Carers Strategies (Wales) Measure – Draft Regulations and Guidance

Alzheimer’s Society welcome the new Carers Strategies (Wales) Measure, which signals a significant step forward in increasing the recognition of and support for carers. However, carers are anxious that there are immediate threats to carers services posed by the cuts in public expenditure over the next few years. The Carers Strategies (Wales) Measure must be matched with commitments to protect those services that support carers in their caring role, recognising the important contribution that carers make as a key part of the workforce supporting people with dementia.

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 are a member of the Wales Carers Alliance. The Alliance is an informal grouping of voluntary organisations working across Wales. We work together to improve life for all carers in Wales by influencing national policy and practice. Alzheimer’s Society was involved in the engagement events facilitated by Wales Carers Alliance for this consultation, and support the response submitted by the Alliance.

2. About dementia

- Dementia is a severe, irreversible condition caused by diseases that attack the brain. The most common cause of dementia is Alzheimer’s disease. Other causes include vascular dementia (strokes), Lewy body dementia and damage to the frontal lobe of the brain. The impact of dementia is profound.
- Every person with dementia experiences their condition differently but common symptoms include confusion, memory problems and hallucinations, mood changes and feelings of anger and anxiety with what is happening to them.
- There are 42,700 with dementia in Wales and there will be nearly 56,000 people by 2021.¹
- Only 36% of people with dementia in Wales receive a diagnosis²

• One in three people over 65 will die with dementia. 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

In Wales, dementia has been identified as an area for action. The Welsh Government has launched a National Dementia Vision for Wales and published four Dementia Action Plans. The Dementia Action Plans emphasise the need to support carers, by providing them with training, information and adequate support to them in their role (including out of hours services) and ensuring that all partners or key family members of the person with dementia are offered a carers assessment. Dementia is a public policy priority and, as stressed in the Dementia Action Plans, the implementation of the Carers Strategies (Wales) Measure must be fully integrated with work to improve dementia care.

3. Carers for people with dementia

Carers are the main providers of support for people who need long term care. They currently provide 96% of our community care. ⁵ Unpaid carers provide much of the support to people with dementia. As the disease takes hold of the brain, people with dementia require increasing amounts of support with daily living and the burden upon the carer increases.

There are estimated to be 600,000 people in the UK acting as the primary carers for people with dementia. ⁶ Unpaid carers provide a significant proportion of the care needed to support someone with dementia. One study found that half of all people with dementia in the community received at least 35 hours of informal care per week.⁷

The costs of caring are significant. Many carers face financial hardship, often forced to give up work and pay high care bills from limited income or private savings. This is despite the fact unpaid carers for people with dementia save the UK £6 billion per annum. This is an average of approximately £10k per annum per carer. ⁸ Supporting carers of people with dementia is therefore

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² Ibid.
part of the solution to current economic challenges. Without carers, the costs of dementia would be significantly higher. Providing effective support services for carers is fundamental to reducing the amount of money spent on dementia support services and care.

Although many carers find caring rewarding, it can be an overwhelming experience, bringing irreversible changes to lives and relationships. Research shows that carers of people with dementia experience greater strain and distress than carers of other older people. There is plenty of evidence that poor carer health is particularly associated with supporting older people with cognitive impairment. Recent research by Alzheimer’s Society (2011) found that only 37% of carers have had an assessment of need, and over half of carers say that they are not getting enough support to carry out their caring role, resulting in frequently perceived negative repercussions, especially for carers’ mental and physical health. While the provision of information to carers is key, carers in Wales must also be guaranteed comprehensive support, including emotional support, assistance with day-to-day caring and access to respite and short breaks to enable them to continue in a caring role.

4. Information
Alzheimer’s Society agrees that comprehensive information for carers must be a priority. This is the first step in making carers a partner in care so that they can fully participate in supporting the person with dementia. Carers say a core set of information, provided free of charge would support them effectively in caring for a person with dementia. A range of information already exists for carers of people with dementia, about dementia and about the caring role. Despite this, people report that their information needs are not met, and information is provided too late, or not at all. A failure to proactively provide people with information appears to be a significant barrier. Alzheimer’s Society welcomes these regulations, which will play a key role in overcoming this barrier, and would stress that gathering feedback from carers on this issue should be a key part of monitoring their implementation.

Dementia is a condition that affects individuals differently. People may experience a different range of symptoms and rate of decline. In addition, their own circumstances and the context in which they are experiencing the condition will vary greatly. The result is that individuals will have very different information needs. Responses to a questionnaire sent to 1500 people with dementia and carers by Alzheimer’s Society demonstrates the wide range of information that people require and value. Respondents were asked to describe the dementia information that they had found most helpful. A broad range of answers was given and the high number of different responses

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12 Survey by Alzheimer’s Society to advise the Department of Health on implementing Objective 3 of the National Dementia Strategy for England.
reflected people’s individual needs. The ten most frequently given responses were:

1. Meeting other people with first hand experience/sharing experience 13.6% (74)
2. Help/advice on financial matters/how to claim benefits/funding 12.3% (67)
3. Support for carers as well as people with dementia 9.9% (54)
4. How dementia/disease is likely to progress/what to expect over time 8.8% (48)
5. How to cope/caring for person with dementia 8.7% (47)
6. Information on respite care/day centres 7.0% (38)
7. Advice/help/info on practical matters/practical tips on caring 6.8% (37)
8. Guidance/information from professionals eg doctors, social workers 6.8% (37)
9. Alzheimer’s Society (local branch) 6.4% (35)
10. Advice on dealing with behaviour problems 5.7% (31)

As part of Alzheimer’s Society Carers Information Programme Project, there has been discussions with over 40 carers to identify their information and support needs. The feedback received from carers was that:

- The depth of information wanted by carers varied quite widely. It seemed to depend on personal preference, temperament, and individual circumstances such as the diagnosis and its impact on the person they cared for.
- Most carers wanted information at the time when they needed it, rather than too far in advance. So, for example, claiming welfare benefits was important to consider as soon as possible, whereas detailed ideas about how to manage more unusual behaviour can be worrying for some, when the situation has not arisen.

