

Alzheimer's Society

Health and Social Care Committee

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Inquiry into residential care for older people – Evidence from the Alzheimer's Society

National Assembly for Wales
Inquiry into residential care for
older people
16 December 2011

Inquiry submission

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.

2. About dementia

There are over 42,000 people with dementia in Wales and this is forecast to increase to 56,000 by 2021.¹ There are currently 750,000 people with dementia living in the UK, over one-third of these people live in residential care.² Two-thirds of people in residential care services are living with dementia. The role of care homes has now become the provision of late stage dementia care and the primary task of the care home sector is providing good quality care to people living with dementia. On average each council in Wales spends 37% of their budgets on residential care for older people.³

Dementia currently costs the UK £20 billion per annum. This is an average of £25,472 per person with late onset dementia. By 2018 dementia will cost the UK £27 billion per annum if nothing is done to improve the cost-effectiveness of dementia services.⁴ The majority of the costs of dementia care come from institutional care, such as residential care and hospital care.

3. Policy context

In Wales, the Health Minister has identified dementia as an area for action. The Welsh Assembly Government has launched a National Dementia Vision for Wales and published four Dementia Action Plans, which includes objectives to improve the quality of general hospital care for people with dementia, reduce their length of stay in hospital and to develop more closely integrated services.

In the past, services for people with dementia in Wales have often been inadequate and poorly funded. A decade-long review of social services in Wales found gaps in the provision of services for people with dementia, from intensive specialist care through to day care and respite.⁵ The availability of

¹ Tesco, Alzheimer's Society and Alzheimer's Scotland (2011) Mapping the Dementia Gap – study produced by Tesco, Alzheimer's Society and Alzheimer's Scotland

² Alzheimer's Society (2007) Dementia UK, a report to the Alzheimer's Society by King's College London and the London School of Economics

³ SSIA, (2011), Better Support at Lower Cost: Improving efficiency and effectiveness in services for older people in Wales

⁴ Alzheimer's Society (2007) Dementia UK, a report to the Alzheimer's Society by King's College London and the London School of Economics

⁵ Care and Social Services Inspectorate Wales and the Wales Audit Office (2009) Reviewing

services in the community is vital to prevent inappropriate admissions to hospitals and care homes. Better coordination of care, greater rates of diagnosis and earlier intervention are essential to improving the quality of life of people with dementia in Wales. There is much that can be done to improve dementia care, as laid out in the Dementia Action Plans. Dementia is a public policy priority and the implementation of this guidance must be fully integrated with work to improve dementia care.

The framework for action, 'Sustainable Social Services for Wales', takes account of the fact that for some people a care home is the right answer, but care and support services must work within a proactive model. This framework also recognises the challenges in providing services to an increasing number of people with dementia.

The forthcoming Social Services Bill will need to meet the needs of people with dementia and their carers or it will fail a core group of service users.

4. The process by which people with dementia enter residential care

Often people with dementia enter residential care as a result of insufficient support to remain independent in their own home. The importance of the support that carers provide is demonstrated by research which found living with a carer means that people with dementia are 20 times less likely to enter a care home.⁶ However, good quality community services are also important in providing care as they can delay entry into residential care. Inadequate care services in the home mean that a person with dementia will often enter a care home at a time of crisis.

Alzheimer's Society Home from Home (2008) report found that a significant number of carers said that it became clear the care home could not meet the individuals' needs soon after admission. This highlights the need for thorough pre-admission assessment to ensure the place of discharge can meet the individuals' needs. This can be neglected, especially when there is pressure to find a care home place quickly for that individual.

Delayed transfers of care from hospitals often mean people with dementia enter residential care. The National Audit Office (2007) has highlighted that whilst there has been significant progress in reducing the number of older patients whose discharge from hospital is delayed, people with dementia are estimated to constitute one half of people who remain in hospital unnecessarily.⁷ The longer people with dementia are in hospital, the worse the effect on their symptoms of the dementia and the individual's physical health and discharge to a care home becomes more likely.⁸ Over a third of

Social Services in Wales 1998-2008. Cardiff.

⁶ Banerjee S, Murray J et al, (2003) Predictors of institutionalisation in older people with dementia

⁷ National Audit Office (2007). Improving services and support for people with dementia. National Audit Office: London.

