

Executive summary

Wales' first dementia strategy is an historic step forward and an enormous opportunity to drastically improve the 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 Alzheimer's Society Cymru welcomes both the progress made to date and the ambition of the Welsh Government to create a dementia friendly Wales.

About us

Dementia can devastate lives. For someone with the condition, as well as their family and friends, dementia means the plans you made, and the future you thought you had, will not be so.

Alzheimer's Society Cymru has a simple vision: a world without dementia. We know that moment will come. Today, too many people with dementia struggle. They cannot access information, help and support. Everyday things people take for granted become difficult.

Our mission is to transform the landscape of dementia forever. Until the day we find a cure, we will strive to create a society where those affected by dementia are supported and accepted, able to live in their community without fear or prejudice.

How we have developed this consultation response

The chapters that follow provide a detailed analysis of the content of the draft dementia strategy, as well as recommendations for where the strategy must go further. This has been based on our own technical analysis of the draft strategy, but also on the significant involvement of people affected by dementia, and their voices are prominent throughout the document. As part of the development of our draft response, we have:

- Jointly facilitated 10 consultation events for people affected by dementia across Wales¹;
- Run an online survey, eliciting nearly 550 responses (predominantly from carers and family members of people with dementia) on the draft strategy's proposals, including a mixture of both quantitative and qualitative data;
- Held specific consultation sessions with underrepresented communities;
- Supported two meetings of the Senedd's Cross-Party Group on Dementia which saw attendance from a range of people living with dementia from across Wales and allowed them an opportunity to contribute their thoughts on the proposals;

¹ Alzheimer's Society Cymru and DEEP will be submitting a separate analysis of the comments and themes raised at the consultation events. However, the points raised have informed and shaped Alzheimer's Society Cymru's response in this document.

- Supported six people affected by dementia to give evidence and share their stories with the National Assembly for Wales' Health, Social Care and Sport Committee during their inquiry into the draft Dementia Strategy.
- Had detailed discussions within our own Service User Review Panels [SURP] across Wales and incorporated comments from many of our own service users, their family and friends, and our staff.

In addition, we also consulted extensively with a wide range of partner organisations, and set out key areas where there was consensus that the strategy should aim to drive change.

These can be read online at alzheimers.org.uk/walesstrategy17

Throughout the consultation process, we have listened to the voices of people affected by dementia – people with dementia, carers, family, friends, loved ones, wider support networks, professionals, and the general public. Throughout this document, we have included direct anonymous quotes from these individuals in **dark blue text boxes** – such as below. The only individuals named are those for whom the quote is in the public domain.

Priority areas

The full response in the pages that follow gives a comprehensive guide to Alzheimer's Society Cymru's view on the Welsh Government's proposals. However, we believe that the following points are particularly fundamental and must be addressed if Wales is to have a strategy that will truly deliver a Dementia Friendly nation:

- **Diagnosis rates:** A diagnosis is of vital importance to people with dementia, as it is the key to unlocking the vital support and treatment to which people have a right. Lack of a diagnosis can leave people unaware of the steps they can take to manage their condition, unable to plan for the future, and distanced from support and care. It is precisely for this reason that the Glasgow Declaration² recognises the right to a timely diagnosis. Furthermore, people affected by dementia were unequivocal during the consultation events and in responding to our survey that improving diagnosis rates should be a key component of the dementia strategy.

"You wouldn't tolerate a 51% diagnosis rate for cancer."

For this reason, **we recommend** that the final version of the strategy should set out clear and more ambitious targets for increasing dementia diagnosis rates in Wales. While a commitment to increasing diagnosis rates by 3% is a good first step, we are concerned that it will take until the end of the strategy's lifetime for Wales to catch up to Northern Ireland – this is clearly not sufficient. **We urge** the Welsh Government to consider increasing the target – possibly setting a target which rises over time (for example, 3% for Year 1, 3.5% for Year 2, 4% for Year 3 and so on) in order that procedures and practices can be put in place at the start of the strategy's lifetime which can escalate the diagnosis rate in later years. This also allows time for the development of high-quality support services for pre-and post-diagnosis to go hand-in-hand with the increasing diagnosis rates. Such support services are vital to ensure that people get the support they need following a diagnosis.

² Alzheimer Europe (2014) [Glasgow Declaration 2014](#), date accessed 30/03/2017.

- **Access to Dementia Support Workers:** We strongly welcome the strategy's target for "all newly diagnosed people with dementia to be offered access to a support worker depending on need after diagnosis". 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. This multi-skilled and multi-role individual should be able to address both health and social care issues, signposting as needed, co-ordinating communication between providers, and be capable of acting as an advocate when appropriate.

