

Executive summary

1 Summary

People with dementia over 65 years of age are currently using up to one quarter of hospital beds at any one time.

Much has been achieved in recent years in the NHS to drive down waiting lists and reduce delayed discharge for significant numbers of people. This result has required the hard work and dedication of significant numbers of hospital staff. Now that it has been possible to improve access to hospital care by increasing capacity and reducing waiting times, there is an opportunity to shift the focus to the quality of the care being provided.

Attention is increasingly focused on the quality of dementia care in an acute setting. This report finds that there is unacceptable variation in the quality of dementia care provided on general wards in hospitals across England, Wales and Northern Ireland. There are many examples of excellent local action, where the challenges of dementia are being recognised and addressed. However, there are also examples of mediocre or neglectful care.

People with dementia stay far longer in hospital than other people who go in for the same procedure. The longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and the individual's physical health; discharge to a care home becomes more likely and antipsychotic drugs are more likely to be used.

As well as the cost to the person with dementia, increased length of stay is placing financial pressure on the NHS.

It is clear from the evidence presented in this report that improving the experience of the large number of people with dementia in hospitals is key to improving the NHS overall and delivering the reform agenda.

- If people with dementia were supported to leave hospital one week earlier than they currently do, this report suggests that savings of hundreds of millions of pounds might be achievable across the system as a whole. The National Audit Office will be publishing a further report into dementia in late 2009 which should add evidence to support the case for change.

- Much of the large sums of money currently spent on dementia in hospitals could be more effectively invested in workforce capacity and development, and community services outside hospitals to drive up the quality of dementia care on the wards, improve efficiency and ensure that people with dementia only access acute care when appropriate.

2 Purpose of report

This report provides evidence from over 2,000 carers and nurses on the quality of dementia care provided on general wards in hospitals across England, Wales and Northern Ireland. This evidence is for commissioners, healthcare services providers as well as health and social care professionals to support the case for a specific focus on improving the care for people with dementia on a general hospital ward within the current policy context.

3 Methodology

Alzheimer's Society collected quantitative and qualitative evidence via a questionnaire from the following groups:

- Carers – 1,291 responses received
- Nursing staff – 657 responses received
- Nurse/ward managers – 479 responses received.

4 Key findings

4.1 Dementia care in hospitals – why must it be addressed?

- 97 % of nursing staff and nurse managers reported that they always or sometimes care for someone with dementia.
- 47 % of carer respondents said that being in hospital had a significant negative effect on the general physical health of the person with dementia, which wasn't a direct result of the medical condition.
- 54 % of carer respondents said that being in hospital had a significant negative effect on the symptoms of dementia, such as becoming more confused and less independent.
- Over a third of people with dementia who go into hospital from living in their own homes are discharged to a care home setting.
- 77 % of nurse managers and nursing staff said that antipsychotic drugs were used always or sometimes to treat people with dementia in the

hospital environment. Of those nurse managers and nursing staff who said that antipsychotics were used, up to a quarter thought that they were not appropriately prescribed to people with dementia.

- 86 % of nurse managers felt that people with dementia either always or sometimes have a longer stay in hospital than people without dementia admitted with the same medical condition.
- 49 % of carer respondents said that the hospital stay was overall longer than they expected it to be.
- The longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and physical health; discharge to a care home becomes more likely and antipsychotic drugs are more likely to be used.
- Additional financial pressure is being placed on the NHS by people with dementia staying in hospital longer than expected.
- This report finds that supporting people with dementia to leave hospital one week sooner than they currently do could result in savings of at least £80 million a year, from work in four condition areas identified in four Hospital Episode Statistics (HES) data codes. It would not be unreasonable to assume that there are savings to be made in care for people with dementia running into hundreds of millions of pounds, which could be more effectively reinvested.

4.2 What is going wrong? Evidence from people with dementia and nurses

- 77 % of carer respondents were dissatisfied with the overall quality of dementia care provided.
- 89 % of nursing staff respondents identified working with people with dementia as very or quite challenging.
- Key areas of dissatisfaction as identified by carer respondents were: nurses not recognising or understanding dementia; a lack of person-centred care; not being helped to eat and drink; a lack of opportunity for social interaction; not as much involvement in decision-making as wished for (for both the person with dementia and carer); and the person with dementia being treated with a lack of dignity and respect.
- Key areas of concern as identified by nursing staff respondents were: managing difficult/unpredictable behaviour; communicating; not having enough time to spend with patients and provide one-to-one care; wandering/keeping people on the ward and ensuring patient safety.
- Problems with the discharge process, including lack of access to additional support such as a physiotherapist, were also identified by carer and nurse respondents.

