportion of their life providing unpaid support to family or friends.

**Carer's assessment:** the purpose of a carer's assessment is to discuss with social services the help a carer needs with caring as well as any help that would maintain the carer's own health and balance caring with other aspects of life such as work and family commitments.

**Capacity to make decisions:** the ability of someone over the age of 16 years to make a specific decision in a given situation.

**Community:** a group of people living in a particular local area or residential setting.

**Delirium:** a sudden state of severe confusion and rapid change in brain function.

**Diagnosis:** identification of an illness or health problem by means of its signs and symptoms.

**Direct payment:** money given to an individual, by a council, to pay for services and supports which he or she has been assessed as needing. It provides the person who uses services or, in certain circumstances, the carer with more choice and control over care received.

**End of life:** the last phase of a person's life, from the point at which it has become clear that the person is in a progressive decline.

**Independent:** in relation to people with dementia is often associated with continuing to live in their own home, but people with dementia can continue to be independent wherever they are living and in a variety of ways.

**Life story:** an account of the series of events making up a person's life and the people important to them.

**Outcome:** at an individual level, this means the impact or end results of supports and/or treatment on a person's life.

**Palliative care:** an approach that improves the quality of life of people and their family facing problems associated with life threatening illness through prevention and relief of suffering.

**Person-centred:** putting both person who uses services at the centre of their support, care and treatment. Ensuring everything that is done is based on what is important to the person from their own perspective.

**Policy:** high-level statement of intent and objectives within an organisation.

**Procedure:** the steps taken to fulfil a policy.

**Psychoactive medication:** a medication that effects brain function such as an anti-depressant or drug to help manage anxiety.

**Risk assessment:** identifying risks to and from an activity and assessing the potential impact of each risk.

## GLOSSARY continued

**Risk management:** identifying, assessing, controlling, monitoring, reviewing and auditing risk.

**Scrutiny bodies:** SCSWIS and HIS are the public bodies charged with improving the quality of social care, social work, children's services and healthcare services. They are also charged with providing more streamlined and better co-ordinated scrutiny of service quality.

**Self directed support:** an overarching term for a number of different approaches to give people in need of care services greater levels of control over how their support needs are met.

**Standards:** the minimum acceptable level of performance, or the level of performance that is generally accepted.

**Telecare and assistive technology:** provides a range of options such as alarms, sensors and communication aids to help support people.

## USEFUL CONTACTS

The organisations in this list can help with understanding of individuals' rights, complaints and general support for people with dementia and their carers.

**Alzheimer Scotland.** This organisation can give advice and practical support to people with dementia and their carers. Tel: 0808 808 300. Website: <http://www.alzscot.org/>

**Citizens' Advice Scotland.** This organisation provides general advice and has a specific project that helps people make complaints about public services. Website: <http://www.cas.org.uk/>

**Equality and Human Rights Commission.** This organisation works to eliminate discrimination and promote human rights. Tel: 0845 604 5510. Website: <http://www.equalityhumanrights.com/scotland/>

**Healthcare Improvement Scotland.** This organisation works to improve the quality of NHS and independent health care. <http://www.healthcareimprovementscotland.org/home.aspx>

**Law Society of Scotland.** This organisation's website can help you find a solicitor. Tel: 0131 226 7411. Website: <http://www.lawscot.org.uk/>

**Mental Welfare Commission for Scotland.** This organisation works to safeguard the rights and welfare of everyone with mental illness, learning disability or other mental disorder. Tel: 0131 313 8777  
0800 389 6809 (freephone number for service users and carers).  
Website: [www.mwscot.org.uk](http://www.mwscot.org.uk)

**Scottish Independent Advocacy Alliance.** This organisation supports the development of independent advocacy. The website has a map giving details of local independent advocacy in all parts of Scotland. Tel: 0131 260 5380. Website: <http://www.siaa.org.uk/>

**Social Care and Social Work Improvement Scotland.** This organisation ensures the quality of social work and registered care services. It can investigate complaints against registered care providers. Tel: 0845 600 9527. Website: <http://www.scswis.com/>

**Scottish Human Rights Commission.** This organisation promotes and protects the human rights of everyone in Scotland. Tel: 0141 243 2721. Website: <http://www.scottishhumanrights.com/>

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Royal College of Psychiatrists

Scottish Dementia Working Group

Alzheimer Scotland

Scottish Care

COSLA

NHS Education for Scotland

Scottish Social Service Council

Allied Health Professionals



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