Delivering Dignity
Securing dignity in care for older people in hospitals and care homes: A report for consultation

29 March 2012
1. About 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.

Alzheimer’s Society responded to the initial Commission consultation and Andrew Chidgey, Director of External Affairs presented oral evidence.

2. Summary

People with dementia are among those most affected by poor quality care. They currently stay in hospital longer than necessary and can be deprived of a good quality of life in care homes. Alzheimer’s Society welcomes the recommendations in this interim report. The Society is particularly pleased that several recommendations make specific reference to people with dementia; however, many of the more general recommendations also go a long way in addressing concerns from the Society.

However, Alzheimer’s Society has identified key areas that the report does not adequately address.

In particular, the report must reflect the government commitment to go further and faster on dementia with the launch of the Prime Minister’s challenge1. The aim of this challenge is to deliver major improvements in dementia care and research in England by 2015 and has three workstreams:

- Driving improvements in health and social care
- Creating dementia friendly communities
- Better research

Given the commitment at the highest level to radically improve dementia care, the recommendations in the Delivering Dignity report must support and address the ambition.

The report also fails to recognise the crisis in funding for social care. There can be no sustainable NHS without reform of social care. Inadequate social care funding has an inevitable financial impact on the NHS. When people do not get the help they need it leads to more emergency hospital admissions,

delayed discharges and longer waiting times.\textsuperscript{2} Alzheimer’s Society’s report Counting the cost found 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.\textsuperscript{3} The Society is concerned that more people with dementia are left unsupported for longer. In 2011, before more councils raised their eligibility criteria, the ‘Support. Stay. Save’\textsuperscript{4} report found that 50% of people with dementia living in their own homes were not getting enough support and care to meet their needs. Alzheimer’s Society calls on the Commission to support the recommendations in the Dilnot report, as well as a sustainable, ring-fenced, long-term care and support funding settlement to ensure fairness and quality of care and sustainability of the NHS. This issue must be acknowledged throughout the report and addressed in the recommendations.

More detailed recommendations are also needed around:

- Improving the identification of people with dementia;
- Ensuring high quality home care services;
- Improving coordination of care;
- Enabling professionals to provide good quality dementia care.

3. The health and social care challenge of dementia

There are 800,000 people with dementia in the UK. This is forecast to increase to over a million by 2025.\textsuperscript{5} One in three people over 65 will end their lives with dementia.\textsuperscript{6}

Dementia is a complex condition and people will require a broad package of care from a range of agencies across health and social care. Dementia is a progressive condition, which means that people with dementia and their carers are coping with a changing pattern of abilities over time. As the disease progresses, people with dementia will need more support. Eventually, they will need help with all their daily activities. Alzheimer’s Society hears reports through its services and helpline of people with dementia not being treated with dignity when being cared for in hospitals and care homes.

People with dementia are core users of health and social care services:

- Two thirds of people with dementia live in the community. Some will be in the early stages of the condition, some will be in the later stages or

\textsuperscript{3} Alzheimer’s Society (2009) Counting the cost-Caring for people with dementia on hospital wards. Alzheimer’s Society: London
\textsuperscript{5} Alzheimer’s Society (2007, updated to reflect 2012 figures) Dementia UK, a report to the Alzheimer’s Society by King’s College London and the London School of Economics. Alzheimer’s Society: London.
at end of life.7

- One third of people with dementia live in care homes. Two thirds of care home residents will have a form of dementia.8
- Up to one quarter of hospital beds are occupied by people with dementia aged over 65 years at any one time.9

The financial cost of dementia in the UK is currently £23 billion each year.10 By 2018 dementia will cost the UK at least £27 billion a year.11 Yet this is not being spent effectively. The National Audit Office’s report in 2007 found that health and social care spending on dementia was late in the condition and was often not contributing to good outcomes for people with dementia.12

In its report, Dementia 2012: A national challenge, Alzheimer’s Society revealed that 17% of people said they are not living well with dementia and 14% felt they were not able to make choices about their day to day life. In addition, 34% of people with dementia who responded to the survey said that the services they receive only sometimes or do not help them to live as independently as they need to. This report recommends that the government implements the recommendations from the Dilnot Commission, but also calls for extra funding for social care. The report highlights the need for a shift in resources from acute and residential care and into community services.

More recently, the All-Party Parliamentary Group on Dementia found that there is considerable potential to increase the cost-effectiveness of dementia services, while at the same time improving outcomes for people with dementia.13

The government’s commitments to drive improvements in health and social care through the Prime Minister’s challenge on dementia are intended to go further and faster in improving dementia care. In addition, Alzheimer’s Society recognises the priority which dementia has been given in the Operating Framework, the Outcomes Framework and the recent CQUIN focusing on dementia. However, these commitments must be followed through in order to ensure that real change occurs for people with dementia and the Commission has a vital role to play in making this happen.

