

Dementia Strategic Action Plan

Alzheimer's Society briefing, January 2017



Overview

The Welsh Government has launched for consultation a draft of [Wales' first ever dementia strategy](#). It sets out actions over the next five years, and will be reviewed and refreshed after three years to ensure it remains relevant and appropriately targeted.

Alzheimer's Society in Wales views the draft strategy as a huge opportunity for Wales to set clear, ambitious targets to improve life for the 45,000 people in Wales living with dementia. There is a great deal in the strategy which we strongly welcome, and it is heartening to see dementia being recognised as “*one of the most significant health and social care issues we face*”¹, costing Wales in the region of £1.4bn per year².

Alzheimer's Society wants the draft strategy to be ambitious in its goals for dementia care, support and services in Wales, but also for it to be achievable – something that all sections of Welsh public services can work towards. We have consulted extensively with partner organisations, and have set out ten key areas where the draft strategy should aim to drive change. These can be read online at alzheimers.org.uk/walesstrategy

Key points

Some of the key points from the draft Dementia Strategic Action Plan include:

- 1)** The Dementia Strategic Action Plan will be overseen by the Older Persons' Delivery Assurance Group (DAG) within Welsh Government.
Calls: Alzheimer's Society wants to see involvement from people affected by dementia in this process, in particular during the refresh in three years. We must ensure the Older Persons' DAG properly reflects the needs of people with younger onset dementia (dementia developed younger than age 65) in its work.
- 2)** A proposal for an annual increase of 3% per year from Wales' existing diagnosis rate of 51% - ie, 54% by 2018, 57% by 2019, 60% by 2020, 63% by 2021 and 66% by 2022.
Calls: Alzheimer's Society wants a more ambitious target for dementia diagnosis. Northern Ireland currently has a 64% diagnosis rate, which Wales would only match by 2021/2022 under the proposed target. In addition, the move to a different

¹ Welsh Government (2017) [Together for a Dementia Friendly Wales 2017-22: consultation document](#), Wales: Welsh Government: p9.

² Alzheimer's Society (2015) [The Hidden Cost of Dementia in Wales](#), Cardiff: Alzheimer's Society.

method of calculating diagnosis rates by Welsh Government³ means that the 2,000-3,000 people in Wales with young onset dementia would not be included in official figures. We must also ensure that there are sufficient services to support an increased number of people with a diagnosis of dementia.

- 3) A pledge that every newly-diagnosed person with dementia will have access to a Dementia Support Worker.

Calls: This is a very welcome proposal, as we know that a support worker is a valued and important first point of contact who can signpost and support people with dementia, as well as their family/carers. Alzheimer's Society wants to see funding provided to ensure enough support workers to meet demand.

Currently, Welsh Government funds 32 DSWs – but with 18,000 people with a dementia diagnosis and an aspiration to increase this number, we will need significantly more of these support workers. This pledge also does not seem to support all those individuals with an existing diagnosis. The Government provided £1 million in 2010 for Dementia Support Worker posts – it would be useful to better understand how the £800,000 for 32 posts builds on this existing work.

- 4) A series of High Level Performance Measures by which progress will be gauged.

Calls: Alzheimer's Society wants these High Level Performance Measures to be measurable, accountable and time-limited in order that the impact of the strategy can be effectively measured.

- 5) Proposals to increase the number of primary care settings, hospitals and care homes that are dementia friendly, as well as targets for memory clinic waiting times for every person referred for an assessment of dementia to receive a first assessment by 28 days and a working/preliminary diagnosis within 12 weeks (when it is clinically possible to do so).

Calls: Alzheimer's Society want to see more detail in due course on how these excellent aspirations will be met.

- 6) Proposals to ensure 75% of NHS employed staff who come into contact with the public are trained in an appropriate level of dementia care (as specified in 'Good Work: Dementia Learning and Development Framework') by the end of 2019.

