

Failings have been identified in dementia care in acute hospitals; to address these nurses should take a person-centred, individualised approach to care

# Improving person-centred care in dementia

## In this article...

- Failings of dementia care in acute hospitals
- How to provide person-centred care for this group of patients
- Managing distressed behaviour in patients with dementia

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**Abstract** Armstrong D, Byrne G (2011) Improving person-centred care in dementia. *Nursing Times*; 107: 46, 12-14. Failings in dementia care in acute hospitals have been reported to the Scottish Public Services Ombudsman and other scrutiny bodies in Scotland and the UK. This article sets out key knowledge and resources to help nurses provide compassionate and person-centred care.

Dementia is a growing illness and figures are expected to double in the next 25 years. Around 82,000 people in Scotland currently have dementia, and each year around 7,000 more cases are diagnosed (Alzheimer Scotland, 2011).

People with dementia are entitled to receive high-quality nursing care and be treated with respect, dignity and compassion but UK ombudsman reports and other evidence document nationwide shortcomings. Patients with dementia who died during admission to acute hospital wards were: less likely than others to receive palliative care; prescribed significantly fewer palliative medications; less frequently referred

to palliative care teams; and less likely to receive specific medical interventions (Sampson et al, 2006). They were also more likely to have poor quality of life and poor recovery rate following hip fracture surgery (Takayama et al, 2001).

## Improving care

Increasingly, the Scottish Public Services Ombudsman receives complaints about the care and treatment of people with dementia who are admitted to general hospitals with other medical problems. Its reports show that, in many cases, patients had managed well at home with support but an acute illness such as an infection or fall led to hospital admission.

In his May 2011 commentary, the ombudsman Jim Martin said:

*"I regret that a common theme that emerges from complaints I receive continues to be failures in the care of elderly people with dementia. One of today's reports is about a woman (Mrs A) who suffered a fall in hospital, and where, among other failings, I found that communication with the patient's family fell far below a reasonable standard."* (SPSO, 2011)

He went on to say:

*"These failures, in addition to the communication failures between healthcare professionals and the family, indicate systematic failures within the board relating to caring*

## 5 key points

**1** The number of people with dementia is expected to double in the next 25 years

**2** UK ombudsman reports show shortcomings in dementia care

**3** People with dementia should have their specific needs and preferences recognised

**4** Nurses should identify and record causes and triggers that may result in distressed behaviours

**5** Delirium can occur in up to half of all those aged 65 years or over who are admitted to hospital



Recognise the specific needs and preferences of people with dementia

## BOX 1. AN EXAMPLE OF SUBOPTIMAL CARE

Mrs C was 66 years old and had previously been diagnosed with Alzheimer's disease. She had been managing well at home and a week before her hospital admission she had been well enough to babysit her grandchildren. She was admitted with a perforated ulcer and stayed there until she died three months later.

Her family complained that their mother's care and treatment in hospital were inappropriate. They felt her care had been ignored due to her Alzheimer's and provided us with examples of her being treated with disrespect; these included

being washed with the curtains drawn back and being left sitting in faeces during visiting time.

The family complained that on numerous occasions Mrs C refused medication and that staff were unaware of her medical history. They were also concerned about her eating and drinking and said she had "starved to death". They described an occasion when dinner had been left in front of her and then taken away untouched, as she was unable to lift the lid. There was no evidence in the nursing notes to indicate that Mrs C's nutritional needs had been met.

The family felt ill-informed about progress, particularly at handover when

staff were too busy to help or unaware of Mrs C's needs when coming on shift.

An important part of the nursing role is to ensure that relatives are well informed and involved in any decision making about care. If a person with dementia is unable to give consent, the proxy decision maker (a welfare power of attorney or welfare guardian) should be sought and a certificate of incapacity completed.

The ombudsman upheld the complaints that Mrs C was managed inappropriately and not treated with respect, her fluid and nutritional care was poor, and her oral hygiene was poor.

Source: Scottish Public Services Ombudsman (2010)

*for people with dementia, which is of grave concern."* (SPSO, 2011)

His closing remarks on this particular complaint show the magnitude of failures in Mrs A's hospital care in more detail.

The case study in Box 1 is one of several examples of suboptimal care reported by the office each year. As well as offering a chance for justice, complaints are a valuable driver for learning and improvement. The ombudsman makes recommendations to appropriate health boards; in this case, it was recommended that the health board:

- » Show that dementia care standards are being monitored and measured;
- » Provide details of the education and training strategy for staff in caring for people with dementia;
- » Ensure an awareness of the Adults with Incapacity Act (Scotland), assessment tools and documentation used;
- » Audit the standard of recordkeeping and communication;
- » Acknowledge and apologise for any failings identified.

