Alzheimer’s Society

HSJ Commission on Hospital Care for Frail Older People
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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 What is happening now in care for the frail elderly in your organisation and health economy?

There are currently 800,000 people with dementia in the UK and this is set to over a million people with dementia by 2021. Dementia is and will continue to be one of the major challenges for the health and social care sector. Current pressure alone is unsustainable with up to one quarter of hospital beds being occupied by people with dementia aged over 65 years at any one time\(^1\) and 80% of care home residents having a form of dementia or severe memory loss.\(^2\)

Alzheimer’s Society’s Counting the Cost\(^3\), Support. Stay. Save.\(^4\) and Low expectations\(^5\) reports outline variation and failings in care and support of people with dementia across care settings. Furthermore, the Society’s Dementia 2012\(^6\), 2013\(^7\) and Building dementia friendly communities\(^8\) reports indicate many people with dementia are unable to live the quality of life they want and that more action is needed across communities to respond to the challenge of dementia.

Dementia is often under diagnosed or diagnosed late which means that people living with the condition do not have access to the right information, services and support. Less than half of people with dementia living in the UK ever receive a diagnosis and current rates vary from as low as 35% in Southwest England, to over 70% in parts of Scotland and Northern Ireland. People also face long waits obtaining a diagnosis, with some people waiting up to a year to access a memory assessment. Commissioning of services, including post diagnostic support, is also highly variable across the country.

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5 Ibid.
Early support in the home can enhance quality of life for people living with dementia reducing avoidable admissions. Yet the homecare sector faces major challenges around commissioning, funding, and pay and conditions. This failure to diagnosis early and provide effective community solutions for people with dementia then leads to additional pressure onto acute care.

The National audit of dementia in hospitals shows unacceptable variation in the quality of care that people with dementia receive with poor governance, patchy staff training on dementia and limited involvement of carers having been raised as issues in the hospital setting9. Furthermore, in its 2012/13 State of health and care report and thematic review10, CQC find that people with dementia continue to experience poor care in hospitals, stay longer in hospital and are more likely to be readmitted. Specifically, deaths in hospital among those with dementia were over a third higher than people with similar conditions. Among people living in care homes, hospital admissions for avoidable conditions are 30% higher for people with dementia compared to those without dementia.

Significant variation in the level of awareness of dementia and training provided amongst health and social care professionals is also problematic. Training in dementia awareness is critical for all professionals, and particular focus is needed on GP training.

3 What needs to change to improve care for this important section of the population? What errors or bad practice should be avoided?

Despite significant political attention over the last two years, ensuring a timely diagnosis for people with dementia remains a contentious issue. The evidence shows us that a timely diagnosis supports people with dementia to access treatments earlier on, to plan and make decisions about their care, and importantly to retain their independence and support people to live well with the condition.

A focusing on preventative and early adjustments in partnership with health and social care colleagues could maximise the potential for savings, enhanced wellbeing whilst also reducing avoidable or early admissions into hospital or care homes. Given that UKHCA estimate 60% of users of homecare have dementia, all staff need training on understanding dementia and delivering good quality dementia care, as well as with other practical elements of care. Staff without sufficient understanding of dementia may be unable to recognise pain or distress and may inappropriately respond to people with dementia’s needs11.

Alzheimer’s Society believes significant reform is needed in the system of funding social care to ensure a fairer system, sharing the costs of care more widely beyond just those who are unfortunate enough to need care. Alongside a more equitable social care system, more money has to be invested in social

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care to ensure people can access high quality services when they need to, rather than only in crisis.

Alzheimer’s Society is concerned, that without amendment, elements of the Care Bill will not support people with dementia living independently for longer. In particular, it is proposed that local authorities assessing eligibility for social care will set the threshold equivalent to FACS ‘substantial’. This will mean people who cannot carry out basic personal care tasks or maintain important family relationships will be ineligible for support from the state. This contradicts the wellbeing and prevention principles of the Care Bill.

Immediate changes are needed in hospitals. Over a third of hospitals participating in the national audit do not include dementia awareness in induction programmes. Basic awareness training in dementia should be provided to all staff, and induction programmes for new staff should include dementia awareness. Training must be extended to include support staff as their interactions with people with dementia also affect the experience of care received.

The national audits also demonstrate the need for ensuring that, while in hospital, care pathways are in place for people with dementia. Only 36% of hospitals had a fully developed care pathway in place. Acute hospital trusts should appoint a senior dementia lead who is responsible for overseeing dementia training and advising colleagues on best practice. It is also important that Executive Boards play an active role in monitoring the hospitals performance help ensure that concerns are promptly addressed. Less than half of participating hospitals Boards are regularly reviewing readmissions, delayed discharges and in-hospital falls of people with dementia12. There is significant potential for hospitals to play a role in prevention and supported discharge. Acute hospital trusts should also commit to becoming dementia friendly and join the Right Care call to action (see question below).

Ultimately, Alzheimer’s Society believes the government should aim to reduce care costs by reducing the level of need throughout the population by the provision of preventive services and meeting the needs of people in the earlier in stages. This must be done to reduce the current pressures on the hospital system.

4 What examples of imitable and scalable good practice in care for the frail elderly have you used or observed?

Alzheimer’s Society is a leading provider of Dementia Adviser services. This service provides people with dementia with a named contact throughout their journey with dementia. The main aims of the service are to provide a quality information and signposting service which is tailored to individual need.

An evaluation of Dementia Advisers pilot in Worcestershire (La Fontaine et al, 2011) that people living with dementia experienced greater confidence in the availability of support, the opportunity to plan for the future including considering financial and care issues, information about local and county wide services and emotional support. The experience from organisations was also

positive with participants noting increased joined up working and partnership working with services and agencies.

In hospital examples of good practice include the Dementia Action Alliance’s call to action The Right Care: creating dementia friendly hospitals. Launched in 2012, there are now 143 acute trusts that have committed to becoming dementia friendly. To support them in fulfilling their commitment the D-Kit was produced, a practical guide on steps to take to become more dementia friendly, and a webinar to link hospital staff with experts in their field. All hospitals should commit to becoming dementia-friendly.

To assist people with dementia to live well with the condition, Alzheimer’s Society has been leading, with its partners, in the development of creating dementia-friendly communities. Dementia-friendly communities are places where people with dementia feel confident that they can contribute and participate in activities which are meaningful to them. We encourage all health and social care organisations and communities, to be part of the dementia-friendly communities movement. Local Dementia action alliances bring together diverse stakeholders to take forward practical actions in their local area. The NHS and social care providers have a critical role to play in ensuring that health and social care is integrated into the community.

Information and advice for people with dementia is an essential component of enabling choice and providing the best care. Lack of information and support for people with dementia, particularly immediately after diagnosis, is a frequent complaint (All-Party Parliamentary Group on Dementia, 2012). The Our Health website, developed in south-west England offers a comprehensive local service directory, along with performance indicators allowing comparisons between areas. This should be made available across England.

For further information:
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