

## **Response to Health, Social Care and Sport Committee's inquiry into the Welsh Government's draft national dementia strategy**

19 January 2017

### **About Wales Carers Alliance**

Wales Carers Alliance exists to represent the concerns and further the interests of carers in Wales. There are over 370,000 carers across Wales providing unpaid care to friends and family, together the 18 member organisations of Wales Carers Alliance work with and for carers to promote the well-being of all carers.

### **Key Points**

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- Wales Carers Alliance broadly welcomes the draft strategy and many of the actions proposed within it. We also welcome the consistent reference to the work of unpaid carers of people with dementia.
- There are around 37,000 people caring for a person with dementia in Wales, the contribution of this care is worth £622 million a year.
- Carers play a critical role in preventing or delaying residential care admissions.
- Although reference is made to carers of people with dementia throughout the strategy, we feel the draft strategy could better reflect the role carers by demonstrating an understanding of the issues they face and by including proposed actions that would support them. For example, by including commitments around providing out-of-hours access to hospital wards for carers or local health boards adopting the 'Triangle of Care for Dementia' model developed by the Royal College for Nursing and Carers Trust.
- We believe there needs to be a bigger focus on the role played by short breaks and replacement care in improving the well-being of both the carer and the individual with dementia, enabling the person with dementia to stay at home for longer. We welcome the

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#### **Aelodau:**

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#### **Members:**

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commitment to exploring a national respite scheme, but believe the draft strategy would benefit from looking at further ways breaks and replacement care could be improved.

- Wales Carers Alliance believes that the high level performance measures could be more ambitious and include more carer-focused measures that look at the impact actions have on carers of people with dementia (ie. improved well-being) rather than the actions themselves (ie. number of carers assessments offered).

## Background

1. Wales Carers Alliance welcomes the opportunity to provide evidence to the Health, Social Care and Sport committee's inquiry into the Welsh government's draft national dementia strategy.
2. There are at least 370,000 people caring unpaid for a friend or family member in Wales. Of those, it is estimated that around 10%, 37,000, care for a person with dementia. The contribution of unpaid carers in Wales is worth £622 million a year<sup>1</sup>.
3. The presence of an unpaid carer brings important benefits to both the person with dementia and health and social care services in Wales. A longitudinal study of 100 people with dementia found a 20-fold protective effect of having a co-resident carer when it comes to preventing or delaying residential care admissions<sup>2</sup>.
4. A recent study by Carers Trust in partnership with the Social Policy Research Unit (SPRU), The University of York and Firefly Research found that there are 10 critical points when information, support and services for unpaid carers of people with dementia are essential, including:
  - When dementia is diagnosed
  - When the carer takes on an 'active' caring role

<sup>1</sup> [https://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=3051](https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=3051)

<sup>2</sup> [https://carers.org/sites/files/carerstrust/media/commissioning\\_wales\\_finallo.pdf](https://carers.org/sites/files/carerstrust/media/commissioning_wales_finallo.pdf)

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- When the capacity of the person with dementia declines
  - When the carer needs emotional support and/or a break from caring
  - When the person with dementia loses their mobility
  - When the carer's own circumstances change
5. There needs to be a fundamental shift in health services in Wales in how the carers of people with dementia are supported, recognised and involved. This includes involvement and support during diagnosis, information and advice around difficult areas such as power of attorney and managing medications and carer-friendly policies in place in hospitals, for example allowing carers out of hours access.
6. Although the role of carers is represented throughout the draft document, we do not feel it is adequately recognised or that the document demonstrates an adequate commitment to put in place the support that carers of people with dementia need.

