

Dementia

Commitment to the care
of people with dementia
in hospital settings



Dementia is a challenge for hospitals. Surveys show that around a quarter of hospital beds are occupied by somebody with dementia; a figure which increases in older people and individuals with a superimposed delirium.

While some hospitals provide high-quality care for people with dementia and their carers, there are others where improvements can be made.

In 2011, the RCN published five principles for improving dementia care in hospital settings. These covered: staff, partnership, assessment, individualised care and environments. The principles have helped take forward a key objective of the national dementia strategy, to improve hospital care for people with dementia.

In March 2012 the Prime Minister launched his challenge on dementia focusing on three key areas: driving improvements in health and care, creating dementia-friendly communities, and better research. A key theme of the health and care workstream of the challenge is to improve hospital care by supporting good practice and encouraging it to be applied across the board.

We are pleased to have worked with the Royal College of Nursing to develop this important resource supporting the further implementation of its five principles for improving the quality of care.

I would encourage everyone who works in hospital settings to make use of this resource, and apply the principles to help deliver the best possible care and support for people with dementia and their carers.

Professor Alistair Burns

National Clinical Director for Dementia, Department of Health

Lead authors:

Rachel Thompson

Dementia Project Lead, Royal College of Nursing

Hazel Heath

Chair, Royal College of Nursing Older People's Forum

Supported by:

Nikki Mills

Dementia Project Co-ordinator, Royal College of Nursing

Working with people with dementia and carers, the RCN and a range of stakeholders have developed principles for the care of people with dementia in hospital settings.

These five principles form a shared commitment to improving care.

SPACE – supporting good dementia care

- 1) **Staff** who are skilled and have time to care.
- 2) **Partnership** working with carers.
- 3) **Assessment** and early identification.
- 4) **Care** that is individualised.
- 5) **Environments** that are dementia friendly.

Based on evidence gathered from people with dementia, carers and practitioners, each principle is considered essential to ensure the appropriate delivery of care. Each principle has a checklist to help identify achievements and areas for further development.

For reports and information about the RCN's dementia project visit www.rcn.org.uk/dementia

This film and guide are for nurses and other staff working in hospital settings, as well as senior managers such as directors of nursing and trust boards. They aim to support the implementation of the SPACE principles.

The film includes five sections reflecting the principles set out in the commitment. Within each section the perspectives of people with dementia, family carers and practitioners are shared.

This guide supplements the film, and offers information and tools to help practitioners implement the principles. Each section can be used independently to support learning, share ideas and encourage practitioners to transform the way care is delivered to people with dementia in hospital. Examples of tools



My hope would be for people to understand it more, to get rid of the stigma of dementia.

Ann Johnson,
person living with dementia

Help us, to help you, to help us.

Norms McNamara,
person living with dementia

are offered but different areas will have tools that fit with their own local pathways.

The guide provides a signpost to a range of resources available from the dementia pages of the RCN's website: www.rcn.org.uk/dementia

These resources can be used along with other initiatives that support innovation and improvement. It is recommended that staff teams use them to support the development of practice in a systematic way which demonstrates real benefits for patients, carers and staff. This requires dedicated leadership, development of shared action plans and evaluating outcomes, particularly patient experience.

There are also links to a gallery of best practice examples where you will find further information from those who contributed to the film, as well as other examples of how some hospitals have delivered change.

People with dementia in hospital settings

Currently around 40 per cent of patients over the age of 75 who are admitted to general hospitals have dementia, with only half having prior diagnosis (DH, 2012).

The increasing importance of dementia care in hospitals is reflected in recent government policy around the UK in initiatives such as:

Acute Awareness: Improving hospital care for people with dementia (NHS Confederation, 2010)
Report of the National Audit of Dementia Care in General Hospitals (Royal College of Psychiatrists, 2011)
Promoting Excellence Framework and Standards of Care for Dementia in Scotland (Scottish Government, 2011)
National Dementia Vision for Wales (Welsh Assembly Government, 2011) and *1000 Lives Plus* (Health in Wales, 2010)
Improving dementia services in Northern Ireland (DHSSPS, 2011)
Living well with dementia (DH, 2009) and the new *Commissioning for Quality and Innovation (CQUIN) Framework* (DH, 2012).

Hospital services are intrinsically geared towards fast and effective responses, assessment, diagnosis, intervention, cure (if possible) and discharge. Services run on the assumption that patients will be able to express their wishes, acknowledge the needs of other patients and move through the system as required. However, for people with dementia, particularly when they are ill or have had an accident, hospital settings can be confusing, challenging and overwhelming. What happens in hospitals can have a profound and permanent effect on individuals and their families, not only in terms of their inpatient experience, but also their ongoing health and the decisions that are made about their future.

Dementia

The term dementia is used to describe a range of conditions which affect the brain and result in an overall impairment of the person's function. The person may experience memory loss, problems with communication, impaired reasoning and difficulties with daily living skills. This can result in changes in behaviour, which can disrupt their ability to live independently and may affect social relationships.

There are more than 100 different types of dementia. The most common type is Alzheimer's disease, where there tends to be a progressive and gradual decline over time. Another common type is vascular dementia, where small blood vessels in the brain become damaged and the circulation is affected. Other types include dementia with Lewy bodies, fronto-temporal lobe dementia, Pick's disease and alcohol related dementia. Each type of dementia has different features and people may experience elements of more than one type of dementia, in which case a mixed dementia may be diagnosed.

Although dementia is more prevalent with increasing age, it is not a normal feature of ageing and approximately only 20 per cent of people aged 80+ will be affected.

Dementia can also affect younger people and it is estimated that more than 17,000 people in the UK under the age of 65 have younger onset dementia.

Dementia is a progressive and terminal condition, which will in most cases lead to increasing cognitive difficulties and dependence on others. How long the person will live depends upon the type of dementia, their age and their general health, but many will live with the condition for several years and can have a good quality of life.