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1 Alzheimer’s Society (2007 ) Dementia UK, a report to the Alzheimer’s Society by King’s College London and the London School of Economics. Alzheimer’s Society: London.
4 Alzheimer’s Society (2007, updated to reflect 2012 figures) Dementia UK, a report to the Alzheimer’s Society by King’s College London and the London School of Economics. Alzheimer’s Society: London.
4. Consultation questions

1. Is the Commission making the right recommendations? If not, how should the recommendations change?

1.1 Key recommendations for hospitals
Alzheimer’s Society highlighted in its oral and written evidence that there is a lack of person-centred care in hospitals and people with dementia are seldom involved in decisions about their care. The needs and preferences of an individual and their carers must be recorded when that person is admitted to hospital. The recommendations, which place responsibility on staff to put the patient at the centre of their care, as well as the recommendations to involve families and carers in a person’s care, are a positive step towards a culture shift.

Staff training and the personal attributes of staff are vital to ensure that staff feel confident in providing high quality and dignified care. Alzheimer’s Society has repeatedly asked for specialist dementia training for health and social care staff. The Society especially welcomes the recommendation to set a benchmark in hospitals for 10% of staff to be dementia experts, 50% to be dementia trained and 100% dementia aware.

The Society also recognises the need for strong leadership and welcomes the recommendation that ward sisters are accountable for the care, dignity and wellbeing of patients on their ward.

1.2 Key recommendations for care homes
Evidence from Alzheimer’s Society highlights that residents with dementia in care homes have few opportunities to participate in activities, to interact with staff and other residents or to access space and gardens. Therefore, the Society welcomes the recommendation that care homes should create an environment which is happy, varied, stimulating, fulfilling and dignified. Alzheimer’s Society wants the provision of meaningful activities for people with dementia to be included in care home inspections.

Alzheimer’s Society has called for the status and role of those working in the care sector to be elevated so they feel valued and supported in their work. Training plays an important part in this and the establishment of a Care Quality Forum would be beneficial in achieving this aim.

The Society is also calling for lay involvement in regulation to improve quality and prevent abuse in care homes should be considered as having an important role to play, for example by adopting a model of Independent Monitoring Boards used in the prison system.
1.3 Further recommendations to consider

1.3.1 Increase funding for social care
Quality care is essential to prevent emergency admissions to hospitals which are costly. Alzheimer’s Society calls on the Commission to support the recommendations in the Dilnot report, as well as a sustainable, ring-fenced, long-term care and support funding settlement to ensure fairness and quality of care and sustainability of the NHS.

1.3.2 Improving the identification of dementia
Alzheimer’s Society supports the recommendation that hospitals provide older people with a geriatric assessment when they are admitted. Nevertheless, the Society urges that dementia must be a significant part of this assessment. The All-Party Parliamentary Group on Dementia\textsuperscript{14} found that a diagnosis of dementia is not seen as a priority in hospitals and mental health screening of older patients who appear confused is not routine. The recent CQUIN on dementia incentivises hospitals to identify dementia in patients who are admitted to hospital by asking a single question designed to spot symptoms of dementia. The Prime Minister has committed £54 billion to be made available through the dementia CQUIN to hospitals for offering dementia risk assessments to 90% of over-75s admitted as emergencies to hospital.

Significant improvements could also be made in the accurate recording of dementia diagnosis, ensuring that patients who have dementia have it correctly coded in their medical notes. This would help not only in ensuring the appropriate care for the person while they are in hospital, but also in highlighting the number of people in hospital with dementia at any one time.

Recognising dementia is important as it ensures that the patient’s care pathway is clear and they receive appropriate treatment. A lack of diagnosis, or lack of knowledge of a diagnosis, prevents adequate discharge planning and can result in longer stays in hospital.

1.3.3 Ensuring high quality home care services
Alzheimer’s Society is calling for a shift in resources away from hospital care and into the community. The All-Party Parliamentary Group on Dementia\textsuperscript{15} found that hospital settings were unsuitable for a person with dementia, nor the most cost-effective way to provide care. The acute clinical setting can be disruptive for people with dementia and have a negative impact on their condition. Good quality community services not only support quality of life, reduce hospital admissions and delay entry into residential care, but they are also more cost-effective. Community services can support people with dementia who live alone and also provide essential help to carers. Alzheimer’s Society believes that the Commission should also call for measures which address the shortfall in social care funding, including transferring resources from the NHS where appropriate. It should also call for

\textsuperscript{14} ibid
\textsuperscript{15} ibid
social care funding to local authorities to be ring-fenced to ensure that it is used for social care and not for other competing local priorities.

