Acute awareness

Improving hospital care for people with dementia
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The NHS Confederation
29 Bressenden Place
London SW1E 5DD
Tel 020 7074 3200
Email enquiries@nhsconfed.org
www.nhsconfed.org


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Executive summary

Dementia currently affects over a half a million people in England alone; this number is set to rise considerably as more people live longer. Sixty thousand deaths a year are directly attributable to dementia, and the current cost to the NHS is estimated at £1.3 billion a year. While this figure is the current estimate, it is probable that the actual cost is higher. This is because a large proportion of people with dementia are undiagnosed; also because many people with dementia go into hospital for a reason not related to their dementia and so the dementia is not coded. Recent Government policy has reflected a growing awareness of the importance of dementia care, with the publication of the first national dementia strategy being followed by increased funding and the appointment of a national clinical director for dementia.

Despite these and other efforts aimed at improving dementia care, there is still considerable scope for improving services in acute hospitals, as identified by the Alzheimer’s Society among others. At a time when cost savings are being keenly sought alongside service improvements, the National Audit Office and the House of Commons Public Accounts Committee have both identified significant potential efficiency savings. This report looks at the key issues for NHS trusts in improving care for patients with dementia, the majority of whom will have been admitted for another condition.

Acute awareness: improving hospital care for people with dementia highlights how hospitals can improve the quality and efficiency of acute care for people with dementia. It showcases the innovative work that both NHS trusts and cross-agency partnerships are undertaking. As dementia is not generally the prime reason for admission to hospital, it can often be difficult to factor into a patient’s care programme. Yet, as the report shows, improving services for patients with dementia has the potential not only to enhance the quality of their care experience but, by shortening their length of stay, to reduce unnecessary costs.

The report concludes with a list of key questions for boards to consider in developing their approach towards caring for patients with dementia, and some suggestions for policy developments that could enhance implementation of the national strategy.
Introduction

What is dementia?

Dementia is a syndrome (a group of related symptoms) that is associated with an ongoing decline of the brain and its abilities. These include thinking, language, memory, understanding and judgement; the consequences are that people will be less able to care for themselves. The occurrence of dementia increases with age, as shown in Figure 1.

Dementia is a common condition:

- in England alone, there are currently 570,000 people living with dementia\(^1\)
- the number is expected to grow to over one million people over the next 30 years\(^1\)
- 60,000 deaths a year are directly attributable to dementia\(^2\)
- the financial cost of dementia to the UK is over £17 billion a year, including £1.3 billion to the NHS.\(^3\)

Not surprisingly, dementia is becoming a higher priority. The Government has acknowledged the need to ensure that people live well with dementia:

- the Department of Health launched *Living well with dementia*, the first national dementia strategy, in 2009
- the dementia strategy includes a specific objective to improve the quality of care for people with dementia in general hospitals
- the dementia strategy was backed by a detailed implementation plan and funding – £60 million was allocated to PCT baseline budgets in 2009, followed by another £90m in April 2010
- Professor Alistair Burns has been appointed as National Clinical Director for Dementia.

Moreover, in recent years there has been a series of other initiatives that support the implementation of the dementia strategy and the development of improved services for people with dementia and their carers. These include:

- the Carers’ strategy\(^4\)
- Lord Darzi’s report *High quality care for all*.\(^5\)
- the Dignity in Care campaign\(^6\)
- the Nutrition Action Plan.\(^7\)

![Figure 1. Occurrence of dementia in people over 65](source: www.nhs.uk/conditions/dementia/Pages/Introduction.aspx)
Despite these efforts, services for people with dementia still need to improve further:

- at the end of 2009, the Alzheimer’s Society launched a report called *Counting the cost*, which looked at the quality of dementia care provided in hospitals. It found that hospitals were failing to provide acceptable standards of care for people with dementia

- in 2010, the National Audit Office (NAO) reported that care should be improved in acute settings in order to ensure the dementia strategy succeeds

- the Public Accounts Committee reported in March 2010 that dementia needed to become a higher priority for the NHS. The report identified key priority areas for hospitals, such as introducing liaison teams.

While the take-off has been slow, there are some examples of good practice in acute care for people with dementia. This independent report focuses on key issues that can improve hospital care for people with dementia and highlights examples where trusts have started taking action. It is intended for acute NHS trust board members and managers, commissioners and policy-makers.