Symptoms of dementia



What people don't see is that I need help in bathing, I can't fasten my shoe laces, I can't fasten my shirts, I miss my mouth more times than I hit it while I'm eating. I have a problem when my wife is not there because I don't know where I am or where she is and I tend to shout for her.

Norms McNamara, person living with dementia

While there are common symptoms of dementia (see box on next page), not all of them may be present and each person will be affected in a different way. This depends on the type of dementia, the stage of the illness, the individual's personality and importantly the way others interact with them. Some people have limited awareness of their difficulties and as the illness progresses, insight tends to decline along with other cognitive abilities.

People with dementia may also experience **depression** and older people who are ill commonly experience **delirium**.



Common symptoms of dementia

- **Memory loss (anterograde amnesia)**
Short-term memory loss is the most common feature of dementia. It becomes worse as the disease progresses and eventually affects long-term memory.
- **Communication (dysphasia/aphasia)**
Difficulty with finding the right words or understanding what is being said.
- **Carrying out tasks (dypraxia/apraxia)**
Difficulty with sequencing and doing everyday tasks such as getting dressed, laying the table, cooking etc.
- **Concentration**
Difficulty with attention for periods of time.

- **Recognition (agnosia)**
Difficulty with recognising familiar objects, people, sights, places, sounds.
- **Orientation**
Difficulty with finding your way around, knowing the time, date etc.
- **Perception**
Misinterpreting or misjudging things (**visuo-spatial difficulties**) or seeing things that are not there (**hallucinations**).
- **Psychological changes**
People may behave in unusual or uncharacteristic ways, such as being disinhibited or irritable, withdrawn or depressed.

What is depression?

Low mood that usually develops over weeks or months but can result in significant problems with concentration, sleep patterns and impaired functioning.

What is delirium?

A disturbance of consciousness and a change in cognitive functioning that develops over a short period of time and which can fluctuate during the course of the day.

Research indicates that many older people who have delirium will either also have an underlying dementia, or have an increased chance of developing dementia.

Distinguishing between the manifestations of delirium, depression and dementia is an important aspect of assessment and all people who present as confused should be assessed carefully. (See Section 3: Assessment and early identification).

For further information about dementia the RCN website hosts a number of useful links and learning resources: www.rcn.org.uk/dementia

The person living with dementia

It is vital to understand that while some general statements can be made about dementia, each individual will be affected differently. Also, while a dementia fundamentally changes the way in which a person functions, it is only one aspect of their life. Rather than seeing 'someone with a dementia' it is essential to seek to understand the individual.

Knowing and respecting each person remains central to the relationship between patients and staff.

This is me is a simple and practical tool that someone going into hospital can give to staff. It provides a snapshot of the person with dementia, with information about them as an individual, their needs, preferences, likes, dislikes and interests. www.alzheimers.org.uk

The Patient Passport is a simple communication tool that articulates a person's normal everyday needs and thus helps services deliver person-centred care. The passport is now being developed as part of the NHS National Programme for IT. www.erylink.org.uk

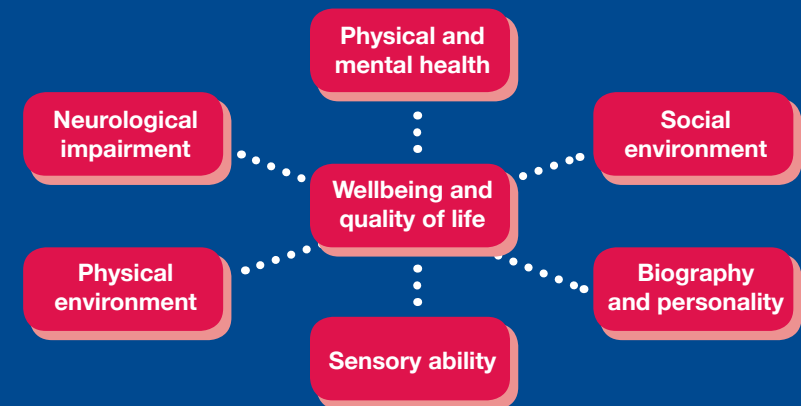
Examples of local tools such as the Forget Me Not developed by St Helens and Knowsley and the Community Passport by Huddersfield and Calderdale are described in the best practice examples page at www.rcn.org.uk/dementia

Person-centred care

Wellbeing in dementia is influenced by a number of factors including neurological impairment, physical health, individual biography, personality and physical and social environment.

Four essential elements of person-centred care (Brooker 2006) are valuing, individuals, perspectives and social (VIPs or very important persons):

- **Valuing** people with dementia and those who care for them.
- Treating people as **individuals**; appreciating that all people have a unique history and personality.
- Looking at the world from the **perspective** of the person and listening to their voice.
- Recognising that all human life is grounded in relationships and that people need to live in a **social** environment, which supports their wellbeing.



Person-centred care (adapted from Kitwood 1997)

Principle 1:

Staff who are skilled and have time to care



There are not enough staff on the wards – it's not really their fault. Staff in hospitals are very caring people. But I'm not sure that all nurses know enough about dementia. With a little bit of training they could make a big difference within a hospital.

Brian Hills, family carer



I won't have staff blamed for what they have never been taught.

Barbara Hodgkinson, family carer

Principle 1: Supporting staff need to be informed, skilled and have enough time to care

- 1) Good quality training and education in dementia that is easy to access, practical and focuses on attitudes/ approach and communication. Training should be made available to all staff based on an analysis of training needs and incorporate perspectives of people with dementia and carers.
- 2) Availability of identified clinical leads for dementia eg dementia specialists/nurses, mental health liaison, dementia champions.
- 3) Careful consideration of staffing levels which ensures that skill mix, ratio and numbers of staff are adequate to support the complex needs and numbers of people with dementia being cared for.

If high-quality care is to be offered to people with dementia and families in hospitals, having sufficient staff with the right skills, knowledge and attitudes is essential.

