Developing the culture of compassionate care: Creating a new vision for nurses, midwives and care givers

November 2012
Alzheimer’s Society welcomes the opportunity to comment on the vision outlined in Developing a Culture of Compassionate Care. There are 800,000 people with dementia in the UK.\(^1\) Two thirds of people in care homes have a form of dementia and a quarter of hospital beds are occupied by someone with dementia.\(^2\) This consultation response identifies some of the ways in which the quality of care received by these people with dementia could be improved.

- A stronger focus on person-centred care is essential to ensure that people with dementia receive good quality care in all settings.
- Sufficient time needs to be given to caring for people with dementia to allow for good communication.
- All staff should receive basic dementia awareness training with options for more specialist training as appropriate to their role.
- There needs to be a continued commitment to reduction in prescription of antipsychotic medicines for people with dementia.
- Senior leadership in hospitals to ensure that the needs of people with dementia are met.

1. Alzheimer’s Society
Alzheimer’s Society is the UK’s leading support services and research charity for people with dementia and those who care for them. It works across England, Wales and Northern Ireland. The Society provides information and support for people with all forms of dementia and those who care for them through its publications, dementia helplines and local services. It runs quality care services, funds research, advises professionals and campaigns for improved health and social care and greater public awareness and understanding of dementia.

2. Consultation Questions
Alzheimer’s Society has the following comments to make on the questions posed in the consultation.

2.1. Through our initial discussions with the professions, have we identified the right shared purpose for nurses, midwives and caregivers?
Alzheimer’s Society welcomes the shared purpose outlined in this document and the recognition that particular attention to providing good quality care for older people is necessary. However, the needs of people with dementia require specific consideration if they are to benefit from the ambition of providing high quality care for all. People with dementia make up a large proportion of those receiving care and their quality of life can be seriously impaired by poor care. Despite this, The National Audit of Dementia care in general hospitals identified that many hospitals were failing to meet basic

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\(^1\) Alzheimer’s Society (2007) *Dementia UK*
\(^2\) Alzheimer’s Society (2007) *Dementia UK*
standards in dementia care. 77% of carers responding to the Society’s Counting the Cost report stated they were dissatisfied with the overall quality of care provided to people with dementia in hospitals. Key reasons for dissatisfaction included: nurses not recognising or understanding dementia, lack of person-centred care, not being helped to eat and drink, inadequate social interaction opportunities, inadequate involvement in decision making and lack of dignity and respect.

A lack of understanding of dementia and the challenges that people with dementia sometimes have with communication can mean that the formal care received by people with dementia often fails to promote dignity and respect and can even breach fundamental human rights. 36% of family carers report that the person with dementia was not being treated with dignity and respect while in hospital.

People with dementia stay longer in hospital than other people admitted for the same reason and inadequate or poor care can deny people with dementia opportunities for a good quality of life and lead to higher overall care costs through early admissions to care. As the number of people with dementia continues to increase, it is essential that the NHS as a whole recognises that dementia is a significant and costly challenge that needs to be addressed.

Key commitments have been made on improving recognition and care of people with dementia in general hospitals through the Prime Minister’s Challenge and other recent initiatives. It is important that the ethos of this work is reflected in the new vision put forward in this consultation.

2.2. What do the six values and behaviours for the professions mean to you?

These six values are all essential when providing high-quality care for all people. However, there are specific aspects of these values which are particularly relevant when caring for people living with dementia.

Failure to appropriately communicate with the person with dementia can result in inappropriate decisions being made about their care and negative consequences for the person with dementia. It is important to allow sufficient time for the care and support of people with dementia since many will find that their communication skills are affected by the condition. Care-givers need to understand what dementia is and how it affects individuals in order to be competent in the care of people with dementia. But there is also a need for strategic leadership to make the shift from task-driven to person-centred care.

The finding from the National Audit’s ward observations is that care and communication is generally reactive and based on an organisationally set, task-driven routine rather than being person-focused, flexible and proactive.