**Hospital care for people with dementia – the case for improvement**

Up to 70 per cent of acute hospital beds are occupied by older people. This represents a large proportion of patients. For quality and efficiency reasons, it is fundamental for hospitals to address their care needs.

The national dementia strategy highlights the need to improve care for people with dementia in hospital. This is, in fact, one of the objectives of the strategy, but hospitals need to act soon if they are to meet the goals of the national strategy and the needs of an increasing number of patients with dementia.

This report showcases some of the innovative work that NHS trusts and cross-agency partnerships are doing in this area, and highlights potential lessons for NHS organisations, as well as some questions for boards to consider in shaping their development strategy. As demonstrated below, improving care for people with dementia is key to improving services and achieving efficiencies. The NHS Confederation will continue its work in this area, with a dementia session planned at its 2010 annual conference.
Improving outcomes, quality and efficiency

Ann Reid’s hospital experience

I have experience of caring for two people with dementia: my mother and my husband. Both of them have been to hospital.

My husband Jim went to hospital when he had a stroke. He was moved around wards. He found the experience very confusing, which made him stressed. Because of this, he was sedated to help him ‘comply’. The problem is I believe it was this long sedation that made him incontinent – he was fully continent when he went into hospital and also during the first days, before he was sedated. To add to this, Jim did not receive a full assessment on discharge, which left me relying on friends’ help, battling my way around the system and not giving me enough time to do the most important job: care for my husband.

My mother went into hospital because of a chest infection. Having dementia, she also found the situation very confusing. At one instance, she began banging the table. Instead of talking to her, one of the staff members left this note on her bedside table:

I am sure improving care for people with dementia does not need to be either costly or complicated:

- Have more flexible visiting times, so carers can help care for the patient, for example by feeding them. This will also help the patient to feel more comfortable.

- Involve carers in issues surrounding the care of patients. After all, their carers have been doing it for a long time and so they are often the best source of information. This goes beyond family members: care home staff can also help.

- Have a dementia lead or a specialist team: we can’t expect all the hospital professionals to be specialists in dementia. After all, people are not normally in hospital because of their dementia and we need someone to treat the condition they have been to hospital for. But if staff know they can call on a team who will help them understand how the care plan can be adapted to include the needs of people with dementia too, we can improve the care of the patient and probably help them leave hospital earlier.

- Increase the level of dementia awareness among all staff: even if they are not specialists, they should have an appropriate level of understanding about dementia, especially as so many patients have dementia.
Research shows\(^1\) that people with dementia experience worse symptoms after being in hospital. A more person-centred pathway or care plan could improve outcomes for patients. Moreover, improvements for people with dementia are likely to lead to improved outcomes for other patients too.

The dementia strategy expects to see about £1.8 billion released from hospitals and long-term care sectors to fund earlier intervention and community care. An NAO report\(^1\) highlighted that this is difficult to achieve and will need more urgency and priority in order to achieve value for money.

Improving efficiency and quality of care for patients with dementia can go hand in hand by, for example:

- the Alzheimer’s Society estimates that the length of stay for patients with dementia can be longer than for other patients, and has called for the average length of stay to be reduced by a week\(^8\)
- reducing readmissions by ensuring people leave hospital with an appropriate care plan
- reducing infection cases, which are linked to length of stay
- reducing complaints by improving care for the patient
- improve staff satisfaction by providing them with the skills to respond appropriately to the needs of patients.\(^1\)

Improving hospital care for people with dementia does not need to be costly. Simple changes such as signage and greater involvement of carers can improve the quality of care and make more efficient use of hospital resources.

The rest of this section highlights areas where changes can be made in acute hospitals to improve the quality and efficiency of care for people with dementia.

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**Identification**

The patients who helped us with this report told us that identifying that they had dementia was a crucial first step in helping them to live well with the condition. This remains a problem and requires cross-organisational working and information-sharing.

Ambulance services and hospitals often come into contact with people with dementia that has not yet been identified and 50 per cent of dementia in general hospital is unrecognised.\(^1\) Early identification in hospitals is essential to effective care planning and can lead to improved outcomes for the patient, as it reduces the likelihood of that patient’s physical and mental health worsening during their stay. The NAO argues that effective identification of patients with dementia at admission, together with more proactive, coordinated management of their care and discharge, could produce savings of between £64 million and £102 million a year nationally.