1. Good quality training and education in dementia

It is important that attention is given to staff training about dementia. This involves listening to the way people with dementia

want to be cared for and hearing the views of family carers.

Surveys of people with dementia, families/ carers and hospital staff (RCN, 2011a, b) reveal that lack of staff understanding and time were the major barriers to achieving good care. Enhancing awareness and understanding among staff, both of the needs of people with dementia and their families/carers, was a clear priority.

It is recommended that:

- all staff are offered training in dementia awareness and are informed
- staff who have regular responsibilities for providing care have an enhanced knowledge and are skilled in dementia care
- each area has a dementia leader and/or support from a specialist with an expert level of skill and knowledge.

Considerations for training and education in dementia

- Focus on values, attitudes and approach of staff, which supports good communication and a relationship-centred approach.
- Adopt a team approach to training and ensure this is supported in practice by dementia champions, specialists and leaders who have further training.
- Include hearing the experience of people with dementia and families/ carers within training.
- Develop understanding and skills to enhance the quality of life for people with dementia with a specific focus on communication, assessment, life story information, pain, nutrition and hydration, continence, activity, rehabilitation, environment and end of life care.

The following resources provide useful frameworks to support good quality training

Skills for Care/Skills for Health's document *Common Core Principles for Supporting People with Dementia – a guide to training the social care and health workforce* is available from www.skillsforcare.org.uk

The *South West Dementia Partnership Competency Framework* offers a stepped model and distinguishes the different competencies from basic awareness to specialist knowledge and skills. Available from www.dementiapartnerships.org.uk/workforce

Scottish Government's *Promoting Excellence: a framework for all health and social services staff working with people with dementia, their families and carers* can be used as a learning tool and an organisational tool to ensure staff have the skills to meet the needs of people with dementia, their families and carers. Visit www.scotland.gov.uk for more information.

Education providers and courses

Appropriate training in the knowledge and skills to care for people with dementia must be available to nurses at pre- and post-registration levels, and to health care assistants and assistant practitioners

appropriate to their role. This includes recognition and management of cognitive impairment, dementia, delirium and depression.

Examples of specific courses for acute care staff

University of Worcester Association of Dementia Studies has developed dementia workforce competencies and a range of courses, including specialist practice in acute hospital dementia care.

Bradford Dementia Group has been sponsored by Yorkshire and Humber Strategic Health Authority to undertake development and evaluation of a sustainable model of workforce development for acute hospitals.

NHS Education for Scotland (NES) has worked in partnership with Scotland Social Services Council (SSSC), Alzheimer's Scotland and the university sector to support and provide ongoing development of leaders via a bespoke leadership programme and continued support of dementia champions via regional learning networks.

The **Dementia Services Development Centre, University of Stirling** has developed a resource pack for staff; *Caring for people with dementia in acute care settings*. It also provides training for health care assistants and other staff working in hospital settings.

NHS London has led a project to develop a series of dementia training modules, specifically targeted at the acute inpatient setting.

For further information about these courses and others see the RCN website: www.rcn.org.uk/dementia

2. Clinical leads and dementia-specific roles

Staff need support in delivering improvements in practice that can be facilitated by clinical leaders such as dementia clinical leads, dementia nurse specialists, nurse consultants, mental health liaison etc (Royal College of Psychiatrists, 2011). There are a range of different roles that have been developed nationally to support this work, including nurse consultants and dementia specialist nurses, older people's liaison teams, Admiral nurses[®] and dementia champions.

Surveys of people with dementia, families/ carers and hospital staff (RCN, 2011a, b) reveal that having a dedicated specialist post was instrumental to delivering changes in practice and providing good quality dementia care. In addition 94 per cent of people with dementia and carers considered having access to a dementia specialist as very important in supporting their care in hospital.

Examples of clinical leads and specialist posts

Admiral nurses[®] offer skilled support to family carers and people with dementia and work collaboratively with other professionals and organisations to facilitate co-ordinated care provision. www.dementiauk.org

Alzheimer Scotland dementia specialist nurses are registered nurses with expertise in dementia care whose posts are supported initially by Alzheimer Scotland. www.new.thebiggive.org.uk

Dementia champions in Scotland have started to help improve standards of dementia care. The evaluation can be found at www.nes.scot.nhs.uk

Ward champion roles are being developed alongside **senior hospital clinical leads**. Visit www.dementiapartnerships.org.uk for more information.

3. Staffing levels

Staff need adequate time to spend with patients to gather information about them as individuals and learn about their needs; to listen, clarify and communicate. Staff in the RCN survey (2011a, b) identified the pressure of existing workload and insufficient staffing as the most significant barrier to delivering good care.

Evidence gathered through the RCN's *Safe Staffing Project* (2012) shows that the vast majority of hospitals still have inadequate basic nursing establishments on older people's wards and unsatisfactory arrangements to provide additional skills support when needed at short notice. There is often simply not enough time and skill to satisfactorily deliver activities such as comforting and talking with patients, yet we know this is of fundamental importance and high value for older patients and those with dementia and a source of distress for nurses if it cannot be carried out.

Guidance on how staffing levels and staffing mix can be determined on hospital wards is offered in the RCN's publication *Safe Staffing for Older People's Wards*.

This can be downloaded from the publications section of the RCN website www.rcn.org.uk Search for publication code 004 234.



In an ideal world there would be more nurses on the ward, then each and every patient would be able to have good quality care as you would have the time not only to be able to see to their hygiene needs and assist patients with feeding but have the time to sit and talk with them – wouldn't that be nice?

Carer in RCN survey (2011a)

The Butterfly Scheme was introduced by a family carer to support staff in hospitals in recognising and developing a targeted care response to people with dementia. For more information visit www.butterflyscheme.org.uk

Principle 2:

Partnership working with carers

Effective care acknowledges the needs of families and carers who have been supporting the person with dementia in the home, usually for some time and with limited support. It is important to learn from carers about the person with dementia and how they function best in everyday life.