The Mental Welfare Commission for Scotland's (2011) report summarised the findings of visits to patients with dementia in general hospitals. It provided examples of extremely good practice – such as staff encouraging the daughter of a man with night terrors to come in and settle him, which avoided the need for medication; improving access to specialist advice and support, such as dementia nurse specialists or consultants – but despite improvements in care, more still needs to be done. MWCS recommended improvements in:

- » Admission and the care journey in hospital;
- » Consent and lawful treatment;
- » Safety and restrictions;

- » The care environment;
- » Staff training and specialist mental health support;
- » Discharge from hospital.

### A person-centred approach

The Scottish Government's (2011) *Standards of Care for Dementia in Scotland* aims to help patients, their families and carers understand and assert their rights; it followed its *Scotland's National Dementia Strategy* (Scottish Government, 2010). The standards of care state that patients should be treated with respect, their physical care environment should be personalised and their specific needs and preferences recognised and included in their care package. An example of good practice is outlined in Box 2.

The essence of person-centred care is to put the person at the centre of care planning; this means finding out exactly who they are. Nurses can use many resources to increase their knowledge and understanding of dementia, and their focus on person-centred care. *Scotland's National Dementia Strategy* recommended:

- » Ensuring staff have better information about the person, for example, using a personal profile (resource) to help them consider the person's unique life story;
- » Improving assessment of people admitted to hospital including emergency departments;
- » Improving information systems so staff have good quality information about a person's diagnosis, which should form the care plan;
- » Reducing unnecessary admissions/transfers and ensuring timely discharge;
- » Ensuring better assessment, treatment and management in hospital of frail, older people who may have multiple problems or suspected dementia.

NHS Education for Scotland (2011) has also launched a learning resource for staff in acute care ([tinyurl.com/NHSScotland-dementia](http://tinyurl.com/NHSScotland-dementia)); it provides information about assessment, care and treatment of people with dementia, as well as tools to understand the person's story.

The Royal College of Nursing has developed a number of resources, as part of its Dignity in Dementia: Improving Care in General Hospital Settings project. These can be accessed at [tinyurl.com/dementia-RCN](http://tinyurl.com/dementia-RCN).

### Managing distressed behaviour

Many complaints focus on concerns raised by relatives about the lack of individualised care and resulting distress they witness, but seeing patients in a state of distress can also be challenging for carers and nursing staff. All distressed behaviour is a way of communicating; it may be the only way the person with dementia can communicate. Behaviours include:

- » Agitation;
- » Wandering;
- » Repetitive questioning/phrases or movements;
- » Lack of inhibition;
- » Suspicion;
- » Misperceptions and hallucinations;
- » Aggression.

These behaviours may be caused by a number of factors; the most common are:

- » Pain;
- » Physical illness;
- » Side-effects of medication;
- » Dehydration;
- » Constipation;
- » Needing to go to the toilet;
- » Being too hot or cold;
- » Sitting or lying in an uncomfortable position;

### BOX 2. AN EXAMPLE OF GOOD PRACTICE

#### Viewpoint of a senior charge nurse

"The ward has implemented the Senses Framework, which uses the principles of relationship-centred care (Nolan and Davies, 2001). This framework proposes that in an 'enriched' environment of care, all people (including patients, relatives, carers and staff) experience six senses: security; belonging; continuity; purpose; achievement; significance.

"Every single patient has a life story to tell and that story helps us build a relationship with the patient and their families and carers. On admission, we ensure the whole family is involved in decision making and include their needs in the assessment. Patients and their families feel more involved and there is a greater 'sense of belonging'. Communication has improved and there is positive feedback from relatives."

- » Overstimulation from light, noise and activity;
- » Changes to routine;
- » Missing family or pets;
- » Alcohol or tobacco withdrawal.

It is important to identify the cause and triggers of distressed behaviours – a behaviour chart can be helpful. At the very least, records should include the behaviour, the trigger (if known) and actions taken.

Pain is one of the most common causes of distress in patients with dementia and should always be considered in the acute care setting. Box 3 outlines a case study on distressed behaviour.