Ambulance services can assist hospitals in this area, as they will often help people with dementia who have come into contact with the health service for a primary incident such as a fall.

Once patients are identified as having dementia it is very important that their particular needs are recognised and understood. Systems need to be in place to ensure that patients can tell hospital staff how long they have had their condition, what makes the patient feel more comfortable, what needs to be done to ensure that meals are appropriate and other important personal details. The Alzheimer’s Society has recently produced *This is me*\(^1\) a leaflet that the person with dementia and/or their carer can fill in when they are admitted to hospital. This captures the above and other important data that will assist with care planning and the effective use of the dementia pathway.
Identification initiatives by Great Western Ambulance Service NHS Trust

As part of implementing the national dementia strategy, the Department of Health Regional Lead for the South West of England has been working with Great Western Ambulance Service NHS Trust to support ambulance crews when they help patients with dementia.

Ambulance crews are in frequent contact with people with dementia, who will often come to the attention of the service because of primary incidents such as falls. Although it is hard to tell if someone has dementia, identification by ambulance crews or their increased knowledge of the symptoms of dementia and of the medication individuals with dementia may take could lead to:

- the sharing of information on arrival at the hospital, so that an appropriate care package can be developed for the patient
- avoiding unnecessary admissions for patients with dementia to hospitals
- providing a clear and more appropriate care pathway so that the patient and carer experience will be a more positive one
- identifying patients who require dementia-appropriate community services and initiating links to these services.

For these reasons, an introductory guide has been produced for ambulance crews. This explains facts about dementia, including the basic skills in communicating and supporting people with the condition, and points ambulance staff to where they can get more information. This leaflet is available at www.southwestdementiapartnership.org.uk/implementation/ambulance-leaflet

Care pathways

Once the patient has been identified as having dementia, it is important to ensure they have an appropriate care plan. The dementia strategy calls for each hospital to develop a care pathway for people with dementia. Healthcare for London has an example of how to develop a dementia pathway for general hospitals.18

Moreover, people with dementia are usually admitted to hospital for a reason other than their dementia. The top five reasons why a person with dementia is admitted to hospital are shown in Figure 2 (see page 10). It is important to check how the dementia care pathway can link into the pathways of these conditions. Hospitals may also want to check links into pathways for other conditions too.

Training

The Alzheimer's Society report Counting the cost found that over half of the nurses who responded to their survey had not received dementia training. Given the high proportion of hospital patients who have dementia, improving the level of awareness and providing training around the condition can benefit trusts in a number of ways, for example:

- by making it easier for staff to identify a patient with dementia, which will improve their ability to develop a more appropriate care pathway
- responding effectively to dementia can release staff time: for instance, if patients are less disoriented and are able to find their way around the ward, nurses may be able to find more time to provide care for other patients.
Awareness can be raised through internal training. Dementia leads play a key role in this, both by ensuring that dementia is high on the hospital training agenda and by being able to support staff who need to improve their knowledge of the condition.

While it is important for professionally regulated staff to receive detailed training on dementia, any training strategy needs to include other front-line staff, ambulance crews working in patient transport, healthcare assistants, porters and catering staff. All these groups should have some knowledge and understanding of dementia.

**The use of antipsychotic drugs**

A particular issue that needs to be addressed when providing training for hospital staff is the use of antipsychotic drugs. According to *Counting the cost*, 77 per cent of nurses reported that antipsychotic drugs were used to treat people with dementia in the general hospital. Yet evidence shows that these drugs can be dangerous. A Government review found that around 145,000 people with dementia were prescribed antipsychotic drugs. However:

- only 36,000 showed any benefits from their medication
- over-prescribing of drugs is linked to an extra 1,800 deaths of older people per year
- around 1,620 additional cerebrovascular adverse events (such as stroke) per year will result from treatment with antipsychotic drugs. About half of these will be severe.

While the review did not look specifically at hospital services, it illustrates how many people with dementia are prescribed with antipsychotic drugs that may not benefit them.

Doctors, nurses, pharmacists and hospital managers can help to ensure that only those who can benefit from the use of antipsychotic drugs receive them. This can be done by ensuring that there is a rigorous needs assessment, both for those patients with dementia who were receiving antipsychotic drugs before being admitted to hospital as well as patients who are going to be prescribed antipsychotic drugs while in hospital. This needs assessment can form part of the hospital dementia care pathway.

