COMMON STANDARDS OF CARE FOR DEMENTIA

Action to support the change programme, Scotland’s National Dementia Strategy (2010)

MARCH 2011
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INTRODUCTION

People with dementia retain the same rights as anyone else in society but the nature of the illness means that people with dementia 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, justifiably, 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.

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 standards are based on two things.

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.

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

They are also to be used by people responsible for providing, commissioning or scrutinising services that people with dementia use.

The standards are intended to raise standards in dementia care, but are achievable and lead to continuous service improvement.

Scrutiny bodies in Scotland (Healthcare Improvement Scotland, Social Care and Social Work Improvement Scotland and the Mental Welfare Commission for Scotland) will use these standards when assessing the care of individuals or the performance of services.

To ensure continuous improvements 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”.

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

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 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
I have the right to a diagnosis.

Charter of Rights for people with dementia and their carers in Scotland states…

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

If this right is respected then

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.
| Receive an accurate and timely diagnosis | Wherever a person is living or the stage of their illness they have the right to a diagnosis….

**NHS Boards will ensure**

Opportunities are provided for people worried about their memory to timely access to services for assessment including those who may be “hard to reach” e.g. homeless people, black and ethnic minority communities.

GP surgeries and hospitals have established pathways to diagnosis in place to include when it is appropriate to refer to a service that specialises in the diagnosis of dementia and. Identification of who is best placed to carry out specific roles in relation to diagnosis and pre and post diagnostic support. *(sp1)*

GP’s and hospitals can refer to people with suspected dementia to services that specialise in the diagnosis of dementia and receive an appointment to attend within four weeks of referral.

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

People being assessed for possible dementia are made aware that to ensure accuracy, a confirmation of diagnosis may not always happen quickly.

Before giving 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 counselling that is likely to be required.

Careful consideration will be given as to the best place to give the diagnosis. Enough appointment time will be allowed to give the person with dementia and their family time to consider what they want to know next.

*sp denotes link to signpost section.*

**Pre diagnosis**

**At time of diagnosis**
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<tr>
<th><strong>Receive information about the illness and the supports and services available</strong></th>
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<tr>
<th><strong>Whether it is the GP, hospital doctor or a specialist service that considers the diagnosis, the assessment is carried out using recognised diagnostic tools by skilled, confident and well trained staff. (sp2 &amp; sp4)</strong></th>
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<tbody>
<tr>
<td>There are clear referral processes for post diagnosis treatment and support for people recently diagnosed and contact details given of a service they can contact for further information and advice.</td>
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<table>
<thead>
<tr>
<th><strong>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.</strong></th>
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<tr>
<td><strong>NHS Boards and local authorities will ensure</strong></td>
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<tr>
<td>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.</td>
</tr>
<tr>
<td>If the person with dementia does not want to receive this information they should be offered the opportunity again at a future date.</td>
</tr>
<tr>
<td>Information provided is available in a variety of formats and aimed at maximising well being and quality of life. It will include</td>
</tr>
<tr>
<td>- Information about the condition, advice on managing symptoms and treatment available</td>
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<tr>
<td>- Support available locally; this should include a directory of local support services including post diagnostic support and counselling either one to one or in groups</td>
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<tr>
<td>- Specific information about continuing to drive following a diagnosis of dementia.</td>
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<td>Have the opportunity to make plans for the future</td>
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*sp denotes link to signpost section.*
Mr Smith, aged 68 years, had noticed for a few months that he was forgetting things more than usual and after a great deal of persuasion from his wife and family he agreed to speak to his GP about it.

His GP carried out a full physical, cognitive and mental health assessment but on this occasion was unsure of the diagnosis so thought that Mr Smith would benefit from attending the local specialist memory assessment service.

Following referral from his GP, 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.

Both Mr Smith and his wife had a very difficult week and were having great difficulty accepting the diagnosis. 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 Brown 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 and their carers.