- There are similarities between the concerns of nurses and the unmet needs of people with dementia that carer respondents have identified. However, nurses do not focus as strongly on person-centred care as a key challenge or as a training need and the majority think that people with dementia are being treated with dignity and respect.
- Nurses are responsible for providing or supervising much of the day-to-day care of people with dementia. They can play a key role in improving dementia care by being supported to place more focus and prominence on person-centred care. Training that addresses the concerns of nurses within the context of person-centred care for people with dementia, and raises awareness of the unmet needs of people with dementia as identified by carers, is vital.

5 Recommendations

Recommendations for change are set out which identify some of the biggest opportunities to deliver on dementia in hospitals to create a more cost-effective system that provides good quality care to people with dementia and carers.

Ensuring implementation of the National Dementia Strategy for England (2009) by recognising the importance of the dementia challenge, prioritising the improvement of dementia care and fulfilling the recommendations of the Strategy is paramount to securing change. Commissioners will therefore need to focus attention on this to achieve urgent changes across the health and social care system as a whole. The forthcoming Wales Dementia Plan will also address care on a general ward and it is essential that it is addressed in a dementia plan for Northern Ireland. Priority must be given to developing and implementing these Plans.

Recommendation 1. The NHS as a whole and individual hospitals need to recognise that dementia is a significant, growing and costly problem for them, which lies at the heart of the agenda to drive efficiency and quality improvement.

Recommendation 2. Reduce the number of people with dementia being cared for in hospitals.

- 2.1 Commissioners need to work with partners to shift funding from inappropriate acute usage for people with dementia into alternative services provided in the community.
- 2.2 Shifting investment and reconfiguring services in the community will require better co-ordination with social care services and joint working with community partners.
- 2.3 An improved system of care will also require that people with dementia have much better access to intermediate care services.

Recommendation 3. Hospitals to identify a senior clinician to take the lead for quality improvement in dementia and for defining the care pathway.

Recommendation 4. Commission specialist liaison older people's mental health teams to facilitate the management and care of people with dementia in hospitals.

Recommendation 5. Ensure that there is an informed and effective acute care workforce in hospitals for people with dementia.

- 5.1 Hospitals need to look at staff capacity for delivering high quality dementia care. They will also need to prioritise workforce development budgets for dementia. These need to be a priority in the current financial context to help increase the capacity and throughput of the service by supporting people with dementia out of hospital as quickly as possible.
- 5.2 Pre-registration training should be improved in line with the requirements of the acute care workforce. The Nursing and Midwifery Council (NMC) consultation on pre-registration training is a vital opportunity to adapt the curricula and requirements to include as mandatory the core competencies required in dementia care. Alzheimer's Society will work with the NMC to inform their work.
- 5.3 To support recommendations 5.1 and 5.2, government departments need to work with all bodies involved in professional and vocational training and continuing professional development to reach agreement on the core competencies required in dementia care.

Recommendation 6. Reduce the use of antipsychotic drugs to treat people with dementia on a general ward.

- 6.1 In the National Dementia Strategy for England, the Department of Health committed to publishing a review of the inappropriate use of antipsychotic drugs for people with dementia across the health and care system. At the time of this report going to print, Alzheimer's Society is awaiting the findings and looks forward to working with relevant bodies to reduce the prescribing of the drugs. This work needs to take place across England, Wales and Northern Ireland.

Recommendation 7. Involve people with dementia, carers, family and friends in the care of people with dementia to improve person-centred care.

- 7.1 Having an individual care plan is essential for good quality care and it must be ensured that every person with dementia has one.
- 7.2 Carers and the person with dementia should feed information into planning as soon as the person with dementia is admitted to hospital in order to build up a profile of an individual's likes, dislikes and needs to ensure person-centred care.

- 7.3 Carers and people with dementia where possible, must be involved in day-to-day care and treatment decisions.

Recommendation 8. Make sure that people with dementia have enough to eat and drink.

- 8.1 The patient profile and individual care plan as discussed in recommendation 7 should be used to understand an individual's needs and preferences at mealtimes.
- 8.2 Nutritional screening must be carried out for all people with dementia as soon as they are admitted to a ward to ensure that those at nutritional risk are identified and appropriate actions implemented.
- 8.3 Carers, family and friends must always be allowed to assist at mealtimes if they wish.
- 8.4 Hospitals should encourage volunteers to support people with dementia at mealtimes.
- 8.5 In the long term, dementia-specific education is required to empower and inform hospital staff. This could incorporate tools such as Alzheimer's Society guide to catering for people with dementia (2009). The Dementia Services Development Centre, Stirling also has useful material, for example a video developed in 2002 to help staff encourage people with dementia to eat and drink well (Dementia Services Development Centre, 2002).

Recommendation 9. Begin to change the approach to care for people with dementia to one of dignity and respect.