**Nutrition**

A poor diet will have psychological and physical effects on a patient. Age carries a significant risk of malnutrition; a patient with dementia may be more likely to be malnourished. As four out of 10 people admitted to hospital have malnutrition on arrival, trusts can play a major role in identifying malnutrition by screening patients when they are admitted. However, not all malnourishment happens before a patient is admitted to hospital and so it is important for hospitals to provide meals that fit the dietary needs of the patient and to ensure that patients have the necessary support to eat them.
Age Concern (now Age UK) calls for the following steps to be implemented in hospitals to ensure that patients have a good diet:

1. hospital staff must listen to older people, their relatives and carers
2. all ward staff must become ‘food aware’
3. hospital staff must follow their own professional codes and guidance from other bodies
4. older people should be assessed for signs or danger of malnourishment on admission and at regular intervals during their stay
5. introduce ‘protected mealtimes’
6. implement and monitor a ‘red tray’ system (whereby the standard brown tray is replaced with a red one, to make nurses more aware of the nutritional needs of the patient)
7. use volunteers where appropriate.

### Nutrition assistants at Harrogate

The role of the ward-based nutritional assistant is relatively new at Harrogate and District NHS Foundation Trust. This is a Band 2 Agenda for Change post, funded from a ward budget. Although funded by wards, job description, duties and training are provided by the nutrition and dietetic department and close links remain between the two. In practice a ward would have one nutrition assistant working from approximately 7:30am to 3:30pm.

The post of the nutritional assistant was introduced to improve the standard of nutritional care on acute hospital wards; they focus solely on nutritional care on wards. Duties include weighing patients, liaising with catering, assisting with meals, one-to-one care, nutritional screening and the implementation of nutritional support on wards.

An internal audit into nutritional screening on six acute wards (including two older people’s care wards) during 2008 found that nutritional care plans attached to the trust’s screening tool were not being followed consistently in practice. The care plans included food record charts, a ‘red tray’ system, nutritional supplements/fortified snacks and dietetic referrals. The audit also found patients were not being weighed regularly during an admission. An observation of the audit was that wards with nutrition assistants achieved more positive results than those without.

A further internal audit carried out in 2009 evaluated the impact on nutritional care following the introduction of nutrition assistants onto two acute wards that had performed below average in all areas during the previous audit. The 2009 audit results suggest the introduction of nutrition assistants improved both incidence and frequency of screening to a level of 100 per cent. Patients were consistently receiving the appropriate nutritional interventions in practice and patients requiring specialist assessment were referred to the dietetic department on time. All at-risk patients were found to have been weighed on a weekly basis. These results suggest a positive impact on nutritional care and the nutritional screening process associated with the nutrition assistants.

The hospital also follows a protected mealtime protocol.
Environment

People with dementia can find hospital admission confusing and it can cause them agitation. This can lead to them staying in hospital longer and can have damaging effects on their physical and psychological health. Providing an environment that is easier to navigate for cognitively impaired patients can make it easier for people to settle in hospital, reducing stress and releasing time from hospital staff to provide care. There are also links to patient safety and improved health outcomes.

Mid Cheshire Hospital – environmental improvements

Mid Cheshire Hospitals NHS Foundation Trust has introduced changes to the hospital environment, to make it more accessible to those with cognitive impairments:

- **coloured privacy doors** to help patients orientate themselves to the ward environment
- **signs** are now suitable for the visually and cognitively impaired as they incorporate a photograph, a symbol and written words, in appropriate colours
- **easy-to-interpret menus and daily routines** utilising photographs and symbols
- **an activity lounge** that runs twice a week, led by the lead nurse for older people, and including social activities such as bingo, dominoes, music and memory boxes.

This service improvement has been developed at a relatively low cost. The local strategic health authority offered some funding and charitable donations were also collected.

The changes have already shown signs of improved outcomes, including:

- improved feedback from patients and carers; both patients with and without cognitive impairments have said how much easier it is to find their way around the wards
- reduced incontinence
- increased dignity for patients
- greater carer and patient engagement
- positive feedback from staff.

The trust is also awaiting audit results following the implementation of the dementia care guidelines and expect these to point to positive outcomes.