**1.3.4 Improve coordination of care**

People with dementia receive support from a range of services across health and social care at any one time. Therefore, the system needs to be considered as a whole. Joint working, planning and commissioning among the range of services involved in supporting people with dementia is vital. The All-Party Parliamentary Group on Dementia\(^\text{16}\) recommended an increased use of key workers to act as a single point of contact and co-ordinator of care, as well as improved sharing of information and data between sectors. Alzheimer’s Society believes that the Commission should recommend a similar system to encourage joint working, planning and commissioning.

**1.3.5 Enable staff to provide good quality care**

Alzheimer’s Society recognises the recommendations from the Commission, which will support the workforce in providing dignified care to older people. With an emphasis on personalisation, care homes should provide personalised care and promote quality of life for residents that is based on their experiences and aspirations. Nevertheless, the Society is concerned that the recommendations do not explain how these will be achieved. The Society calls for the Commission to make recommendations on:

- Ensuring that the regulatory system is robust and inspections prioritise the experiences of people with dementia;
- Providing suitable training to staff working in all care settings;
- Sharing good practice across all bodies;
- Working with organisations to achieve their aims.

Volunteers can also play an important role in improving the quality of care for older people. According to a report as part of the Connected Communities project, volunteering, peer support and befriending all have a role to play in preventative and support services.\(^\text{17}\)

2. Are you aware of a particular tool, set of guidance or example of care that the Commission should highlight to help spread existing good practice?

**2.1 Prime Minister’s challenge on dementia\(^\text{18}\)**

The aim of this challenge is to deliver major improvements in dementia care and research in England by 2015. The challenge has three workstreams, which position dementia as a challenge to society. One goal is to drive improvements in health and social care. Included in this aim are commitments to improve the quality of care people receive, providing better support for carers and piloting dementia clinical networks to share expertise.

\(^{16}\) ibid

\(^{17}\) Morris D and Gilchrist A (2011) *Communities connected: Inclusion, participation and common purpose*, RSA, London

amongst clinicians. From April 2013 there will be quantified, local ambitions for diagnosis rates across the country, underpinned by robust and affordable local plans. The Prime Minister has committed £54 billion to be made available through the dementia CQUIN to hospitals for offering dementia risk assessments to 90% of over-75s admitted as emergencies to hospital. This commitment from government will go further to change the experience of care for people living with dementia in all care settings.

2.2 Improving the identification of dementia
Coordinated or integrated services would ensure that people with dementia in the community are identified on admission to hospital. In the Isle of Wight, general surgery and anaesthetic departments have worked to carry out screening for dementia before patients are admitted to hospital. This means the person can receive targeted interventions and allows for better discharge planning. The Isle of Wight NHS suggests that all trusts should identify a lead clinician in the anaesthetic department to be responsible such work.

2.3 High quality home care services
In Waveney, Suffolk, the county council and local PCT commissions a flexible domiciliary care service for people with dementia at times of crisis. This short-term service allows people to stabilise situations and for an assessment as to their ongoing needs. In 18 months it worked with 110 people and avoided 46 hospital admissions and 16 placements into residential care.

2.4 Coordinated care
Dementia advisers provide a point of contact for people with dementia and their carers. They provide information and advice about dementia and help on an ongoing basis to signpost people with dementia and carers to additional help and support.

Barnsley Dementia Service have piloted a ‘care navigators’ role to guide the person and the carer through their journey with dementia. The role of the care navigator is to provide a central point of contact for the person and their carer in accessing health and social care services. The impact of this service has reduced isolation for people with dementia, but also reduced admissions to dementia assessment wards by 20% from the two GP practices.

3. What would you like to see included in the action plan?
Clinical Commissioning Groups will play an important role in delivering good quality care for people with dementia. Therefore, Alzheimer’s Society makes the following recommendations.

- Helping clinical commissioning groups to commission care that is coordinated.

Older people, in particular people with dementia, access a wide range of services across health and social care. Therefore, a coordinated approach to service provision is vital to ensure smooth transition between services.
• Helping clinical commissioning groups to shift resources from acute care and into the community.

Good quality community services support quality of life, reduce hospital admissions and delay entry into residential care.

Alzheimer’s Society is happy to work with the Commission in its future work.

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