Calls: Alzheimer's Society want to see commissioned staff appropriately trained as well. Training must ensure staff have adequate skills and understanding of dementia to respond to people's needs in an appropriate and sensitive manner that protects their dignity and respect and minimises distress. Training should also recognise the importance of mental and physical aspects of dementia and other health concerns of people living with dementia. Undergraduate health and social

³ Under the new strategy, Welsh Government will move from the Delphi consensus system of measurement to the CFAS prevalence estimate. Both approaches have their merits, but CFAS does not include data for under-65s living with dementia.

care courses should include dementia awareness and formal training pathways. People with dementia should be involved with training and developing training.

- 7) Monitoring the number and percentage of carers offered an assessment and for those with 'eligible needs' to be offered a support plan and a commitment for Welsh Government to examine a national approach to respite care.
Calls: Alzheimer's Society wants to see firmer targets for carers' assessments and a proper plan for respite care, to avoid this important area falling between different aspects of Welsh Government's ongoing policy development work. We must ensure that carers' assessments reflect the realities of living with dementia – for example, that dementia is a terminal condition that is degenerative, and may need regular review. All healthcare professionals should be able to access information on a patient's carer in order to provide support. There should be better recognition for and involvement of carers, supported by implementing the Triangle of Care in Dementia, which is a "therapeutic alliance between service user, staff member and carer that promotes safety, supports recovery and sustains wellbeing"⁴, and introducing a national approach to involving carers, including training for health and care home staff in identifying, supporting and involving carers of people with dementia. We must recognise and value the carers journey and ensure a commitment to adequate respite, support, and training for carers.
- 8) Proposals for District General Hospitals to have a psychiatric liaison service / support worker team in place.
Calls: Alzheimer's Society wants to ensure this service is age-appropriate, in order to have the expertise necessary to identify and intervene as early as possible in the patient's experience in the hospital. It should also have an understanding of the distinct requirements of individuals with younger onset dementia. The pattern of substance misuse in older people, a key indicator and cause of some forms of dementia, can also be different in older people than in younger adults.⁵
- 9) An ambition to build a *Dementia Friendly Wales* by increasing the number of Dementia Friends, Dementia Friendly Communities, and dementia friendly corporate/public bodies in Wales, and to promote the *Creating a Dementia Friendly Generation* educational resources developed with Alzheimer's Society.⁶
Calls: Alzheimer's Society wants to better understand how Welsh Government will aim to underpin and support this work.
- 10) Proposals for a reduction in the percentage of people with a diagnosis of dementia prescribed antipsychotic medications and a reduction in duration of treatment. This

⁴ Carers Trust (2013) [The Triangle of Care - Carers Included: A Guide to Best Practice in Mental Health Care in England](#), 2nd edition, London: Carers Trust, p.3.

⁵ Connelly, P. & Perera, N. (2013) [Developing an ideal old age service](#), London: Royal College of Psychiatrists.

⁶ Alzheimer's Society (2016) [Dementia information for children, teenagers and young adults](#).

is an area where the Older People's Commissioner for Wales, the Royal College of Psychiatrists Wales, and the Royal Pharmaceutical Society Wales have all been active in promoting the approach that antipsychotics should not be routinely prescribed to treat behavioural and psychological symptoms of dementia, and when necessary only the lowest dose should be prescribed for the shortest time.⁷⁸

Calls: Alzheimer's Society want to see more information on how this will be implemented and what will be reported to local mental health partnership boards by June 2018. We must ensure that people have a full explanation of the medication they may be prescribed and choice in their treatment. We should ensure that people with dementia prescribed antipsychotics have support from carers, loved ones, or advocates. Multidisciplinary support and regular reviews should be available to reduce over-use of antipsychotics.