Changes to the hospital environment do not need to be expensive or complicated. Simple improvements could include a social area, signage, or easy-to-read information (for more examples see the case study below). These changes will lead to more dignity and privacy for patients.

It is important to involve patients and carers before making any change. Effective and empowered engagement will ensure that these changes lead to positive improvements.
Effective discharge

Dementia is a predictor of a higher probability of inappropriate or delayed discharge. The opportunities of improvement through better discharge are significant. Reviewing the process and auditing readmissions associated with dementia are an important part of ensuring high performance in this area. Coding of secondary dementia and improving the data available will need to improve to achieve this.

Patient groups often highlight how discharge can be stressful and confusing for the patient. This is especially true when the person with dementia is discharged to a different setting than the one where they were living before being admitted to hospital.9

The Department of Health has published a supplementary checklist to help discharge planning from hospital for people with dementia. Using this checklist together with the hospital’s discharge procedure can help to ensure people will receive quality care after they leave hospital.23

Leadership

There is a persuasive case for identifying a senior clinician within each trust to take the lead for quality improvement in dementia. This was strongly emphasised by the Public Accounts Committee and NAO. This role could include:

- being a champion for dementia at both the strategic and operational level
- developing a care pathway for people with dementia
- helping to improve the knowledge of dementia within the hospital
- liaising with teams internally and externally to promote dignity in all wards, increasing the involvement of carers and patients and building strong partnerships with other agencies, all of which can help in the discharge process.24

National leadership is supported by the recent appointment of the National Clinical Director for Dementia, Professor Alistair Burns.

Liaison teams

Liaison teams have proven to have a significant impact in the care that patients with dementia receive when they are in hospital. The NHS Confederation and the Mental Health Network published a briefing, Healthy mind, healthy body in 2009, showing how liaison with psychiatry teams can improve care, both for dementia sufferers and those with other mental health problems. The Public Accounts Committee’s report on dementia services9 called for liaison teams to be available in every hospital. We also showed how liaison teams could bring cost savings by reducing length of stay and re-attendances. The briefing shows examples of liaison teams around the country. It demonstrates that liaison services can:

- improve service user experience
- reduce emergency department waiting times
- enhance the knowledge and skills of hospital workers
- improve clinical outcomes
- decrease length of stay
- ensure patients receive adequate treatment while using fewer healthcare resources
- reduce readmissions and costs
- help improve staff skills.
Mental health liaison team in Leeds

The Older People’s Mental Health Strategic Development Board in Leeds (a cross-city all-agency group) reviewed the dementia care pathway in 2008. The results led to the introduction of:

- an expanded liaison service in the acute hospital trust
- a rapid response team in the community
- specialist short-term mental health home care
- intermediate care beds for people with dementia.

The programme was supported with £4.2 million from the Partnerships for Older People Projects (POPPs). The results show that, for people with dementia, over three years there was an average reduction in hospital length of stay of four days per admission. Apart from releasing bed time, there are indications that the service has led to other savings. However, the team has not been able to calculate these accurately, as there is currently no national tariff for mental health services.

The liaison team has played a major role in delivering the programme. The multi-disciplinary team is formed of psychiatrists, mental health nurses and administrators. They provide input into medical and surgical wards through specialist mental health assessments, direct clinical care and supervision, and support and education of hospital colleagues. Since its introduction care has become more patient-centred, and more patients have been diagnosed and signposted to appropriate services.

Involvement of patients and carers

Listening to patients and their carers and engaging with them in a meaningful way is key to treating patients with dignity and compassion. Apart from being involved in designing the individual care plan, patients and carers can be a helpful resource for the hospital if they are:

- developing a dementia care pathway: input from patients and carers will ensure the pathway works
- making improvements to the ward: patients and carers can help managers to design a ward with signage and colour-coding that is easier to navigate
- developing informative documents: patients and carers can ensure these are easy to read.

Moreover, carers can also be involved in the day-to-day care of the patient. For example, they may wish to help the patient to eat and drink. This will give a sense of continuity to the patient and help them to feel more relaxed.

Involving patients and carers is also at the heart of the Dignity in Care campaign.6

’Listening to patients and their carers and engaging with them in a meaningful way is key to treating patients with dignity and compassion.’
Conclusions

Older people are the biggest consumers of acute services. Although not all older people have dementia, the number with the condition is substantial, and a significant number of people under 60 years old also have dementia. Coping with being in hospital can be complex and stressful for people with dementia, and there are indications that hospitalisation can worsen their physical and mental health.