⁸ Alzheimer's Society (2009) Counting the cost: caring for people with dementia on hospital wards. Alzheimer's Society: London.

people with dementia who go into hospital from their own homes are discharged to a care home setting.⁹

5. Availability of alternative community-based services

The SSIA report, 'Better Support at Lower Cost', states that some councils are beginning to look at more community-based services for people with dementia and some councils include dementia care as part of their reablement services helping people manage their conditions. One or two councils have established specialist dementia domiciliary care teams that are specifically trained to help people with the condition manage at home. The statistics show that some councils support around 10% of older people to live in the community, whereas others support less than 6%. This shows that the availability of alternative community-based services across Wales is inconsistent. Some areas have good services, whereas others have none at all.

The example of Monmouthshire County Council used in the afore-mentioned report shows that it is possible to reduce the use of residential services and increase the number of people supported to live at home. The future of their success depends on developing reablement services, remodelling residential care and building further working partnerships with other bodies.

The report also notes that Welsh councils' biggest challenge is how to change the prevailing culture within adult social care. The old system has created a paternalistic and protective set of services based on institutions and has built dependency both from service users and staff. The report goes on to say that building a care and support system that focuses on keeping older people out of residential care and using reablement models of care may assist not only in achieving better outcomes for individuals but also in reducing demand for services that may have otherwise occurred.

6. Quality of residential care services

Despite the hard work of many care staff and care providers there are many thousands of people who cannot access the quality care and support that they need to have a good quality of life. The latest report from Age UK¹⁰ and others show that the system is not simply in need of repair but is fundamentally broken. Two thirds of people living in care homes are people with dementia. Therefore, the provision of care and support in residential services has to respond to the care and support needs of people living with dementia and their family carers.

Alzheimer's Society recently carried out research into the quality of care for people with dementia. One carer highlighted the importance of the consistency of care. In order for the person with dementia to build trust with staff, there should only be a small number of carers looking after them.

⁹ *ibid*

¹⁰ Age UK (2010) *Care in Crisis: causes and solutions*. Age UK. London

In the Home from Home report, inactivity was identified a major issue for carers. An Alzheimer's Society survey found that the typical person in a home spent only two minutes interacting with staff and other residents over a six-hour period of observation, excluding time spent on care tasks.

The same report also identified poor standards of personal care in some homes. Carers found this to be particularly upsetting and cited that their relative would be unhappy that their standards of personal hygiene were not met. In its recent research one carer told the Society of basic nursing care standards not being met in a range of nursing homes, for example a soiled commode, a catheter with mould growing in it and a blocked catheter leading to hospital admission. Other carers told of examples of residents being harmed for example by mistakes in drug administration made and covered up and of a serious sexual assault by another resident.

Activities and engagement

Inactivity can lead to loss of physical function, social isolation, behavioural symptoms and a poor quality of life. In the Home from Home report, Alzheimer's Society found out that activity and engagement is an unmet need. Research shows that residents with more severe cognitive impairment had their physical needs attend to, but little time was left for social, emotional or occupational needs.¹¹

Access to gardens can be beneficial to people with dementia living in care homes. For example, they can continue with their gardening hobby or benefit from taking exercise or being in the fresh air. Evidence from carers of people with more severe dementia often report that the gardens were off limits to their friend or relative as there were no care staff to accompany them to the garden. Nevertheless, many care staff consider having more time to spend chatting and interacting with residents would bring more job satisfaction.

As the Dementia Action Plan states, the CSSIW will inspect care home on their availability of meaningful activities for people with dementia. Ensuring that people's personal preferences are taken into account, this measure should improve people's experiences of care homes.

Involvement of friends and families

A majority of carers still want to be involved in care of their relative after they have moved into a care home as this helps to maintain good relationships and can be linked to quality of life and engagement in activity. In the Home from Home report, nearly a third of carers said they did not get enough information and updates from the home about their relative or friend's medical condition and treatment. In fact, carers often face an uphill struggle to find out what happened after seeing their loved one with bruises.

¹¹ Ballard et al (2002) in Alzheimer's Society (2008), Home from Home: A report highlighting opportunities for improving standards of dementia care in care homes

In addition, a number of carers feel unable to make complaints as they fear that this would make life even more difficult for their friend or relative. Some carers complain after their relative has moved to another home or has died.