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

This lead onto other discussions about other things like 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 thought 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 that changes.
EXAMPLE OF WEAK PRACTICE

Mr Young aged 85 years was admitted to a care home about three years ago, he had been living at home with his wife but he had severe arthritis that made it difficult for him to move around and he was physically very frail.

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 and she started 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 how long Mr Young had been diagnosed with dementia for. 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 gave a diagnosis of dementia and referred Mr Young to the local community mental health team for advice on how to manage some of the behaviours that he had. Mr Young was placed on the dementia register at the GP practice to ensure a minimum annual review.

Following assessment, the mental health nurse put in place a care plan to help staff work with Mr Young, to understand why some of the behaviours were occurring and to prevent them. The nurse was able to explain to Mrs Young about 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.
<table>
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<th>SIGNPOSTS</th>
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<tbody>
<tr>
<td><strong>SUPPORTING LEGISLATION</strong></td>
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<tr>
<td>Part 2 of the Adults With Incapacity(Scotland) Act 2000 gives a competent adult the right to appoint a person to make decisions on their behalf in the event they lose capacity (a power of attorney). <em>(sp4)</em></td>
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| **EXISTING STANDARDS, BEST PRACTICE GUIDANCE** |
| Standards for Integrated Care Pathways for Mental Health timely diagnosis, standard 10,14, and 21 [http://www.icptoolkit.org/](http://www.icptoolkit.org/) *(sp1)* |

| SIGN 86 management of patients with dementia, an evidence based clinical guideline, 2006 reviewed 2009 [http://www.sign.ac.uk/guidelines/fulltext/86/index.html](http://www.sign.ac.uk/guidelines/fulltext/86/index.html) *(sp2)* |

| Promoting Excellence: A framework for health and social care staff working with people with dementia, and their families and carers. NHS Education for Scotland and Scottish Social Services Council April, 2011 *(sp3)* |

| Facing dementia; A booklet for those who are either worried about dementia or who have been diagnosed. 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/](http://www.healthscotland.com/) |
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…

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.
If this right is respected then

*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 effect them now and in the future.
- And
- Will not experience inhuman or degrading care or treatment.
<table>
<thead>
<tr>
<th>People with dementia will.....</th>
<th>Service providers will ensure that the actions of their staff and their policies and procedures demonstrate</th>
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<tbody>
<tr>
<td>Be treated with dignity and respect.</td>
<td>An awareness of what the person with dementia and their family might be experiencing.</td>
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<tr>
<td></td>
<td>Appropriate action is taken to ensure the dignity of the person with dementia is best respected.</td>
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<td>An understanding of different cultural, ethnic and knowledge barriers to good communication and taking steps to overcome these.</td>
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<tr>
<td>Have their individual needs, preferences and aspirations met.</td>
<td>The person with dementia has access to their own personal belongings and memorabilia to personalise their physical environment.</td>
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<td></td>
<td>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</td>
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<td></td>
<td>Care plans are person centred and strive to maintain the relationships, natural supports and routines important to the person with dementia.</td>
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<td></td>
<td>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.</td>
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<td></td>
<td>Knowing if the person with dementia has appointed someone as their welfare power of attorney or if there is a welfare guardian. <em>(sp1)</em></td>
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<td>The person with dementia retains as much choice in day to day activities as possible</td>
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<tr>
<th>Be listened to, feel included and treated fairly.</th>
<th>e.g. what and when to eat, when to get up and go to bed.</th>
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<tbody>
<tr>
<td>Receive information and the necessary support they need to continue to participate in decisions which effect them now and in the future</td>
<td>Staff use a variety of communication aids to help communication including the use of life story books, talking mats, digital stories and referral to speech and language therapy.</td>
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<td>People with dementia have equitable access to services in the same way as any other person.</td>
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<td>Assistance by way of advocacy is available should a person with dementia want to make a complaint about the service they are receiving and the complaints process is considerate of the needs of people with dementia. (sp2)</td>
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<td></td>
<td>There is timely access to independent advocacy services and support is give to people with dementia to contact and use this service.</td>
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<td>Staff understand that an individual’s capacity can fluctuate depending upon particular circumstances and do not make assumptions about capacity to be involved in decision making.</td>
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<td></td>
<td>Staff give people with dementia the opportunity to be involved in making decisions and choices; the person is afforded adequate time and information is given in a variety of formats.</td>
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<td></td>
<td>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.</td>
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*sp denotes link to signpost section.*
EXAMPLE OF GOOD PRACTICE