We are, however, **concerned** that this proposal will not support individuals with an existing diagnosis who may need support, particularly given the nature of dementia as a condition that progresses over time. People affected by dementia may require the support of a DSW throughout the dementia journey, not just at the start, and this needs to be reflected. **We recommend** that the pledge to improve access to a DSW should be offered to all people affected by dementia, regardless of need, and it should be possible to access a DSW later in an individual's journey with dementia if they need support at a later stage. We believe that this access to a DSW should, at the latest, be in place by the end of the strategy's lifetime.

"All I want is for someone to talk to, someone to listen."

Alzheimer's Society Cymru wants to see funding provided to ensure enough support workers to meet demand. Currently, the Welsh Government funds 32 Dementia Support Workers as part of Wales' GP clusters – but with 20,000 people with a dementia diagnosis and an aspiration to increase this number, we will need significantly more of these support workers. To do this, we would like to better-understand the rationale behind the target of one Dementia Support Workers per two GP clusters target and what the evidence base is for this to be the appropriate level, especially in rural areas. In particular, we would like to understand what workload the Welsh Government is assuming each DSW to have. There may be necessity, in order to enable support workers to be able to provide high-quality person-centred support, to set a recommended case load or limit for case work, as is done for social workers via Social Care Wales.

- **Training of health and social care professionals:** The strategy proposes that, by 2019, 75% of NHS employed staff who come into contact with the public should be trained in an appropriate level of dementia care (as specified in *Good Work: dementia learning and development framework*).

Whilst we welcome this aspiration, **we would also strongly recommend** that commissioned staff should also be included in targets for training, not just those employed by the NHS. This could be achieved through commissioning arrangements.

We also recommend that people with dementia should be involved with delivering and developing training wherever possible, as they are the true experts on dementia. This will maximise the opportunity for staff to learn how to respond to people's needs in an appropriate and sensitive manner that protects their dignity and minimises distress. Staff must also feel able to ask for more support, and feel valued through training.

- **Young onset dementia:** Dementia is not just an older person's condition. A dementia diagnosis is complex and difficult to deal with at any age, but many of the complexities of being diagnosed under the age of 65 mean that access to specialist services is vital. People affected by young onset dementia may present with atypical symptoms, be diagnosed with rarer forms of dementia, and are more likely than older people to be diagnosed with a genetically inherited form of dementia. As a result, younger people with dementia often struggle to access appropriate care and support because dementia services are often designed to meet the needs of older people.

Both in our online survey and at the consultation events, a recurring theme was the lack of services for people affected by young onset dementia. We estimate there are around 2-3,000 people with young onset dementia in Wales, and it must be recognised that this group has different and specific needs.

Alzheimer's Society Cymru remain concerned that the Welsh Government's decision to move from the DELPHI consensus to CFAS when calculating prevalence of dementia in diagnosis rates does not properly reflect the number of under-65s affected by dementia. **We recommend that**, in order to offset this lack of consideration, Welsh Government should collect more accurate figures and establish the number of people with young onset dementia in each local health board and of the variants of dementia with which people are being diagnosed.

"What about young-onset? How it affects all the family, work and money. We nearly lost our house, my husband had to go part-time and I lost my job. I only got a social worker because I broke my leg – not because I had dementia."

Furthermore, the plan for the strategy to be monitored by the Older Persons' Delivery Assurance Group (DAG) leaves open the possibility that the needs of younger people with dementia could be ignored. **We therefore recommend** that the terms of reference for the DAG should explicitly reflect the needs of people with younger onset dementia in its work.

We also recommend that the Welsh Government ensures GPs are properly aware of the need for people with young onset dementia to get a diagnosis, and to be aware of it when diagnosing. GPs are likely to turn to other answers before dementia – leading to significant under-diagnosis. Worryingly, the lack of awareness amongst health care professionals and young onset dementia means that many people are often misdiagnosed with a differential diagnosis of depression. In some instances, women are being delayed a referral for dementia because of the similarity of symptoms with the menopause. **We also believe** that there is a need to develop a network of specialist Dementia Support Workers (at least one per LHB) with knowledge and experience of younger people with dementia and the specific challenges they face.

- **Cross-cutting themes:** We welcome that the strategy has been structured to reflect the 'life course' of dementia from prevention through diagnosis and support through to end of life care. This was a strong theme that came out of the consultation sessions, as something that people affected by dementia wanted to see. However, whilst this structure is helpful in many ways, it does risk a range of cross-cutting issues not being tackled in the strategy as fully as they should be, precisely because

they are present throughout the dementia life course and, as such, require consideration in the round.