Individuals’ personal preference regarding how much information they receive and in which format also differs. The questionnaire of people with dementia and carers asked in which format people liked to receive information. They could tick more than one answer. Results were as follows:

- 82% prefer printed information
- 65% face to face
- 23% internet
- 11% telephone
- 6% DVD or video
- 2.4% CD-rom

This evidence clearly demonstrates that an Internet only information resource would be insufficient to meet the information needs of people with dementia and their carers, and that information should be made available in a range of formats to meet people’s different needs and preferences.

The new carers strategies produced under the Carers Strategies (Wales) Measure must reflect the need to individually tailor information to meet these needs.

5. Consultation questions
Q.1 Are the attached draft Regulations sufficiently clear and comprehensive to implement the Carers Strategies (Wales) Measure?
We have no further comments on this question.

Q2. Does the attached Guidance accurately reflect the Regulations?
We have no further comments on this question.

Q3. Is the Guidance sufficiently clear and comprehensive to implement the Carers Strategies (Wales) Measure?

With regard to sections 3.23-3.28 of the guidance, we would emphasise that carers must be actively engaged, and on a regular basis. Simply including them in surveys will not be enough. Involvement must be an ongoing dialogue and must not be tokenistic. It is not enough to merely include people, for example by inviting just one carer who uses services to a meeting or sending a consultation document to carers who use services without providing the support and information they may require to respond. There must be adequate information prior to a consultation event and there must also be clarity about what a person’s role is in being consulted – for example, whether they are involved as an individual, giving feedback based on personal experience, or whether they are responding as a representative for a group of people. Where an individual is asked to respond as a representative of others, they should be given support to understand what the wider issues are and engage with those people they represent. They must also be given sufficient time to do this. This is crucial to enabling people to make a meaningful contribution to discussions. Alzheimer’s Society welcomes the emphasis at 3.12 in the guidance that ‘Engaging means not only providing written information to carers but also talking to them’. However, we would suggest that this could be expanded further so that there is a shared understanding of what is meant by engagement and involvement.

Alzheimer’s Society would stress that consideration needs to be given to the impact of processes of involvement and consultation on individuals. In order for involvement of carers to be effective it will need to be properly resourced. This could, for example, entail payment for:
- Travel expenses
- The costs of replacement care

This recommendation should be strengthened in the guidance at 3.27.

At 3.57 of the guidance, Alzheimer’s Society recommends that there is a time frame given for Welsh Ministers to approve or reject the strategies submitted by the Local Health Boards. This will enable planning of services and the implementation of their strategy.

Alzheimer’s Society would also recommend that there is detail added to the guidance on cross border issues. For example, how the Carers Strategies (Wales) Measure will apply to carers who live in Wales when the person they care for accesses health services in England.

6. Examples of service and practice that benefits carers
Provides relevant and timely information and advice

**Alzheimer's Society Cardiff Carers Bus**

In Cardiff, Alzheimer’s Society have a mobile information and support service, provided in an adapted bus. The bus provides information and support to carers through signposting to local agencies, and co-ordinates the provision of therapeutic treatments including reflexology and Indian head massage in the treatment room at the back. The bus visits a variety of locations around the city, such as leisure centres, supermarket car parks and churches offering information and advice to carers in locations that are convenient for carers.

**Carers Information Programme**

A good example of information provision is the development of Alzheimer’s Society Carers’ Information Programme, which will ensure carers can access quality-assured information face-to-face from local Society staff. The programme addresses the aspects of caring that are unique to dementia, based on the Society’s considerable experience in dementia services and support. It will equip carers to care with confidence and respond to the many symptoms of dementia, delivering a higher quality of life to both the person with dementia and the care. The programme will also refer carers to peer support services and be deliverable at a reasonable cost. Early evaluation shows that carers find the Information Programme very valuable.

- Operates effective consultation procedures that fully involve carers in decisions regarding the person they care for

Carers of people with dementia are strongly involved in the Alzheimer’s Society’s work. For example, our Quality Research in Dementia programme is a network of 180 people with dementia, carers and former carers who are trained and experienced in taking part in consultations.

Alzheimer’s Society are also in the process of developing Community Dementia Forums, with the first forums launched in Wales in December 2010. These include people with dementia, carers and others with an interest in dementia, to understand local need, offer scrutiny and to find solutions. Alzheimer's Society would envisage having strong links with local authorities and Health Boards in facilitating the involvement of carers of people with dementia in writing their new strategies, to meet the new requirements of the Carers Strategies (Wales) Measure. We would be happy to discuss this further.

We hope that these comments have been useful. Please do not hesitate to contact us if you have any further questions.

Yours sincerely,

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