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

Anna is 80 years old and 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; she was now starting to forget a lot of English and 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 put around her room in the care home. They also asked her husband to make sure she came in with plenty of her personal mementos and favourite snacks. The social worker spoke to Alexander and wrote down some common phrases and words in Polish that Anna would understand. The social worker gave these to the care home manager and these were copied and given to the care home staff.

The care home manger 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 and was able to have a care plan in place on the day of the admission.

The first night in the care home Anna found 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.
EXAMPLE OF WEAK PRACTICE

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

The ward he lives in is attached to a small community hospital and sometimes Robert tries 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 are worried that next time he may manage to leave on the bus so they decide to use an electronic tagging device to alert them when he leaves. He is given a tag to wear like a watch and if he goes past the front door this sets off an alarm.

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

Later the visitor notices Robert walking around the ward with just his underpants and a t-shirt on. The visitor asks the staff if he can help Robert get dressed but the staff say they just leave him to do this as they are too frightened to intervene in case he hits them.

The visitor makes a complaint to the hospital manager about how Robert is being treated. He feels staff are not treating Robert with dignity or respecting his human rights because he feels…

- The alarm used is stigmatising, it identifies Robert as having particular needs.
- Staff gave 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.
- Staff were too frightened to intervene which means it is likely they do not have the appropriate training or expertise to care for Robert and that needs reviewed urgently.

The hospital manager decided to arrange an immediate multi disciplinary review of the care and treatment Robert was receiving including an assessment of the need to use mental health and / or incapacity legislation, the use of the alarm system, whether the ward team with support and training from the mental health team could meet Robert’s needs with dignity or if Robert would receive better care and treatment elsewhere.

The hospital manager contacted independent advocacy services to arrange an advocacy worker to come and meet with Robert.
## SIGNPOSTS

### SUPPORTING LEGISLATION

Adults With Incapacity (Scotland) Act 2000
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). *(sp1)*

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.

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. *(sp2)*

Regulation of Care (Scotland) Act 2001 This Act establishes the Scottish Commission for the Regulation of Care and the Scottish Social Services Council.

The Human Right Act 1998 adopts the articles of the European Convention of Human Rights giving them a legal basis in the UK. The Act effects the way that public bodies such as hospitals and local authorities treat people when carrying out their functions.

The Equality Act 2010 brings together nine separate pieces of legislation into one single Act simplifying the law and

### EXISTING STANDARDS, BEST PRACTICE GUIDANCE

**National care standards;**
- Care homes for people with mental health problems
- Care Homes for Older People
- Housing Support Services
- Support services:
  - Care at Home
  - Nurse agencies

Dementia: ethical issues Nuffield Council on Bioethics 2009
SUPPORTING LEGISLATION (cont)

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).
I have the right to access a range of support and treatment.

The Charter of Rights for people with dementia and their carers in Scotland states…

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.

If this right is respected then

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.

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

Will not experience inhuman or degrading treatment.
People with dementia and their carers will.....

Have access to independent advocacy services.

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

*sp denotes link to signpost section.

**All service providers will ensure**

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 *(sp1 & sp7)*

*Local authorities and NHS Boards will ensure*

Information on supports and services are advertised locally in a variety of formats and include who to contact for more information. They should provide information about eligibility criteria, service prioritisation, and assessment and care management processes.