Taking into account the high number of people with dementia who use hospital services and the fact that this number is increasing rapidly, it makes sense for hospitals to re-think the way they provide services. Improving services for people with dementia can also lead to efficiencies for the hospital, although more evidence should be collected as hospitals improve services following the launch of the dementia strategy. Key candidates for efficiency savings include:

- early identification of dementia can lead to shorter stays
- shorter stays can help reduce hospital infections
- an appropriate care plan when leaving hospital can reduce the risk of readmission.

The dementia strategy is the first step in recognising the importance of the issue nationally and driving changes locally. The NHS Confederation welcomes the Department of Health’s aim to improve services for people with dementia and expects to see this effort continuing over the next years. There are, however, some barriers stopping NHS organisations from implementing the strategy more quickly. The main ones are listed below.

- While the strategy allocated an additional £60 million of additional baseline funding to PCTs, this is not ring-fenced and dementia is not a ‘national priority’ (as set out in the Operating Framework). PCTs have to decide how they focus on this area against all the other local and national priorities. While the NHS Confederation supports local prioritisation, lack of emphasis in national frameworks can make it more difficult to argue the case for dementia spending locally.
- The NHS needs more information on the cost-effectiveness of all the objectives in the dementia strategy.
- It will take time to close the knowledge gap about the needs of people with dementia.
- Savings achieved from improved quality and efficiency are not always to be re-invested in the same organisation that makes the savings. This makes it more challenging for managers to make a business case for improvement.
- There is a lack of quality measures of the care of people with dementia in acute settings. The NHS Information Centre database of quality indicators includes three indicators for dementia, but these are all focused on primary care.

Despite these barriers, acute trusts will continue to make improvements in care for people with dementia. The NHS Confederation therefore presents below suggested questions for boards, managers, commissioners and policy-makers to ask when considering their strategy in this area. We hope that they find this report helpful when developing national and local policies, plans, and business cases.

Improvements in dementia care could also be replicated in the community; key players will include PCTs, GPs and ambulance services. This report has shown how ambulance services can help to identify patients with dementia early. Other examples of care being considered for patients include setting up alternative care pathways between ambulance services and mental health providers that specifically provide dementia services. This supports the case for a whole-system approach to achieving the best outcomes for patients with dementia, and their carers.
Key questions for boards

There are a number of questions that hospital managers and NHS board members may want to consider when reviewing their dementia services:

- Do you know how many people with dementia are in the hospital and which wards they are in?
- Do you know how long people with dementia stay in hospital compared to people without dementia admitted with the same condition?
- Are there strong information-sharing protocols in place, so that other agencies can inform the hospital when a patient has dementia?
- What procedures are in place to ensure efficient identification of people with dementia?
- Is there a designated dementia lead?
- Is there a liaison team in the hospital covering dementia?
- What is the staff level of knowledge about dementia?
- Is there awareness training for staff?
- Does the hospital have systems in place to ensure nutritional needs are met?
- Are carers and patients involved in decisions about individual care plans?
- Are there opportunities to improve the discharge process?

Further information

For more information on issues covered in this report, or to respond to any of the issues raised, please contact Patricia Suarez, Senior Policy and Research Officer, at patricia.suarez@nhsconfed.org
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Acute awareness

Dementia currently affects over a half a million people in England alone; this number is set to rise considerably as more people live longer. Sixty thousand deaths a year are directly attributable to dementia, and the current cost to the NHS is estimated at £1.3 billion a year. Recent Government policy has reflected a growing awareness of the importance of dementia care, with the publication of the first national dementia strategy being followed by increased funding and the appointment of a national clinical director for dementia.

Despite these and other efforts aimed at improving dementia care, there is still considerable scope for improving services. This report looks at the key issues for NHS trusts in improving care for patients with dementia, the majority of whom will have been admitted for another condition.

Acute awareness: improving hospital care for people with dementia showcases the innovative work that NHS trusts and cross-agency partnerships are undertaking in this area to enhance patient care. It describes how significant improvements can be achieved in terms of both the quality and efficiency of patient care, and offers suggestions for policy developments to accelerate the pace of change.