### **Raising Awareness and Understanding**

7. On page 17 it would be beneficial if the strategy also committed to raising awareness of the role played by carers among health staff. A lack of understanding of the role of the carer can negatively impact the well-being of the carer and the individual with dementia. This was the reason for the 'Triangle of Care for Dementia' jointly developed by Carers Trust and the Royal College of Nursing. The Royal College of Nursing project Dignity in Dementia; Transforming General Hospital Care (2011) highlighted that involving carers was highly instrumental in supporting improvements in care and will lead to better outcomes for patients, carers and ultimately the professionals supporting them<sup>3</sup>. The key standards that form the Triangle of Care are:
- Carers and the essential role they play are identified at first contact or as soon as possible thereafter
  - Staff are 'carer aware' and trained in carer engagement strategies

<sup>3</sup> <http://www.rcpsych.ac.uk/pdf/NAD%20NATIONAL%20REPORT%202013%20reports%20page.pdf>

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- Policy and practice protocols regarding confidentiality and sharing information are in place
- Defined posts(s) responsible for carers are in place
- A carer introduction to the service and staff is available, with a relevant range of information across the care pathway
- A range of carer support services is available

## Recognition and Identification

8. Over half (52%) of carers of people with dementia reported difficulties in obtaining a diagnosis of dementia for the person they cared for in Carers Trust's Road Less Rocky research<sup>4</sup>. Professionals should be educated in properly supporting and involving carers to help improve the diagnosis process.
9. Wales Carers Alliance welcomes the commitment in the document to provide 'all individuals' with access to a dementia support worker. However, we feel that the role of this worker in supporting/working with carers should be clarified.
10. We welcome on page 25 of the draft strategy the recognition of the needs of carers and the emphasis placed on carer support provided by the Carers Trust Network (which includes Crossroads services) and Alzheimer's Society. However, we feel that there needs to be a stronger commitment, in health settings, to providing information and advice to carers of people with dementia. More than half of carers (56%) had not been given information on legal issues, such as lasting power of attorney, and 55% had not been given information on managing money<sup>5</sup>.

## Living as well as possible for as long as possible

11. We believe that the document should address the important role played by replacement care and short breaks in supporting the well-being of both the person with dementia and the carer. When a carer is supported, they are more likely to remain healthy themselves, 35%

<sup>4</sup> [https://professionals.carers.org/sites/default/files/dementia\\_report\\_road\\_less\\_rocky\\_final\\_low.pdf](https://professionals.carers.org/sites/default/files/dementia_report_road_less_rocky_final_low.pdf)

<sup>5</sup> Ibid.

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of carers without good support experienced ill health compared to 15% of those with good support<sup>6</sup>. Providing information, support and services to carers of people with dementia can help the person with dementia to stay at home and both to live as well as possible for as long as possible.

12. We welcome the recognition that taking a 'team around the carer' approach with the carer as part of the team is desirable (P. 37) and the recognition that it is important to avoid carer breakdown or hospital admission.
13. Wales Carers Alliances welcomes the commitment in the draft strategy to 'examine a national approach to respite care'. The pressure on replacement care and breaks services means it is becoming increasingly difficult for all carers, including those of people with dementia, to access the support that they need. Wales Carers Alliance strongly believes that a national scheme should be put in place that meets the needs of carers and takes into account lessons learned elsewhere, for example with the long-running and successful Short Breaks Fund in Scotland.

### Good Care in Hospitals

14. We believe that this section should also recognise the importance that hospitals are not only 'dementia supportive' but also carer-friendly and that a proposed action would be to improve staff awareness of the role of carers of people with dementia and to put in place carer-friendly policies such as out-of-hours access to wards.

### High level performance measures

15. High-level performance measures could include more carer-focused commitments, for example number of local health boards implementing a 'Triangle of Care for Dementia' model or the number of hospitals signed up to the principles of the carer-friendly campaign 'John's Campaign'<sup>7</sup> which calls for the right of people with dementia to be supported by their carers.

<sup>6</sup> [https://carers.org/sites/files/carustrust/media/commissioning\\_wales\\_finallo.pdf](https://carers.org/sites/files/carustrust/media/commissioning_wales_finallo.pdf)

<sup>7</sup> <http://johnscampaign.org.uk/#/>

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16. We care concerned that the high level measure around carers assessments only measures the number of carers being offered assessments and support plans. This measure does not take into account with the quality of the assessments or the support plans, whether the carer was suitably involved in developing the assessments or support plans, or whether the actions included in the assessments or support plans were delivered.

## Contact

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