People with dementia and their carers are given information about self directed support, such as direct payments, and are given assistance to access this.
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<thead>
<tr>
<th><strong>Receive a good quality, timely and integrated assessment.</strong></th>
<th><strong>Local authorities and NHS Boards will ensure</strong></th>
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<tbody>
<tr>
<td>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 want to achieve.</td>
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<tr>
<td>The person with dementia and their carer will have an active 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.</td>
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<tr>
<td>Assessment will include looking at the supports that are already available and the relationships important to the person with dementia that must be maintained.</td>
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<tr>
<td>Life story and personal preferences will be recorded and taken fully into consideration during the assessment process.</td>
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<tr>
<td>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.</td>
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<td>There will be a lead person identified that the person with dementia and their carer can contact who will coordinate the assessment and ensure agreed services are put in place.</td>
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<tr>
<td>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.</td>
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<tr>
<td>Carers are made aware of their entitlement to an assessment of their needs.</td>
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<tr>
<td>Procedures are in place to ensure staff have the time, resources and skills necessary to undertake quality assessments and engage with the person with dementia and their carer on an ongoing basis.</td>
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*sp denotes link to signpost section.*
| Experience a person-centred approach to support and care. | **Local authorities, NHS Boards will ensure**

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 the person’s needs have changed.

Support provided is reliable and flexible to allow for changes in the physical and mental health of both the person with dementia and their carer.

If there is evidence that the person with dementia is at risk of harm, exploitation or abuse then there are local procedures in place to protect them and the staff take account of the person’s views about risk. *(sp8)*

Extra support is available at times of transition e.g. returning from hospital, moving to a care home.

The person with dementia wherever they are living can continue to participate in social, recreational, religious and other activities.

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| Receive treatment that is in line with the law. | **NHS Boards will ensure**

Systems are in place to ensure that capacity to consent to treatment is considered and appropriate documentation in place where necessary. *(sp3)*

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<table>
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<tr>
<th>Receive treatment that is likely to be of benefit, including a range of non-drug based treatments.</th>
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**NHS Boards will ensure**

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

- 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. *(sp4 & sp5)*

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

- 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. *(sp5)*

- When psychoactive medication (including anti-depressants and tranquillisers) 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.

- Regular audits of the use of psychoactive medications for people with dementia are carried out to ensure prescriptions are regularly and robustly reviewed.

- A range of non-pharmalogical 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. *(sp4)*

- Referral is available to a psychologist for assessment and tailored intervention if behavioural or psychiatric symptoms are ongoing and distressing.

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

<table>
<thead>
<tr>
<th>Systems are in place so staff can easily identify someone with dementia, who may need extra support</th>
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<tr>
<td>Each general hospital has access for advice and/or assessment to a liaison service specialising in the diagnosis and management of dementia.</td>
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<tr>
<td>Systems are in place to request and record key personal information about people with dementia and ensure that is shared with staff who are in direct contact with them.</td>
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<tr>
<td>Guidelines on the management of delirium are available to all staff who provide care to acutely unwell people.</td>
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<tr>
<td>Systems are in place to monitor the number of moves people with dementia are subject to when in hospital.</td>
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<tr>
<td>Regular audit of the physical environment using the dementia design checklist and appropriate action to meet any deficits. (sp6)</td>
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<tr>
<td>Along with local authority partners, discharge planning arrangements will consider a range of care and support options. Robust systems are in place to review decisions taken to transfer someone with dementia who previously lived at home to a care home.</td>
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*sp denotes link to signpost section.*
EXAMPLE OF GOOD PRACTICE

Al cares for his wife Marion who has dementia; they live in a city centre. Marion has been assessed as needing one hour and 45 minutes of personal care per 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 the same bad practices as the first agency. Al made complaints about the service but felt they had no impact, as he felt 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 with better understanding of dementia. This 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’s Scotland – let’s get personal, personalisation and dementia.
EXAMPLE OF WEAK PRACTICE

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 to 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 interviewed by a member of the nursing staff, the ward doctor, the anaesthetist, the pharmacist and the physiotherapist. All 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 or 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.
EXAMPLE OF WEAK PRACTICE (cont)

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

### SUPPORTING LEGISLATION

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. (sp1)

Social Work (Scotland) Act 1968 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. In addition, it provides local authorities with a duty to assess the needs of carers and to provide relevant information to carers. (sp2)

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.

