

# Alzheimer's Society Response

National Assembly for Wales' Health and  
Social Care Committee  
Inquiry into the work of the Healthcare  
Inspectorate of Wales

20 September 2013

Consultation Response

## **1. Alzheimer's Society**

1.1 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. Background to dementia**

2.1 There are 44,598 people with dementia living in Wales today.<sup>1</sup> People with dementia are core users of health and social care services. Up to one quarter of hospital beds are occupied by a person with dementia aged over 65 at any one time<sup>2</sup> and at least 80% of people in care homes have dementia or significant memory loss.<sup>3</sup> Further to this, two-thirds of people with dementia live in the community<sup>4</sup> and the remaining third live in care homes.<sup>5</sup>

2.2 A robust system of regulation is needed to ensure that service users are protected from poor treatment and abuse and harm, and are provided with care that is safe and promotes their dignity. Impairments in capacity caused by dementia can make people with dementia more vulnerable to poor treatment and less able to make a complaint when something does go wrong. It is vital that there is swift action to identify and act on these failures to ensure that poor quality care is eliminated.

## **What people with dementia should expect from the Healthcare Inspectorate Wales**

### **3. A regulatory system with sufficient resource and powers to drive up quality**

3.1 HIW will not be able to drive improvements in quality unless they have sufficient resources and powers to do so. Inspection is a vital part of understanding the care provided to people with dementia and must be an integral part of any review system. It is clear that if HIW are to focus on quality improvement across the healthcare sector, as opposed to enforcing actions against the worst providers, HIW must have additional resources to enable them to deliver change.

<sup>1</sup> Alzheimer's Society (2012) <http://www.alzheimers.org.uk/infographic>

<sup>2</sup> Alzheimer's Society (2009), Counting the Cost: Caring for people with dementia on hospital wards, Alzheimer's Society, London

<sup>3</sup> Alzheimer's Society (2013), Low Expectations: Attitudes on choice, care and community for people with dementia in care homes, Alzheimer's Society, London.

<sup>4</sup> Alzheimer's Society (2007), Dementia UK, Alzheimer's Society, London

<sup>5</sup> *ibid*

## **4. An effective and responsive system**

4.1 Alzheimer's Society believes that a focus on adherence to essential or minimum standards does not do enough to promote high quality or personalised care. The growing number of people with dementia, the seriousness of the condition, the cost it imposes and the widespread poor standards of care mean that there is a need for HIW to particularly focus on improving the quality of dementia care. Standards must be sufficiently robust that they promote and incentivise high quality dementia care, rather than meeting minimum standards.

4.2 The need to support quality care for people with dementia must be a priority for HIW. Yet there is continuing evidence of a need for significant improvements in hospital ward environments, staff training and the overall approach to care delivery for patients with dementia (Royal College of Psychiatrists, 2011; Older People's Commissioner for Wales, 2011; Alzheimer's Society, 2009).

4.3 In particular, performance in the 2011 and 2012 National audit of dementia in hospitals demonstrates the clear need for improvements in quality, care and regulation of hospitals in Wales.

4.4 In 2012, 17 hospitals in Wales participated in the audit. Some of the more alarming findings indicated that only a minority of Executive Boards are regularly reviewing information on readmission rates, delayed discharges, and in-hospital falls relating to people with dementia. This is unacceptable and represented little change from the findings in 2011. Further to this, important elements of mental health assessment are not routinely being carried out.

4.5 Only 65% of hospitals have a training strategy identifying necessary skill development for working with people with dementia. Just over a third of hospitals include dementia awareness in their staff induction programmes.

4.6 These findings demonstrate significant shortcomings in the provision of care and regulation of care in Welsh hospitals. It is unacceptable that these findings have been allowed to repeat themselves over the course of the two audits that have been conducted.

4.7 Alzheimer's Society welcomes HIW focus on dignity and respect 'spot checks' but to address these audit findings there is a clear case for greater references to the care of people with dementia throughout survey and observational inspection tools. Alzheimer's Society considers it essential that dementia training be mandatory for all hospital staff, across health and support roles.

## **5. Transparency**

5.1 Public information about the quality of health and social care services is fundamental for people to make informed choices about their care and to have confidence in the care system. People with dementia and their carers

often say they find it difficult to access such information. HIW has a key role to play in publishing information about the regulation and quality of services, including inspection reports in a user-friendly way. This information must be made easily accessible and available in a range of formats. This transparency would help to build public confidence in care services and the ability of HIW to ensure that services are of a high standard.

5.2 In particular, the public need more detailed information to enable them to make informed choices about health services. At the current time there is a lack of indicators of excellence or good practice, other than compliance with minimum standards. This does not allow a service user to understand the differences between the quality of care provided by different services, and therefore does not support informed choice. Alzheimer's Society believes that the HIW should consider new ways of providing public ratings.

## **6. Regular inspection**

6.1 Inspection is a vital part of understanding the care provided to people with dementia. It is vital that inspectors use techniques such as the SOFI observational process, so that the real-life experiences of people with dementia can be understood. The EHRC 2012 human rights review highlighted that better inspection of all care settings is needed to ensure that people who use health and social care services are not subjected to inhuman or degrading treatment (Article 3 of the Human Rights Act). Alzheimer's Society believes that inspection must be an integral and frequent part of any review system. This must include unannounced inspections.

6.2 Given the number of people with dementia who are accessing health and social care services across a range of settings, it is vital that inspectors and assessors carrying out inspections have an understanding of dementia and other key issues such as the Mental Capacity Act. Training in these areas must be a priority for all inspectors and assessors and such training should involve people with dementia and their families themselves.

6.3 Further to this, people who use services are the experts in how well a service addresses their needs and their feedback must be at the heart of any assessment or inspection of services. HIW must empower and encourage service users to feed back information about quality of services and should do so in an inclusive way through a variety of media, either directly to the regulators or via independent bodies.

## **7. Effective and robust enforcement**

7.1 When prescribed standards are not met, there must also be rapid responses to prevent harm and to ensure public faith in the regulatory system. By the time that inspectors have detected problems poor practice may have already become established, so it is vital that there is quick action to address this, and minimise the harm to recipients of care services and give support to services to make improvements. HIW must have the capacity and resources

to intervene earlier and to report to the public on enforcement actions, as this is integral to building faith in the regulatory system.

7.2 The Society would welcome the opportunity for ongoing dialogue with HIW and look forward to outputs of this review. Unfortunately, at this time we are unable to provide oral evidence.

Yours sincerely,

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