11) Proposals for health boards, local authorities, primary care clusters and third sector providers support people to plan ahead for the end of life, identify professionals for training in initiating serious illness conversations, and work with bereavement services to recognise the differing needs of families and carers of those with dementia. We welcome the recognition that dementia is a terminal diagnosis "*which can lead to poor care, inconsistent quality of care and inadequate pain management*", that was highlighted in *Living and Dying with Dementia in Wales*⁹, and that it is the explicit wish of most people, with dementia and without, to die at home, yet hospital often ends up being the 'default' option.

Calls: Alzheimer's Society wants to see a national review of the current provision of palliative and end of life care. Where possible and desired, people should be enabled to die at their place of residence with support from professionals such as community nurses. Welsh Government should ensure that better dementia training is available for hospice staff, and all relevant health and social care staff are trained and supported to help people with dementia develop advanced care plans.

12) Ensuring that services are sensitive to the BAME community, the LGBT+ community, and individuals with learning disabilities or sensory loss. According to Welsh Government, "*services should take steps to address this locally to improve equity, such as developing different information resources and/or appointing outreach workers*". The draft calls for health boards and local authorities to develop actions to increase access for individuals with protected characteristics.

Calls: Alzheimer's Society wants to see more specific actions that Welsh Government expect health boards and local authorities to meet. Wales has diverse communities and cultures, all of which may have distinct requirements for dementia care which need to be addressed. Families are reluctant to use services

⁷ Royal Pharmaceutical Society Wales (2016) [Improving Medicines use for Care Home Residents](#), Cardiff: RPSW.

⁸ Older People's Commissioner for Wales (2014) [A Place to Call Home? A Review into the Quality of Life and Care of Older People living in Care Homes in Wales](#), Cardiff: OPCW.

⁹ Alzheimer's Society and Marie Curie (2015) [Living and Dying with Dementia in Wales: barriers to care](#), Penarth: Marie Curie.

that do not meet cultural or religious needs and try to carry on alone. Services need to be co-designed with locally prevalent communities and families should be involved in delivering and designing care. Work should be done to reach out to BAME communities to increase awareness of dementia and to design culturally sensitive services. Services should work to lower barriers to the gypsy and traveller community accessing services. Services should aim to be proactively friendly towards the LGBT+ community, and promote diversity inclusion and present the environment as non-discriminatory. Awareness of diverse sexual and gender identities (and the diversity within those) should be present throughout health and social care training, and should ensure staff do not make assumptions about sexuality and gender identity.

13) Proposals for health boards to improve access to a diagnosis and care in the Welsh language. These are very welcome, as people with dementia may revert to their first language as a result of their condition. The draft Dementia Strategic Action Plan recognises that this represents a clinical need. Additionally, there is a commitment from Welsh Government to engage with researchers to ensure there is a clinically validated dementia assessment tool for use in the Welsh language. **Calls:** Alzheimer's Society want to see more detail on how this excellent series of measures will be taken forward. Action is needed to mainstream the "Active Offer" principle into dementia services as they are designed and implemented.

14) An acknowledgement that rural areas face specific challenges in delivering dementia care – something which we have highlighted through our own research¹⁰. **Calls:** Alzheimer's Society wants the final strategy to include a more detailed section on dementia in rural Wales, setting out how Welsh Government will develop a better understanding of the extent, impact and growth of dementia in rural Wales. We must ensure current services are accessible to people in rural areas and are designed with rural areas taken into account, as well as ensuring those responsible for designing services are accountable for this.

Conclusion

Wales' first dementia strategy is a historic step forward and an enormous opportunity to drastically improve the lives and wellbeing of people affected by dementia in Wales. We have come a very long way in developing such a strong and comprehensive draft strategy, and the calls above hopefully identify some of the areas where the Health, Social Care & Sport Committee can raise questions during the inquiry and the ongoing Welsh Government consultation.

As always, we are happy to provide further information or tailored briefings to committee Members if they require any further detail.

¹⁰ Alzheimer's Society (2016) [Dementia in Rural Wales: the three challenges](#), Cardiff: Alzheimer's Society.

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