Adults With Incapacity(Scotland) Act 2000, Part 5. Some people with dementia may not always be able to give a valid consent for any proposed treatment. The law in Scotland recognises this and has put in place procedures and safeguards to protect people. (sp3)

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

### EXISTING STANDARDS, BEST PRACTICE GUIDANCE

SIGN 86 management of patients with dementia, an evidence based clinical guideline, 2006 reviewed 2009 [http://www.sign.ac.uk/guidelines/fulltext/86/index.html](http://www.sign.ac.uk/guidelines/fulltext/86/index.html) (sp4)

NHS Quality Improvement Scotland “Standards for integrated care pathways for mental health”. (sp5)

- 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

Design for People with Dementia: Audit Tool University of Stirling/The Dementia Services Development Centre. (sp6)

Working with independent advocates Mental Welfare Commission for Scotland 2009 [www.mwcscot.org.uk](http://www.mwcscot.org.uk) (sp7)
**SUPPORTING LEGISLATION (cont)**

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.

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. *(sp8)*

Regulation of Care (Scotland) Act 2001. This Act establishes the Scottish Commission for the Regulation of Care and the Scottish Social Services Council. It also provides for the registration by these bodies of care services and of social workers and social service workers.

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.

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.

**EXISTING STANDARDS, BEST PRACTICE GUIDANCE (cont)**

National care standards;
- Care homes for people with mental health problems
- Care Homes for Older People
- Housing Support Services
- Support services:
  - Care at Home
  - Nurse agencies

Alzheimer’s Scotland –Let’s get personal -personalisation and dementia (2010).
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...

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.

If this right is respected then

**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.
People with dementia will

Be supported to remain as independent as possible

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

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

Access to self directed support including direct payments and other types of assistance to maximise a person with dementia and their carer to direct and determine their own support package.

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.

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

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. (sp 1)

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

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. (sp2)

*sp denotes link to signpost section.*
<table>
<thead>
<tr>
<th>Have the opportunity to be included in community life and meaningful activities as they wish</th>
<th><strong>All service providers will</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Give people with dementia the support they need, wherever they are living, to continue to be involved in their ordinary activities such as involvement in music, dance, social events and religious activity and to become involved in new activities and experiences.</td>
<td></td>
</tr>
<tr>
<td>Encourage and support the person with dementia to maintain the family and social relationships important to them.</td>
<td></td>
</tr>
<tr>
<td>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.</td>
<td></td>
</tr>
<tr>
<td>Support people with dementia who may wish to volunteer in their own local communities e.g. at day centres, peer support groups.</td>
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</tbody>
</table>
EXAMPLE OF GOOD PRACTICE

*Ann enjoyed an active social life until recently. She was a professional artist, keen gardener and bee keeper. She loved being outdoors and hill walking. She was also an active member of the church.

Ann became disconnected from her social life in the two years prior to her diagnosis of Alzheimer’s disease. This was largely due to her mobility deteriorating to the extent she could no longer go out unaccompanied. Additionally, many of her friends had passed away or their health had deteriorated such that they were unable to leave their homes.

At the point of referral to the post diagnostic team Ann was depressed, isolated and considering long term care. Ann’s awareness of the changes in her abilities and of the changing dynamics in her established relationships with others at church and at the artist group she was a member of had a negative impact on her sense of self and self esteem. Due to these factors she was not interested in re-establishing these links.

Project staff helped Anne to develop coping strategies for her short term memory loss. This impacted positively on her mood and on her sense of isolation. They also worked with Ann to establish new community links, based on her long term interests allowing her to redevelop skills and form new relationships, impacting positively on her self-esteem.

Ann is now a member of a community art group. Recently project staff arranged a person centred planning meeting with Ann, her daughter and her community psychiatric nurse, to help ensure that she and her daughter are able to take control of decisions about her future care. They discussed self-directed support as a personalised option.