It is also important, however, to recognise that carers may themselves feel vulnerable and in need, for example they may have physical health problems, emotional difficulties due to changes in their relationship and the strain of caring and problems with travelling to hospital.

Carers are often happy to assist in the care of their loved ones but it is important to seek their advice on how they wish to be involved.



The staff have to make me feel that I am part of the care, and that my husband is definitely part of it because, particularly for people with dementia, it has to be a joint venture.

Kate Harwood, carer

1. Recognition and assessment of carers needs

Carers of people with dementia can experience high levels of anxiety, depression and stress as a result of caring and their needs often go unrecognised. It is essential that carers are identified and assessed as having their own needs and a hospital admission for the person with dementia may provide an ideal opportunity to identify potential concerns. Carers or supporters may include spouses, adult children, grandchildren or friends.

Principle 2: Family carers and friends are seen as partners in care.

This will be supported by:

- 1) recognition and assessment of carers' needs
- 2) involvement of families/friends in assessment, care planning and decision making
- 3) flexible visiting and flexible approaches to routines so that family carers/supporters can be involved directly in care where desired.

National Institute for Health and Clinical Excellence/Social Care Institute for Excellence (NICE/SCIE, 2006) *Guidelines on improving care for people with dementia*, recommend that those carrying out carers' assessment should seek to identify any

psychological distress and the psychosocial impact on the carer as well as providing access to practical support and respite services. Carers should also be offered information and guidance.

Information and support for carers

Uniting Carers, Dementia UK. A national network of family carers, former carers, family members and friends of people with dementia who aim to raise awareness and increase people's understanding of dementia. www.dementiauk.org

Carers UK, Carers Scotland, Wales and Northern Ireland. Assessment, hospital guide and best practice examples. www.carersuk.org

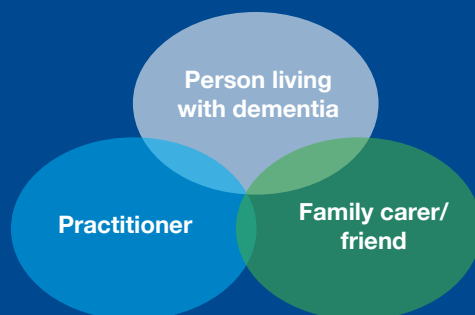
Carers Trust (Princess Royal Trust for Carers and Crossroads merged). www.carers.org

NHS Choices. Carers Direct. Information, advice and support for carers. www.nhs.uk/carersdirect

2. Involvement of families/friends in assessment, care planning and decision-making

Working in partnership with family carers and friends is not only important for delivering the right care but can also be helpful for staff. Families often hold valuable information that can help staff get an accurate assessment, provide care which meets the needs of the individual, as well as facilitate effective discharge planning.

Relationship-centred care identifies three people or agencies involved in the care of people with dementia: the person with dementia, family or friends, and practitioners. Quality of care is dependent on the relationships between each of these agencies.



Resources

Carers UK factsheet *Coming out of hospital*. Publications line: 0845 241 0963

Princess Royal Trust for Carers/ National Mental Health Development Unit (2010) *The Triangle of Care: Carers Included; a guide to best practice in acute mental health care*. See: www.carers.org

Skills for Care/Dementia UK *Dementia: workers & carers together – a guide for social workers on supporting family and friends carers of people with dementia*. See: www.skillsforcare.org.uk

3. Flexible visiting and flexible approaches to routines so that family carers/supporters can be involved directly in care where desired

Evidence gathered through surveys of people with dementia, families/carers and hospital staff (RCN, 2011a, b) indicated that flexible approaches to visiting and provision of care are important in improving the quality of care for people with dementia in hospital.



We have tended to isolate people with dementia from their carers and this has been a big problem. We need to think about how we integrate and develop a partnership.

Jo James, lead nurse for dementia

Principle 3:

Assessment and early identification of dementia



Early assessment and diagnosis of dementia is really important. Often this means that people have been worried about their memory get an answer so they can start to plan for their future.

Michelle Parker, consultant nurse

Assessment is fundamental to good care and vital to achieve the services that a person with dementia will need in hospital and after. Prior to any assessment it is important to create a good environment for communication and ensure that the person with dementia can see and hear to the best of their ability with aids as necessary.

Hospitalisation can give an opportunity to ensure proper diagnostic assessment but also to ensure that while in hospital and on discharge, reasonable adjustments are made to the person's care to take account of their dementia. Systematic identification of patients with cognitive impairment is also likely to improve the detection of delirium and depression and give opportunities to support them better.

The National Dementia CQUIN (Commission for Quality and Innovation, DH, 2012) pathway has three stages: find, assess and investigate, refer (FAIR).

- **Stage 1:** Find. Identify all patients with a diagnosis of dementia who should have a diagnostic review if clinically indicated.
- **Stage 2:** Assess and Investigate: carry out a diagnostic assessment including investigations to determine whether the presence of a dementia is possible.
- **Stage 3:** Referral: for specialist diagnostic assessment by a clinician with appropriate skill or training.

Principle 3: A dementia assessment will be offered to all those at risk, to support early identification and appropriate care.

Assessment will be supported by:

- 1) use of agreed screening and assessment tools
- 2) skilled knowledgeable practitioners
- 3) clear delirium protocols and dementia pathways
- 4) clinical review of medication to support the appropriate use of antipsychotic medication.

The DH Dementia CQUIN

incentivises the identification of patients with dementia and impaired cognition in acute trusts and aims to promote appropriate follow up.

www.dementia.dh.gov.uk



The thing with Alzheimer's or dementia is that we appear quite normal. People can't see our problems. Patients should be assessed for their cognitive ability because only then can you assess whether there is something wrong with it.

Ann Johnson, person living with dementia

1. Use of agreed screening and assessment tools

It can be difficult when a person does not have a diagnosis of dementia but seems to present with symptoms. As the diagnosis of dementia is complex, most screening tools are used to identify the presence of cognitive impairment. The term cognitive impairment is an overarching term for someone who may be experiencing problems with memory, perception, judgment and reasoning. It is recommended that there are agreed approaches and processes for screening and assessment in hospital so that those with a possible cognitive impairment receive the right treatment and care, depending on whether they have dementia, delirium and/or depression.

