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 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 failings between healthcare professionals and the family, indicate systematic failures within the board relating to caring 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).

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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); 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.

Managing distressed behaviour

Many complaints focus on concerns raised by relatives about the lack of individualised care and resulting distress they witnessed, 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;
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)