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

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 B 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 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.
EXAMPLE OF WEAK PRACTICE

Isobel is 82 years old and lived in her own home, a fist floor flat in a large city. She was widowed 20 years ago and lived in the flat since she was first married.

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. The thieves stole some of her precious belongings and made a mess in her flat.

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 anyway she had already refused offers of assistance.

When Isobel was told about this she was horrified and was adamant 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 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 there 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 advocacy worker.

Isobel didn’t want to accept help but the guardianship order used to move her to a care home could instead have included powers requiring her to accept help and support at home. This would have been a far less restrictive plan than her moving to the care home and losing contact with her friends and community.
### SIGNPOSTS

<table>
<thead>
<tr>
<th>SUPPORTING LEGISLATION</th>
<th>EXISTING STANDARDS, BEST PRACTICE GUIDANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults With Incapacity (Scotland) Act 2000 <em>(sp1)</em></td>
<td>Design for People with Dementia :Audit Tool</td>
</tr>
<tr>
<td>Regulation of Care (Scotland) Act 2001</td>
<td>University of Stirling/The Dementia Services Development Centre <em>(sp2)</em></td>
</tr>
<tr>
<td>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).</td>
<td>National care standards;</td>
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<tr>
<td></td>
<td>- Care homes for people with mental health problems</td>
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<td></td>
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<td>- Care at Home</td>
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<td>- Nurse agencies</td>
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</tbody>
</table>
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...

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.

If this right is respected then

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 who come into contact with people with dementia will have an understanding of the condition and that improve outcomes for people with dementia.

All health and social care staff will know about and promote the interests of people with dementia.
<table>
<thead>
<tr>
<th>Carers will be recognised and valued as partners in care and be supported in their role</th>
<th>A carer is someone who spends a significant part of their life providing unpaid support to a family member or friend</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Paid care staff</strong></td>
<td><strong>All service providers will ensure</strong></td>
</tr>
<tr>
<td><em>sp denotes link to signpost section.</em></td>
<td>Carers are involved in the assessment, planning and review of support, care and treatment for the person with dementia.</td>
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<tr>
<td></td>
<td>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.</td>
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<tr>
<td></td>
<td><strong>Local Authorities and NHS Boards will ensure</strong></td>
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<td></td>
<td>Carers of people who have recently been diagnosed with dementia are given access to educational resources about dementia.</td>
</tr>
<tr>
<td></td>
<td>Carers are given information about the right to request a carer’s assessment and up-to-date information on carers’ support in their local area is available. (sp1)</td>
</tr>
<tr>
<td></td>
<td>The carer support plan will include assessment of the financial, emotional and practical support that is required.</td>
</tr>
<tr>
<td></td>
<td>Peer support, individual and group counselling is available locally for carers of people with dementia.</td>
</tr>
<tr>
<td></td>
<td>Supports available to carers include the provision of short breaks and flexible respite.</td>
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<tr>
<td></td>
<td><strong>All service providers will ensure</strong></td>
</tr>
<tr>
<td></td>
<td>Carers of people with dementia are invited to contribute to staff training and development.</td>
</tr>
</tbody>
</table>
Staff have the level of knowledge and skill specific to their role and contact with people with dementia and their carers.

The level of knowledge and skill required by individual staff will be guided by Promoting Excellence: This framework outlines the skills and knowledge health and social care workers should have depending on the role they play in supporting people with a diagnosis of dementia and their families and carers. *(sp2)*

Staff receive the appropriate levels of supervision and opportunities to reflect on their practice.
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 she 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 arranged these payments to employ a personal assistant for George a few hours a week so she could manage her hours at work. It also provided occasional overnight care to allow Joan the chance to visit her friends in Glasgow to catch up and relax.
EXAMPLE OF WEAK PRACTICE

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

The diagnosis took a long time to be made because other psychiatric and physical illnesses needed to be excluded. It was a very stressful and busy time for Alice and her husband Jim with lots of hospital tests and appointments.