#### Dementia and delirium

Delirium is a severe and extremely common syndrome in which there is an

TABLE 1. DEMENTIA AND DELIRIUM: A QUICK GUIDE

Domain	Dementia	Delirium
History	Slow onset over months/years	Recent sudden onset
Awareness	Usually unaffected	Distracted, reduced or changes rapidly
Sleep pattern	Stable over time	Significant change from usual pattern
Memory	Recent memory affected – difficulty learning new materials	Immediate and recent memory difficulties
Thinking	Difficulty reasoning or understanding	Disorganised, jumping from one subject to another
Physical function	Slow progressive change	Sudden loss or change
Perception	May misperceive objects in the environment	May see/hear/feel things vividly that are not there

Source: Adapted from NHS Education for Scotland (2011)

acute decline in mental state and behaviour. It is most common in older people, and often occurs in older people with underlying dementia presenting with an acute illness such as infection (NHS Education for Scotland, 2011). While the symptoms are similar to dementia, they develop over a short period of time (hours or days) and the level of confusion fluctuates throughout the day. The changes witnessed by relatives and carers can be pronounced and extremely distressing. For this reason, hospitals receive a significant number of complaints about the care of people with dementia or delirium.

Delirium can occur in up to half of all patients aged 65 years or over admitted to hospital; the number is even higher for surgical and intensive care admissions. People with dementia who are physically ill have a high risk of developing delirium and, consequently, a greater risk of dying. Table 1 is a useful guide to differentiating between delirium and dementia.

#### Conclusion

The ombudsman and scrutiny bodies across the UK are key to driving improvement but this can only be achieved as part of a coordinated scheme including education and development. The King's Fund (2009)

identified three elements to ensure caring is given the priority it deserves:

- » Strong clinical leadership;
- » Relationships combined with robust governance arrangements;
- » The right information.

Nurses are in a unique position to see the person behind the dementia; they must use their skills to be more confident in caring for these patients. We know people with dementia and their carers and families may be dissatisfied and frustrated by their experiences in hospital. As demographics alter and we face public spending challenges, we must all address the issues raised. **NT**

#### References

- Alzheimer Scotland** (2011) *Statistics: Number of People with Dementia in Scotland 2011*. Edinburgh: Alzheimer Scotland. [tinyurl.com/dementia-scot](http://tinyurl.com/dementia-scot)
- Mental Welfare Commission for Scotland** (2011) *Dementia: Decisions for Dignity. Our Visits to People with Dementia in General Hospitals – September to December 2010*. Edinburgh: MWCS. [tinyurl.com/dementia-visits](http://tinyurl.com/dementia-visits)
- NHS Education for Scotland** (2011) *Acute Care Dementia – Learning Resource*. Edinburgh: NHS Education for Scotland. [tinyurl.com/NHSScotland-dementia](http://tinyurl.com/NHSScotland-dementia)
- Nolan MR, Davies C** (2001) *Working with Older People and their Families: Key Issues in Policy and Practice*. Buckingham: Open University Press.
- Sampson EL et al** (2006) Differences in care received by patients with and without dementia who died during acute hospital admissions: a retrospective case note study. *Age and Ageing*; 35: 2, 187-189.
- Scottish Government** (2011) *Standards of Care for Dementia in Scotland: Action to Support the Change Programme, Scotland's National Dementia Strategy*. Edinburgh: Scottish Government. [tinyurl.com/action-change](http://tinyurl.com/action-change)
- Scottish Government** (2010) *Scotland's National Dementia Strategy*. Edinburgh: Scottish Government. [tinyurl.com/dementia-scot-strategy](http://tinyurl.com/dementia-scot-strategy)
- Scottish Public Services Ombudsman** (2011) *Ombudsman's Commentary*. [tinyurl.com/Ombudsman-comment](http://tinyurl.com/Ombudsman-comment)
- Scottish Public Services Ombudsman** (2010) *Case 200802381: Lanarkshire NHS Board. Summary of Investigation*. [tinyurl.com/Ombudsman-investigation](http://tinyurl.com/Ombudsman-investigation)
- Takayama S et al** (2001) Factors that influence functional prognosis in elderly patients with hip fracture. *Environmental Health and Preventive Medicine*; 6: 1, 47-53.
- The King's Fund** (2009) *From Ward to Board: Identifying Good Practices in the Business of Caring*. [tinyurl.com/Ward-Board](http://tinyurl.com/Ward-Board)

### BOX 3. CASE STUDY – DISTRESSED BEHAVIOUR

Mr A, who had become increasingly more frail and had dementia, was admitted via A&E to an acute admission ward and his family informed. He 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 annoyance at the level of disturbance. Mr A's family visited him, and found him to be noisy

and distressed; thinking this was caused by discomfort, they asked for him to be given pain relief. He responded well to treatment.

Mr A's family were upset that no plan had been in place to manage his expected physical deterioration, and that their views had not been sought about how this should be managed. They felt his transfer to the general hospital had been unnecessary and distressing for him.

Source: Adapted from Scottish Government (2011)