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3 Healthcare Quality Improvement Partnership (2011) Report of the National Audit of Dementia Care in General Hospitals
4 Alzheimer’s Society (2009) Counting the Cost
5 Alzheimer’s Society (2009) Counting the Cost
Only 5 out of 105 wards reported practice which was person-centred more often than not. No one hospital submitted data where all the participating wards were clearly described as being person-centred.\(^7\) Although progress has been made with person-centred care, this vision of compassionate care will contribute to an area where further work is clearly needed.

The misinterpretation of attempts to communicate pain or distress is one of the key reasons for the over-prescription of antipsychotic medicine to people with dementia. While there are some situations in which such prescriptions may be appropriate, the majority of antipsychotic drugs are not licensed for use by people with dementia and they can them of their quality of life, with side effects including sedation, increased risks of falls and an estimated 1,800 avoidable deaths each year. In 2009 it was estimated that 180,000 people in England were prescribed these drugs, with two thirds of these being inappropriate prescriptions.\(^8\) Counting the Cost found that antipsychotic drugs are widely used to treat people with dementia in a hospital environment and a quarter of nurses surveyed felt that this use is inappropriate.\(^9\)

An audit of antipsychotic prescriptions for people with dementia has revealed that antipsychotic prescriptions for people with dementia have reduced by 52 per cent between 2008 and 2011.\(^10\) This progress has only been achieved through a substantial commitment across the sector to improve practices. But this remains an area where more commitment is necessary.

Another area in which these values are key to the care experiences of people living with dementia is in ensuring that they supported in making their own decisions about their care and day to day life for as long as possible. It is important to recognise that a diagnosis of dementia does not necessarily mean that individuals can no longer make decisions for themselves. People with dementia lose capacity over time and the rate at which a person’s condition deteriorates varies from individual to individual. With earlier diagnosis and new treatments, people are retaining capacity for longer. All practical steps must be taken to help an individual participate in decision-making. This requires competence, communication and commitment.

2.3. What steps are needed to embed the values and behaviours into every contact and all the care we deliver?
Embedding these values and behaviours into all the care delivered will require strong strategic leadership as well as high quality training for all front-line staff.

Strategic leadership is the essential prerequisite for good quality care. Alzheimer's Society argues that hospitals should:

- Identify a senior clinician to take the lead for quality improvement in dementia and for defining the care pathway.

\(^7\) Healthcare Quality Improvement Partnership (2011) Report of the National Audit of Dementia Care in General Hospitals
\(^8\) Sube Banerjee (2009) The use of antipsychotic medication for people with dementia
\(^10\) NHS Information Centre (2012) National Dementia & Antipsychotic Prescribing Audit
Commission specialist liaison older people’s mental health teams to facilitate the management and care of people with dementia. There is wide variation between participating hospitals on key dementia related standards, but with an overall low standard of performance. The majority of hospitals have yet to consider and implement measures which would address the impact of the hospital experience on people with dementia. The National Audit found that only 6% of hospitals had a care pathway in place for people with dementia, although a further 44% had one in development. It identified a lack of leadership at both the Trust/Board level and at hospital level in terms of identifying champions and identifying required resources. This needs to be improved in order to create the environment for good quality care for people with dementia.11

Despite the importance of a strategic approach, the National Audit casework studies demonstrate that there is little correlation between hospital policy and actual practice as indicated by casenotes. For example, the percentage of casenotes showing that a mental state assessment had been carried out was not significantly different between those hospitals that had a policy specifying the assessment and those that did not.12

In order to improve the experience of people with dementia all staff should receive basic dementia awareness training with options for more specialist training as appropriate to their role. 89% of hospital nursing staff report that they found working with people with dementia very or quite challenging. Many also responded that they felt they had received inadequate training on dementia: 54% nurses said they had not received any pre-registration training on dementia; 52% said they had not received any work-based development or learning opportunities in dementia care.13 Only 5% of hospitals have mandatory training in awareness of dementia for all staff, and 23% of hospitals have a training and knowledge framework or strategy identifying the necessary skill development in working with and caring for people with dementia.14

Alzheimer’s Society is pleased that training on cognitive impairment will now be mandatory for trainee nurses. However, it is important that training programme providers recognise the need for training on cognitive impairment to include specific focus on caring for people with dementia. There is also a need to provide learning opportunities for those already working in a care setting.