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. Jim described leaving the consultation with his world in absolute tatters and left completely alone to deal with it. Jim spent a lot of time on the internet trying to find out more information and much of this was frightening and conflicting. Jim said he spent the next three months in a daze.

The next appointment only confirmed the diagnosis again but there was a promise made to refer 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 twenty minute time slot to ask about all the questions and 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. They needed him to be strong but no one was supporting and helping him.

Eventually through a family friend Jim got in touch with some other carers and he was angry 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.

Jim compares what happened with him and Alice with what would happen if she had been diagnosed with cancer and says there was no comparison. He says that you would not treat someone with cancer and their carer in the way he feels he and Alice were treated.
### SUPPORTING LEGISLATION

The Carers (Recognition and Services) Act 1995 & Community Care & Health (Scotland) Act 2002.  *(sp1)*

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.


### EXISTING STANDARDS, BEST PRACTICE GUIDANCE

Promoting Excellence: A framework for health and social care staff working with people with dementia, and their families and carers. NHS Education for Scotland and Scottish Social Services Council 2011 *(sp2)*


Alzheimer’s Scotland –Let’s get personal -personalisation and dementia. 2010

National Care Standards
- Care homes for older people; standard 5, management and staffing arrangements
- Care homes for people with mental health problems; standard 5, management and staffing arrangements
- Short breaks and respite, standard 5, management and staffing arrangements
- Support services; standard 2, management and staffing arrangements
**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…

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.

If this right is respected then

*People with dementia*

- Will have access to the full range of palliative care services and good quality compassionate care towards the end of life.
- Will receive the support they need to die with dignity and in the place of their choosing.
- Will 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.
**People with dementia will**

- Have access to a full range of palliative care services.
- Receive end of life care that respects their wishes.

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

*NHS Boards will ensure*

Following diagnosis, the person with dementia will be given the opportunity, if they wish, to consider an anticipatory care plan and advance care planning. *(sp1)*

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

Assessment and review of palliative care needs using recognised assessment tools will include physical, social, emotional and spiritual needs. *(sp2)*

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

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

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

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

**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

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

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

Staff caring for the person with dementia know about any advance planning that has been made, if a decision has been made about resuscitation and active management of symptoms. (sp3)

If a decision has been made not to resuscitate then this will be in accordance with national guidelines. (sp3)

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

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

Staff respect the faith and cultural preferences of the person with dementia and seek information about these if these are not already known.

In the last days and hours of life, the care given should be guided by the Liverpool care pathway. (sp4)

Staff are able to direct family and friends to bereavement support services.
EXAMPLE OF GOOD PRACTICE

Mr Smith was diagnosed with dementia around the time of his retirement at age 60 years. 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.

Mr Smith was worried about his death, he did not fear death itself but worried that he might not be in control of what was happening and this was what frightened him the most. He had seen his own father die in pain and distress and he 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, where he would choose to die and if he wanted to be resuscitated if he suffered a cardiac arrest.

Mr Smith prepared a statement of wishes relating to his future care, this was signed and witnessed and a copy placed in his medical notes. The practice nurse also prepared an anticipatory care plan, this 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 and dementia register. This meant that the anticipatory care plan formed part of a palliative care summary that with Mr Smith’s consent enabled 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 that 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.
EXAMPLE OF GOOD PRACTICE (cont)

He was referred to specialist palliative care services who provided care, advice and support including pain management and they worked in conjunction with the community mental health team.

In the week prior to his death his wife had to call out of hours medical services for further support but all the details about Mr Smith’s care were already registered and available for the attending doctors so this made things a little easier.

Mr Smith died peacefully in his own home surrounded by his family in accordance with his wishes.
EXAMPLE OF WEAK PRACTICE

Mr Andrew was admitted aged 82 years 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 dip.