A dementia screen should be carried out including:

- routine haematology
- biochemistry tests (electrolytes, calcium, glucose, and renal and liver function)
- thyroid function tests
- serum vitamin B12 and folate levels.

Perform a midstream urine test if delirium is a possibility.

Conduct investigations such as chest x-ray or electrocardiogram (ECG) as determined by clinical presentation.

Cognitive assessment

A cognitive assessment should include an examination of:

- attention and concentration
- orientation
- short- and long-term memory
- language
- executive function.

There are a number of commonly used screening tools for cognitive impairment highlighted below.

- **abbreviated mental test score tool**

The abbreviated mental test score tool (AMTS) 10 is commonly used in hospitals. It involves asking a series of 10 questions for which each correct answer scores one point. Usually scores of seven or eight are used as an indicator for further investigation.

- **six item cognitive impairment test (6-CIT)**

The 6-CIT is sometimes preferred as it avoids the use of culturally specific questions.

- **GP (Cog)**

The GP (Cog) requires the presence of a carer, which can improve accuracy. It is not influenced by the cultural and linguistic background of a person, making it useful in multicultural patient settings.

For further information regarding **dementia management** see www.cks.nhs.uk

It is recommended that a decision is taken locally as to which tool is used and this is agreed within a dementia pathway.

For more in-depth assessment by a dementia specialist or liaison mental health staff:

- mini mental state examination (MMSE®)
- the Addenbrook's cognitive examination (ACE-R)
- Montreal Cognitive Assessment (MoCA).

Guidance on cognitive assessment

Scottish Intercollegiate *Guidelines Network 86 – Management of patients with dementia: a national clinical guideline.* www.sign.ac.uk

For further guidance by the Department of Health and the Alzheimer's Society on the assessment of cognitive function, please visit:

www.dementia.dh.gov.uk

Delirium

Delirium is a 'disturbance of consciousness and a change in cognition that develops over a short period of time and which can fluctuate during the course of the day'.

Delirium affects up to a third of older hospital patients and people who develop delirium suffer high mortality, high complication rates and longer hospital stays. People with dementia have a fivefold risk of developing delirium and, in someone with a dementia, risk factors include medications, immobilisation, malnutrition, infection, an indwelling catheter, environment or psychosocial influences.

Delirium may be prevented in up to one third of older patients through effective interdisciplinary prevention, diagnosis, treatment of the underlying cause and supportive nursing care.

For a copy of the tool and information on the management of delirium for older people see: www.rcplondon.ac.uk

Delirium assessment tool

The confusion assessment method (CAM) (Inouye et al 1990) differentiates delirium from other causes of cognitive impairment.

The CAM focuses on four features:

- 1) acute onset and fluctuating course
- 2) inattention
- 3) disorganised thinking
- 4) altered level of consciousness.

Depression

Depression is common among older people and those with dementia. The Royal College of Psychiatrists (2011) estimated that the prevalence of depression in older people in hospitals is 30 per cent.

Symptoms of depression can mimic symptoms of dementia such as poor concentration, agitation or restlessness, disturbed sleep, and changes in functioning but depression can be treated with medication and psychological therapies.

It is important to assess for possible depression (particularly in people with a past history of depression or a chronic physical health problem with associated functional impairment) and consider asking:

“During the last month, have you often been bothered by:

- **feeling down, depressed or hopeless?**
- **having little interest or pleasure in doing things?”**

Information and guidance

Royal College of Psychiatrists information leaflets on delirium and depression.

www.rcpsych.ac.uk

BGS guidelines for the prevention, diagnosis and management of delirium in older people in hospital.

www.bgs.org.uk

The National Institute for Health and Clinical Excellence (NICE) guidance on the management of delirium and depression. www.nice.org.uk

2. Skilled knowledgeable practitioners

Having skilled, knowledgeable practitioners to support accurate assessment is instrumental to ensuring appropriate care and treatment. The NICE Dementia Quality Standard (2010) specifies that this should be provided by a service that specialises in the diagnosis of dementia. Older people's mental health liaison services are recommended in national dementia strategies and have been shown to improve outcomes and reduce length of stay (Parsonage & Fossey 2011). Older people's liaison, nurse consultants or dementia nurses can also have a significant role in supporting better assessment and identification.

3. Clear delirium protocols and dementia pathways

In most cases people with dementia are admitted to hospital for clinical reasons other than their diagnosis of dementia and tend to have worse outcomes in relation to length of stay, higher mortality rates and deterioration in health. It is therefore important that dementia is taken into account throughout a person's hospital stay and that a care pathway is in place to ensure the needs of the patient are met, both for the dementia and the primary reason for which the person has been admitted. As dementia and delirium share commonalities, having an agreed pathway in place for people with dementia and delirium can help ensure that people receive the right treatment and care wherever they are in the hospital. This should be supported by a clinical lead with responsibility for dementia care in the organisation.

An example of a dementia pathway for hospital care was developed by Healthcare for London (2009).

4. Clinical review of antipsychotic medication

Due to illness or the stress of hospitalisation, people with dementia can be pushed beyond their limit of coping, become distressed, agitated or even aggressive. Understanding the individual through personal profiles and discussions with those closest to them can help to predict and prevent distress. It is important to understand that distressed behaviours are not always due to dementia.