We therefore suggest that a further section is added to the strategy in order that these cross-cutting themes can be fully explored. These themes include, but are not limited to, the following groups:

- First-language Welsh speakers: We strongly welcome the fact that language is recognised in the draft strategy as a clinical need. Alzheimer's Society Cymru wants to see more detail on how proposals to support Welsh language speakers will be taken forward, and **we recommend** that steps are taken to ensure that diagnosis and support in Welsh language are available.
- People with dementia in rural areas: Our Dementia in Rural Wales project³ has opened a dialogue about rural dementia. We want to work with the Welsh Government and other stakeholders to unite against dementia and make sure services meet the needs of people affected by dementia in rural Wales. We estimate that at least 17,000 people affected by dementia live in rural Wales, and the figure is likely higher – it is only likely to increase, given Wales' ageing population. **We recommend** the Welsh Government invest in research so that we can better understand the extent of the problem.
- People with dementia from LGBT groups: Lesbian, gay, bisexual and transgender (LGBT) people with dementia, and their carers, partners, friends and relatives, face additional and specific challenges. **We recommend** that services should promote diversity inclusion and that there is board-level support for doing this. We also call for better information to be collected on the impact of dementia on LGBT communities.
- People with dementia from BAME and GRT communities: Black, Asian and Minority Ethnic (BAME) and Gypsy, Roma, and Traveller (GRT) communities are more likely to be diagnosed late and less likely to be diagnosed or use dementia services. There are substantial health inequalities that face these communities and high barriers to accessing services. Families may be reluctant to use services that do not meet cultural or religious needs and try to carry on alone. **We recommend** the provision of culturally appropriate services and raising awareness of dementia among minority ethnic communities. Work should also be done to hear the voices of BAME and GRT communities to increase awareness of dementia and to design culturally sensitive services.
- People with disabilities and sensory loss: In particular, we have undertaken specific consultation work with people who are deaf, hard of hearing, or have sight loss or impairment. This community has unequal opportunity to access dementia education, information and support. **We recommend** that all of the key actions and high level performance measures should be reviewed to ensure that they are inclusive of people with disabilities and make sure that they have fair access to dementia awareness, diagnosis and post diagnostic support. Local work between health, social care and third sector needs to be established so resources that can support people who are deaf and/or blind can be shared.

³ Alzheimer's Society (2016) [Dementia in Rural Wales: the three challenges](#), Cardiff: Alzheimer's Society.

- People with dementia living alone: Around a third of all people with dementia live on their own. Whilst Alzheimer's Society Cymru fully supports the notion that people with dementia who want to remain in their own homes should be supported to do so for as long as possible, evidence shows that people who have dementia and live alone are at greater risk of social isolation and loneliness. Our research has found that 62% of people with dementia who live alone feel lonely compared to 38% of all people with dementia.⁴ **We recommend** that all of the strategy's key actions should be sensitive to the needs of people with dementia living alone.

Furthermore, a recurring theme of the consultation events, the submissions from members of our SURPs, and engagement with other stakeholders was that the draft strategy draws too much from the 'medical model' of dementia. We strongly welcome the publication of *Good Work: a dementia learning and development framework for Wales* - this is an excellent project that people affected by dementia had the opportunity to feed in to, and we believe the dementia strategy could usefully borrow from its use of language in reflecting the wider social needs of people living with dementia, not simply the narrow medical approach. More broadly, there needs to be a better understanding by providers of the social model.⁵

Finally, **we believe** that the "high level performance measures" listed in the strategy need to have SMART targets attached to them, and that this should include detail of what additional resources will be made available to support the strategy's implementation. Spending on improving dementia care is an investment, and careful investment can transform the lives of individuals, communities, and society.

Next steps

We look forward to working further with the Welsh Government and other partners – in particular, people affected by dementia – as part of any group overseeing the strategy's implementation and delivery. We also believe that there is a huge opportunity during the next three years prior to the strategy's refresh for a wider conversation to happen with people from across Wales affected by dementia to feedback on the strategy's impact on the ground. The consultation events which helped to inform the strategy demonstrated that there is a largely untapped resource of experts across the country who have strong and constructive views on how support and services could be improved. We must listen to them.

⁴ Alzheimer's Society (2017) [People with dementia living alone](#), London: Alzheimer's Society, date accessed 30/03/2017.

⁵ Royal College of Psychiatrists and the British Psychological Society (2007) [Dementia: The NICE-SCIE guideline on supporting people with dementia and their carers in health and social care](#), date accessed 14/03/2017.