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 and 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.
<table>
<thead>
<tr>
<th>SUPPORTING LEGISLATION</th>
<th>EXISTING STANDARDS, BEST PRACTICE GUIDANCE</th>
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</thead>
<tbody>
<tr>
<td>There is no specific legislation covering palliative care in Scotland. It is covered</td>
<td>Standards for Integrated care pathways for mental health, NHS Quality Improvement Scotland 2007</td>
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<td>under general duties within the National Health Service (Scotland) Act 1978.</td>
<td>Standard 29, End of life care (sp1)</td>
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<tr>
<td>Those with palliative care needs may also be eligible for a range of social or</td>
<td>Scottish Government (2008), Living and Dying Well: A national action plan for palliative and end of life</td>
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<td>community care services to support them in day to day living.</td>
<td>care in Scotland <a href="http://www.scotland.gov.uk/publications">www.scotland.gov.uk/publications</a> (sp2)</td>
</tr>
<tr>
<td>The key piece of legislation is the Social Work (Scotland) Act 1968 which provides</td>
<td>Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) - Integrated Adult Policy ,NHS Scotland, 2010 (sp3)</td>
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<tr>
<td>local authorities with the duty to assess the community care needs of anyone that</td>
<td>Decisions relating to cardiopulmonary resuscitation; British Medical Association, Resuscitation Council</td>
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<td>requests it, but also to deliver a package of care in order to meet those needs.</td>
<td>(UK) and Royal College of Nursing (2007). <a href="http://www.resus.org.uk/pages/dnar.pdf">http://www.resus.org.uk/pages/dnar.pdf</a></td>
</tr>
<tr>
<td>There is no specific legislation in Scotland that covers making advance decisions</td>
<td>Liverpool Care Pathway for the Dying Patient <a href="http://www.mcpcil.org.uk/liverpool_care_pathway">www.mcpcil.org.uk/liverpool_care_pathway</a> (sp4)</td>
</tr>
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<td>about refusing or asking for particular treatments or making a “living will”.</td>
<td>Making good care better: National practice statements for general palliative care in adult care homes in</td>
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<tr>
<td>However treatment given that conflicts with a competent advance statement could be</td>
<td>Scotland <a href="http://www.palliativecarescotland.org.uk/publications">www.palliativecarescotland.org.uk/publications</a></td>
</tr>
<tr>
<td>ruled unlawful by a court.</td>
<td>Scottish Government ,National Care Standards: Care homes for older people</td>
</tr>
<tr>
<td>The Adults with Incapacity (Scotland) Act 2000. The general principles of the Act</td>
<td>-  Standard 19 is about support and care in dying and death. It states that people living in care home</td>
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<td>include ensuring that the present and past wishes of the adult (so far as they can be</td>
<td>can be confident that the home’s staff will be sensitive and</td>
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<td>ascertained by any means of communication) are taken into account when determining</td>
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<td>if an intervention under the Act should be made.</td>
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<td>Part 2 of the Act gives a competent adult the right to appoint a person to make</td>
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<td>decisions on their behalf relating to general welfare and/or their finances in the</td>
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<td>event they lose capacity (a power of attorney)</td>
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<td>SUPPORTING LEGISLATION (cont)</td>
<td>EXISTING STANDARDS, BEST PRACTICE GUIDANCE (cont)</td>
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<td>Article 3 of the European Convention on Human Rights (ECHR), not to be subjected to torture or to inhuman or degrading treatment.</td>
<td>supportive during the difficult times when someone dies.</td>
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<tr>
<td>Scottish Executive (2001), Regulation of Care (Scotland) Act 2001, The Stationery Office Ltd <a href="http://www.opsi.gov.uk/legislation">www.opsi.gov.uk/legislation</a></td>
<td>- 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.</td>
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<td></td>
<td>Gold Standards Framework (provides a framework in primary and community care for effective person centred planning during last 12 months of life) <a href="http://www.gsfs.scot.nhs.uk/">www.gsfs.scot.nhs.uk/</a></td>
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<td></td>
<td>Promoting Excellence: A framework for health and social care staff working with people with dementia, and their families and carers. NHS Education for Scotland and Scottish Social Services Council 2011</td>
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</tbody>
</table>
GLOSSARY

TO BE COMPELTED