Reducing distress experienced by people with dementia and carers should be a priority. Reaching for medication to suppress symptoms may seem like an easy fix, and medication has its place in treatment, but the dangers associated with antipsychotics are now clear. Good fundamental care can prevent the need for medication in most situations, and a broad range of interventions that do not use drugs has now been identified. The NHS Institute for Innovation and Improvement and the Dementia Action Alliance have developed an online community to support their current call to action to improve the quality of life of people with dementia and their carers by reducing the inappropriate use of anti psychotics for these people. For further information see **the right prescription** at www.institute.nhs.uk

Resources

Optimising treatment and care for people with behavioural and psychological symptoms of dementia: a best practice guide for health and social care professionals.
www.alzheimers.org.uk

Reducing the use of antipsychotic drugs: a guide to the treatment and care of behavioural and psychological symptoms of dementia.
www.alzheimers.org.uk

Sturdy D et al (2012) *Antipsychotic drugs in dementia: a best practice guide*. Available from RCN Publishing, or can be downloaded from www.rcn.org.uk/dementia from the link *responding to distressed behaviour*.

General resources on assessment and care of older people

Acute care toolkit 3: acute medical care for frail older people
www.rcplondon.ac.uk

Delivering dignity: securing dignity in care for older people in hospitals and care homes. NHS Confederation, Local Government Association, Age UK. www.nhsconfed.org

See also www.rcn.org.uk/olderpeople for a range of resources and examples of good practice which inform and support the care of older people.

Principle 4:

Care plans which are person centred and individual



Once you have met one person with dementia, you have just met that one person with dementia – you cannot generalise their care.

Mona Siyang, dementia nurse

Ensuring that care is based on the individual, their biography, preferences and an understanding of their abilities is particularly important for people with dementia in achieving person-centred care. This requires an understanding of the way dementia affects that person and how care can be adapted to compensate for and meet individual needs. Care plans should be developed collaboratively and be communicated clearly with those providing care.

For information about understanding and supporting the specific needs of older people see the RCN elearning module:

www.rcn.org.uk/olderpeople

Principle 4: Care plans will be person-centred, responsive to individual needs and support nutrition, dignity, comfort, continence, rehabilitation, activity and palliative care.

This will be supported by:

- 1) routine gathering of personal life story information
- 2) involvement of family and friends in care planning
- 3) use of mental capacity assessments, advance care planning, nutritional tools, pain assessments and safety tools
- 4) provision of appropriate activity to encourage social engagement, maintenance of function and recovery
- 5) availability of dementia specialists/ leads
- 6) access to and availability of palliative care specialists.

1. Routine gathering of personal life story information

The benefits of life story work include having a better understanding of the person and the delivery of person-centred care, improved relationships with family carers and promotion of participatory care (Thompson, 2011). Personal life story information can be gathered using a range of formats such as albums, books or collage. In hospital settings shorter leaflet versions such as *This is me* or similar initiatives such as *All about me* or *Forget me not* are being used more widely. For further information see best practice examples page on www.rcn.org.uk/dementia

2. Involvement of family and friends in care planning

Carers are vital partners in the care of people with dementia and need to be involved in assessment, care planning and decision making wherever possible. (See Principle 2, Partnership working with carers.)

3. Use of mental capacity assessments, advance care planning, nutritional tools, pain assessments and safety tools

Assessment of the following areas should be included as an integral part of developing individualised care plans.

Mental capacity assessment

People with dementia may have difficulties with decision making and their ability to make decisions or consent to care and treatment may fluctuate.

Understanding the issues of capacity and consent is therefore crucial in working with people with dementia and their families. Assessment of mental capacity should be conducted within the law of the land, codes of practice and national guidance, for example the *Mental Capacity Act 2005* (www.legislation.gov.uk) or *Adults with Incapacity (Scotland) Act 2000* (www.scotland.gov.uk).

This should include an assessment of whether the person:

- understands information relevant to the specific decision being made
- can retain that information for as long as is required to make a specific decision
- can use that information as part of making a decision
- can communicate the decision.

Every effort should be made to include people with dementia and an assessment of capacity should be carried out every time a decision is made, using skilled communication and following guides on best practice. If the person lacks capacity to make a specific decision then a decision should be made in their best interests based on previous preferences and through consulting those who know the person best.

Guidance and toolkits

British Medical Association (England and Wales). *Mental Capacity Act Toolkit* www.bma.org.uk

Mental Health Foundation. *Assessing Mental Capacity Audit Tool* (AMCAT) www.amcat.org.uk or www.mentalhealth.org.uk

Social Institute for Excellence. *Mental Capacity Act Assessment Audit Tools*. www.scie.org.uk

Best interest decisions www.bestinterests.org.uk

Advance care planning

Advance care planning is recognised as being an important way of supporting people with dementia and their families to make positive choices about their future care. People with dementia and their families should be encouraged to consider making advance plans and/or advance decisions about their care while they have capacity.

Resources

Dying Matters Coalition *Time to talk? Starting end of life care conversations with people affected by dementia*. Copies from www.dyingmatters.org.uk

Difficult conversations: making it easier to talk to people with dementia about the end of life. Copies from www.ncpc.org.uk

Gold Standards Framework: *Advance Care Planning*. www.goldstandardsframework.org.uk

National End of Life Care Programme guide: *Planning for your future care*. www.endoflifecareforadults.nhs.uk

SCIE Dementia Gateway: *Making decisions and Making decisions in a person's best interests*. www.scie.org.uk/dementia

Nutrition

Nutrition and hydration are vital for health and wellbeing and for recovery from illness, surgery or accident. Nutrition and hydration for older people in hospital have been recognised as a major issue (Age Concern, 2010).

People with dementia can experience particular challenges in maintaining adequate hydration and nutrition.

- **Memory problems:** the person may forget when they last had something to eat or drink.
- **Agnosia:** the person may not be able to recognise a cup, plate, cutlery or food.
- **Dysphasia:** the person may be unable to understand what staff are saying or to express that they are hungry or thirsty.
- **Dysphagia:** the person may develop problems with chewing or swallowing.

People with a dementia can be particularly at risk of dehydration if ward environments are hot and dry. Adequate nutrition is essential, particularly if the person is active, for example walking. Supplemental foods and snacks may be necessary.

People with dementia should receive nutritional screening to ensure those at risk of under-nutrition or dehydration are identified and appropriate care plans implemented.