Conversely, many carers see relatives groups as an important resource in improving services in the care home. They also provide a forum for interaction between carers and give them opportunities to compare experiences.

Management of care home closures

Local authorities have a duty to provide care home places for people in need of them, meaning, should a care home close, residents have to be found an alternative place in another care home. If there is not capacity in the local area, people may be moved some distance to an alternative care home. However, human rights law means that people cannot be forced to move care homes where there is significant risk to their health; this applies even when care homes face closure.

There is little research evidence on moving people with dementia from one care home to another and the impact this can have on their health and wellbeing. However, the Society knows such moves can be unsettling and confusing for people with dementia and risk disrupting continuity of care. Staff in a person's new care home may not understand their preferences and needs and even in the best cases, will take time to deliver quality care.

7. Capacity of the residential care sector to meet the needs of people with dementia, in terms of staffing resources

According to the Alzheimer's Society report Home from Home, carers think that the staff team is the key to a dementia care home. In fact, according to the report, care managers believe that the biggest challenges they face relate to developing a staff team with the right attributes and skills and keeping them motivated.

Good induction and ongoing training are needed to develop a good staff team and this has benefits for both staff and residents. Research from Alzheimer's Society and other organisations shows that dementia care training can reduce staff turnover and increase job satisfaction.¹² Training can help staff to overcome some of the challenges they face while supporting people with dementia. The Welsh Assembly Government's commitment to improving training is welcome. This will help to prevent staff sickness and a high staff turnover.

People with dementia dominate the care home population; therefore, the impact of dementia can be felt in most care homes. In a report from Alzheimer's Society, staff in care homes found communication with people with dementia can be particularly challenging. People with dementia communicate through behaviour that may be seen as challenging. As a

¹² NICE / SCIE (2007), Dementia: the NICE SCIE guideline on supporting people with dementia and their carers in health and social care, London

result, people with dementia are increasingly vulnerable to exclusion and isolation. They may even be neglected and ignored if care staff do not have the skills to communicate effectively.

As pointed out in the National Dementia Vision for Wales, some people with dementia will only be able to understand or communicate in their first language as their illness progresses. Therefore, the need for bilingual provision of services may be a necessity for someone diagnosed with dementia.

The National Dementia Vision for Wales states that people with dementia have the right to be treated with dignity and respect. However, Alzheimer's Society has found examples of staff showing a lack of respect to people with dementia, for example by making fun of residents or talking about them in a disparaging way. Some carers reported that residents were treated like objects while personal care tasks were carried out.

Staff working in care homes are accorded a low status. Therefore, it is difficult to attract staff, which is a major issue. The status given to care home staff is also reflected in the level of pay and rewards. Working with people with dementia can be emotionally and physically demanding and there are other jobs which are less stressful and pay a similar wage.

8. Regulation and inspection arrangements and scrutiny of service providers' financial viability

Better market intelligence and improved information sharing can highlight any potential problems before they arise. However, Alzheimer's Society would like to see information publicly available in accessible formats. This is so that people with dementia and carers can make an informed decision when choosing a care home. Improved transparency is key to detecting providers at risk of failure. Therefore, it should be mandatory for providers to publish audited accounts and enhanced information.

In the current financial climate, local authorities may not have the resources to intervene and manage a situation to avoid the failure of a provider. There must be measures in place for central government to take control of a situation if a single local authority is not able to do so.

The role of CSSIW inspectors is central to improving dementia care. Regular inspections could help to detect providers who may be at risk of failure and inspectors could feed this information back to the relevant body.

9. Recommendations

- Ensure good quality community services are available to delay entry into residential care.
- Develop specialist assessment procedures which are systematic and standardised in approach.

- Introduce a thorough pre-admission process to ensure the person with dementia finds a residential service which best meets the individual's needs.
- Monitor the availability of meaningful activities for people with dementia through CSSIW Inspections.
- Encourage the involvement of relatives and carers in the care of the person with dementia.
- Introduce mandatory training in dementia care for all care home staff.
- Introduce systems for sharing good practice among care homes.
- Recognise the need for bilingual provision of services for some people with dementia.

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