2.4. Will a focus by nurses, midwives and care-givers on the six priority areas we have identified deliver the vision and the shared purpose?

The provision of high quality care to people living with dementia requires a whole system approach. If these priority areas are successfully implemented

11 Healthcare Quality Improvement Partnership (2011) Report of the National Audit of Dementia Care in General Hospitals
12 Healthcare Quality Improvement Partnership (2011) Report of the National Audit of Dementia Care in General Hospitals
13 Alzheimer’s Society (2009) Counting the Cost
14 Healthcare Quality Improvement Partnership (2011) Report of the National Audit of Dementia Care in General Hospitals
then they could have a positive effect on the experiences of people with dementia. However, their successful implementation depends on staffing levels being sufficient.

Hospitals in particular can be very difficult places for people with dementia: 47% of family carers say 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 their medical condition; 54% of family carers say that being hospital has a significant negative effect on the symptoms of dementia, such as becoming more confused and less independent. In order to minimise the negative effect of hospital stays, three particular areas of emphasis are required: the skills of nursing staff, the physical environment of the hospital, and the length of hospital stay.

All staff need to have a good understanding of dementia, this includes auxiliary staff such as porters etc and not just nurses. Staff also need to be aware that the involvement of family carers is essential to the implementation of these six values. They are the best placed to maximise the well-being of people with dementia while they are in hospital and it is therefore very important that they are involved in care.

A hospital environment which helps people with dementia to orient themselves to their surroundings and to guide themselves around the ward can provide reassurance, help maintain independence and avert distress. The use of colour and clear signage as well as positioning of familiar items can improve the experience of people with dementia. Currently only 15% of wards use colour schemes to help people to find their way around. The use of space to provide breaks from the ward environment can also help to reduce the confusion of people with dementia. Designated rooms are currently only available in 47% of wards.

49% of family carers say that the hospital stay was overall longer than they expected it to be. The longer that 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. It is therefore important that their stay is kept as brief as possible. One way to do this is to commence planning for discharge as soon as they are admitted to hospital, but in about half of audited case notes this was found to have not happened despite their being no specified reason for this.

15 Alzheimer’s Society (2009) Counting the Cost
16 Healthcare Quality Improvement Partnership (2011) Report of the National Audit of Dementia Care in General Hospitals
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19 Healthcare Quality Improvement Partnership (2011) Report of the National Audit of Dementia Care in General Hospitals
2.5. What national and local initiatives are you aware of that support the six priority areas?

Alzheimer's Society is involved in a number of initiatives to improve care in hospitals which would support the six priority areas outlined in this vision. These initiatives are outlined below.

A tool called This is Me has been produced by Alzheimer's Society. This aims to improve care by helping hospital staff understand the individual needs of a person with dementia. It can be filled out and given to hospital staff when people with dementia go into hospital. It aims to provide a 'snapshot' of the person behind the dementia, giving hospital staff information such as the person's habits, hobbies, likes and dislikes. This should enable staff to treat each person as an individual, thereby reducing distress for the person with dementia and their carers and helping to prevent issues such as malnutrition and dehydration. This tool has been supported by the Royal College of Nurses and is very popular within hospitals.

In partnership with the Dementia Action Alliance, The NHS Institute has launched two calls to action which are relevant in this context: Right Prescription considers the use of antipsychotic drugs for people with dementia; and Right Care considers how hospitals can be made dementia friendly. The areas of improvement outlined by these initiatives are directly relevant to the vision of a culture of compassionate care.