Resources

Age UK (2010) *Still Hungry to be Heard* offers examples of schemes in hospitals. www.ageuk.org.uk

British Association for Parenteral and Enteral Nutrition (BAPEN) *Nutritional Screening Tool*. www.bapen.org.uk

Social Care Institute for Excellence Nutrition resources. www.scie.org.uk

For further information on **nutrition and hydration** see: www.rcn.org.uk

Pain and discomfort

Pain is one of the most common but under-recognised and under-treated symptoms in dementia. It is important to recognise pain in people who are less able to communicate, for example through:

- facial expressions (frowning, looking frightened, grimacing)
- vocalisations (groaning, signing, breathing noisily or becoming verbally abusive)
- body movements (rigid posture, tension, rocking, gait changes)
- behaviour changes (refusing food, changes in routines, wandering or pacing)
- mental status changes (confusion, crying, irritability, distress).

Wherever possible, self-reported pain assessment scales should be used in people with mild to moderate dementia and observational pain tools in severe dementia.

Pain assessment tools and guidance

Abbey Pain Tool: an easy-to-use pain scale for people with end or late stage dementia who are unable to articulate their needs (Abbey et al 2004). See the pain assessment tools section of prc.coh.org

Doloplus 2 pain assessment: a brief observation-based pain assessment tool that is easy to use in patients with dementia. prc.coh.org

British Pain Society and British Geriatrics Society *Guidance on the assessment of pain in older people*. See www.bgs.org.uk

4. Provision of appropriate activity to encourage social engagement, maintenance of function and recovery

Time spent in hospital can result in the deterioration of daily living skills, confidence and independence for all patients and, while the effects of a dementia cannot be ignored, it is vital that the multiple abilities and needs of individuals are acknowledged. To prevent excess disability compounding functioning that is already compromised, care should proactively promote re-enablement and rehabilitation to optimum individual potential. Each person's abilities and coping strengths, along with those of their carers, should be maximised, and rehabilitative approaches could incorporate memory skills support, the use of memory aids and maintaining skills for everyday living.

People with a dementia have commonly been excluded from access to multi-professional rehabilitation services on the mistaken assumption that they will be unable to benefit. Multi-professional assessment of individuals should determine which services are offered and improved services should result in more people with dementia accessing rehabilitative support and intermediate care.

Resources

NHS Institute for Innovation and Improvement. *Distraction toolkit for demented patients on an acute general ward*. www.institute.nhs.uk

SCIE Dementia Gateway: *Keeping active and occupied*. www.scie.org.uk

5. Availability of dementia specialists/leads

The availability of dementia specialists leads is important for the delivery of individualised care that is appropriate to the needs of the person with dementia. These roles have been identified as instrumental to improving care (RCN, 2011a) and are an important focus for supporting and advising other staff in delivering good quality dementia care. In addition some areas where specialist wards/units with enhanced staffing have been developed, significant improvements in care are emerging.

See best practice examples at: www.rcn.org.uk/dementia

6. Access to and availability of palliative care specialists

Access to, and support from, specialist palliative care teams can be instrumental in ensuring that those in hospital who are at the end stage of their life get the right support.

Palliative and end of life care

About 55 per cent of deaths occur in hospital and many of these people will have a dementia. People with a dementia at the end of life can experience multiple and complex problems including swallowing difficulties, malnutrition, poor mobility, falls, multiple infections, constipation and then urinary and faecal incontinence. Pain and discomfort can lead to behavioural problems and they often experience major problems informing staff of their needs. In addition, it can be more complex to identify the point at which individuals begin to die.

Palliative and end of life care for people with dementia has traditionally not been good but awareness of the importance of palliative and end of life care for people with dementia is increasing through national end of life care programmes and the use of the Gold Standard Framework, Liverpool Care Pathway and the Amber Care Bundle.

For further information about these initiatives, search for end of life care under supporting people with dementia at: www.rcn.org.uk/dementia

Resources

National Institute for Clinical Excellence NICE *End of Life care for people with dementia commissioning guide*. www.nice.org.uk

National End of Life Care programme

- *Care towards the end of life for people with dementia: a resource guide*
- *The route to success in end of life care – achieving quality in acute hospitals. 'how to' guide*
- *Support Sheet 11: Quality Markers for Acute Hospitals*.

www.endoflifecareforadults.nhs.uk

National Council for Palliative Care (NCPC) *Priorities for Dementia Care within the End of Life Care Strategy's Quality Markers and Measures for Commissioners*. www.ncpc.org.uk

Marie Curie Cancer Care. Project report: *End of life care for people with dementia*. www.mariecurie.org.uk

Principle 5:

Environments that are dementia friendly



The environment can have a significant impact on people with dementia both positive and negative. What you need is a calming environment that promotes orientation, comfort and familiarity.

Emma Ouldred, dementia nurse

Principle 5: Environments will be dementia friendly and support independence and wellbeing.

This will be supported by:

- 1) minimal moves to avoid unnecessary distress.
- 2) appropriate lighting and floor coverings plus aids to support orientation and visual stimulation.
- 3) personalised bed area.
- 4) adequate space and resources to support activity and stimulation.
- 5) availability of staff to support rehabilitation eg occupational therapy, physiotherapy, activity co-ordinators.
- 6) inclusion of trained volunteers to support activity and pastoral care.

Hospital environments can be very difficult for people with dementia; they can be confusing, noisy and difficult to navigate. Emergency departments are commonly the first point of contact for patients coming into hospital and, due to the pace and noise of emergency care, these environments can be among the most challenging faced by people with dementia and their carers.

Guidance

The Silver Book: Quality Standards for the Care of Older People with Urgent & Emergency Care Needs.

www.bgs.org.uk

British Geriatrics Society *The older person in the A&E Department.*

www.bgs.org.uk



There's nothing worse than going into a strange environment...it's hard enough normally but when you've got dementia it's even worse.

Trevor Jarvis, person living with dementia

1. Minimal moves to avoid unnecessary distress

Being moved between different environments can be very distressing. In surveys of people with dementia, family carers and practitioners (RCN, 2011a, b), frequent moves between wards and units was considered a significant barrier to providing good quality care. It is essential that we make every effort to minimise the number of moves between wards.

2. Appropriate lighting and floor coverings plus aids to support orientation and visual stimulation

Dementia generally causes progressive changes in how people interpret what they see, hear and feel. People with a dementia commonly find it difficult to orientate to an unfamiliar environment and have a reduced stress threshold to environmental challenges. As the King's Fund (2012) highlight, the design of the built environment can significantly help in compensating for the sensory loss and cognitive impairment associated with dementia, as well as

supporting the continued independence of people in hospital who have dementia. New projects are demonstrating that relatively inexpensive interventions, such as changes to lighting, floor coverings and improved way-finding, can have a significant impact.

3. Personalised bed area

For someone with dementia in an unfamiliar hospital environment, being able to identify their bed can be a lifeline. Personalising bed areas with familiar objects, clothing, life story books, images on the wall or photographs which are clearly visible can be helpful.

4. Adequate space and resources to support activity and stimulation

People with dementia in hospital may at times require support to reduce distress and/or to provide stimulation. Hospital wards can be difficult environments in which to offer a relaxing, calming space or a place where activity can be offered, yet these are important considerations for hospital design.

5. Availability of staff to support rehabilitation eg occupational therapy, physiotherapy, activity co-ordinators

In order to promote re-enablement and rehabilitation, input from specialist therapy staff is vital. An assessment of individual needs and potential should take into account the person's cognitive impairment, so that focused rehabilitative support can be adapted and offered as soon as

possible. This may include the use of memory prompts, assistive technology, alternative communication tools and flexible approaches. The availability of activity coordinators to maintain engagement and promote activity whilst the person is in hospital can also be invaluable.

6. Inclusion of trained volunteers to support activity and pastoral care



We have a set of volunteers who work with the service providing one to one engagement with patients with dementia. They also help staff identify what kind of activities might help keep people occupied while in hospital.

Michelle Parker, nurse

Resources

Kings Fund, Enhancing the Healing Environment (EHE) programme has developed an assessment tool for hospital wards: *Developing supportive design for people with dementia*.
www.kingsfund.org.uk

Social Care Institute for Excellence Dementia gateway resources. *The Environment, Why activity matters; Activity resources and approaches*.
www.scie.org.uk

AT Dementia: Resources on assistive technology for people with dementia. *The benefits and limitations of assistive technology; The ethical use of assistive technology*.
www.atdementia.org.uk

The support and inclusion of trained volunteers is being increasingly supported in hospitals as a valuable support to other staff in providing activity and pastoral care.

This may include sitting with patients, engaging in conversation, offering individualised or group activity sessions such as games, music, social activities. Volunteers may also offer invaluable support at meal times and training plus supervision should be in place for those providing such support.

Assessing quality of care and evaluating outcomes

The SPACE principles offer a useful benchmark against which staff can assess how care is delivered within hospitals. See: www.rcn.org.uk/dementia

Other frameworks such as the South West Dementia hospital standards may also be useful and are being monitored using a peer review process. See: www.dementiapartnerships.org.uk

In order to assess the impact of and evaluate initiatives which aim to improve the experience of care for people with dementia and their carers/supporters in hospital, the following frameworks have been identified as being useful.

Dementia care mapping

Dementia care mapping (DCM) is a method designed to evaluate quality of care from the perspective of the person with dementia. It involves briefing staff and clients about DCM in the area to be mapped, observing a number of people with dementia over a period of time and recording information about their experience of care, analysing and

interpreting the data and then feeding it back to staff. This information is then used to draw up an action plan to bring about change and improvements. See: www.brad.ac.uk

The Short Observational Framework for Inspection 2 (SOFI 2)

A collaboration between Bradford Dementia Group and the Care Quality Commission (CQC) is based on the DCM tool and process and is used to gather information about the experience of care from the point of view of people using a service, alongside other information an inspector would usually gather during an inspection. See: www.brad.ac.uk

Person, Interaction and Environment (PIE) observations

PIE is a qualitative observational tool designed for use by staff in a national audit of care received by people with dementia in hospital wards. It aims to help staff understand and reflect on elements of patient experience and to develop ward action plans for person-centred practice. See www.rcpsych.ac.uk for more information.

15 Steps Challenge toolkit

This toolkit has been developed with patients, relatives, volunteers, staff, governors and senior leaders, to help look at hospital care through the eyes of patients and relatives, helping to hear and see what good looks like. It provides a series of questions and prompts to guide patients, carers and NHS staff through their first impressions of a ward. The challenge helps to gain an understanding of how patients feel about the care provided, and how high-quality levels of confidence can be built.

Please visit www.institute.nhs.uk to find out more.

Other initiatives supporting the care of people with dementia in hospital

Improving the experience of people with dementia and their families in acute care; call to action. This call to action led by NHS Institute for Innovation and Improvement and the Dementia Action Alliance aims to enable people with dementia to experience high quality care in acute hospitals. www.institute.nhs.uk

Releasing time to care – the productive ward focuses on improving ward processes and environments to help nurses and therapists spend more time on patient care thereby improving safety and efficiency. www.institute.nhs.uk

Delivering the NHS safety thermometer (May 2012)
The NHS safety thermometer is a local improvement tool for measuring, monitoring and analysing patient harms and 'harm free' care. www.dh.gov.uk

Other resources to support the NHS safety thermometer are available at: www.harmfreecare.org

Dignity in care
The Department of Health (England) work on dignity in care aims to drive up standards of care with respect to dignity for the individual. www.dh.gov.uk

RCN Dignity resources
For information on the RCN resources on dignity see: www.rcn.org.uk/dignity

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The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.

www.rcn.org.uk/dementia

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