Alzheimer's Society aim to improve knowledge, skills and understanding of dementia by providing effective support, high quality information, education and training. A recent partnership with CKHS combines a benchmarking tool with a programme of training which can help healthcare organisations to improve in the areas identified. The diagnostic assessment combines data analysis with an independent on-site review and expert consultancy support to create a powerful performance measurement and improvement tool. The training includes a range of workshops, including:

1.1 Dementia awareness for staff in acute settings
1.2 Caring for people with dementia in acute hospital settings
1.3 Meeting the complex needs of people living with dementia
  1.3.1 Communicating with people with dementia
  1.3.2 Behaviours that challenge
  1.3.3 End of life care for people with dementia.

2.6. How do we strengthen working between the health and care sector in these six priority areas?

People with dementia are particularly adversely affected by the lack of integration between the health and social care sectors. This section outlines some of the ways in which this impacts on people with dementia as well as suggesting ways in which the current situation could be improved.

Dementia is a complex condition combining features of chronic neurological disease, mental illness, physical frailty and communication problems.

20 More information about the action plans and signatories is available online.
Because of this complexity and the fact that people with dementia often move between care settings, they often receive formal care from a range of health and social care services. Effective coordination between community care, hospital care and care home across health, social care and housing is therefore essential if the needs of people with dementia are to be met.

The 2007 National Audit Office report on dementia care in England found services for people with dementia are often poorly coordinated and do not represent value for money. Only a quarter of respondents to Alzheimer's Society's 'Support. Stay. Save.' report said the services the person with dementia received worked well together, with over a fifth responding that they did not work well together.

Poor coordination between services is a significant barrier to people with dementia getting the support and care they need. It can inhibit people with dementia's access to care and support, limiting their choices in care and resulting in crisis admissions to hospitals and care homes. Lack of coordination of care contributes to people with dementia remaining in hospital for longer than expected. People with dementia stay in hospital far longer than other people admitted for the same reason, partly as a result of lack of coordination of care in the community and also within hospitals themselves.21

Effective coordination of services may be able to reduce emergency admissions into hospital or long term care, as evidence from studies such as the Department of Work and Pensions Link Age Plus pilots22 and the Partnership for Older People Projects have shown.23 Furthermore, coordinated formal care services means services may be more effective in responding to changes in circumstances.

Alzheimer's Society offers four suggestions for ways in which effective coordination of formal care can be ensured:

- Care plans for people with dementia should be holistic, covering health and social care services and based on involvement of the person with dementia, their carer and family and professionals. Care services should be based around this care plan, rather than organisational or services boundaries.
- Commissioning should be a joint and collaborative exercise between health and social care, based on local needs assessment and focused on quality. People with dementia and their carers should be involved in the commissioning process and in informing the design and delivery of services.
- Those not at a stage of needing formal care should be signposted to support services and should be informed of avenues for accessing formal care services.

23 Personal Social Sciences Research Unit (2010) The national evaluation of the Partnerships for Older People Projects
People with dementia should have access to dementia advisers and care coordinators to help guide them through the support and care system.

2.7. Are there any obstacles to delivering the vision and embedding the values and behaviours? What would you want to see in place to address these?
The main obstacles to delivering this vision are financial. Three quarters of care providers say that over the past 12 months the councils they work for have become more interested in securing a low price than a quality service. However, there is significant evidence that investment in early intervention and high quality care for people with dementia can actually reduce costs overall through prevention of emergency admittance to hospitals or care homes.

2.8. Are the terms ‘people we care for’ and ‘care-givers’ helpful to use in this context, or are there alternatives?
Whatever terms are used it is important to acknowledge that those providing formal care are not the only care-givers. It is important to recognise that family and friends of the people being cared for can play an important role and should be allowed to support the person in hospital, e.g. at meal times.

Alzheimer's Society would very much welcome further discussions with the Commissioning Board on all aspects of improving care for people with dementia, but especially on commissioning practices.

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24 United Kingdom Home Care Association Commissioning Survey (2012)