

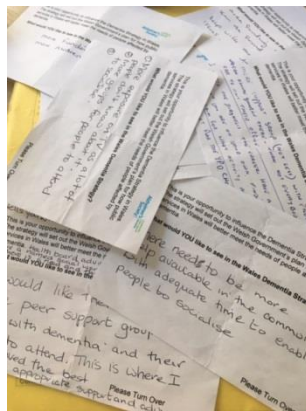
## Welsh Dementia Strategy

### a collaboration between Alzheimer's Society in Wales and DEEP

As well as all the work highlighted in the ['Wales Dementia Strategy: a starter for ten'](#) blog, Alzheimer's Society in Wales have been working in collaboration with DEEP (the dementia engagement and empowerment project) to ensure people affected by dementia have a voice in the development of the Wales Dementia Strategy. We believe that any policies, strategies or service developments should be directly influenced by people affected by dementia – the experts on their own experiences. As one of the Society's and DEEP's ambassadors, Chris Roberts, quotes '**nothing about us, without ALL of us**'.

Therefore, when both organisations were informed about the Welsh Government's proposed Dementia Strategy, a proposal was made to deliver a variety of engagement events throughout Wales to ensure that the development of the Strategy continually echoed the needs of people affected by dementia in Wales. Five consultation events were held across Wales in addition to a variety of engagement methods involving people affected by dementia from the Society's services; including visits to our Service User Review Panels.

The ten point letter set out common areas where Alzheimer's Society and a dozen other organisations believe that Welsh Government needs to drive change. We will ensure that these ten points are reviewed as a result of the collective voices of people affected by dementia. It will now be a collaborative effort from all organisations and individuals involved with the Strategy to make sure that the needs and voices of people affected by dementia are accurately reflected and met in the new Dementia Strategy.



**The most common themes as reflected by people affected by dementia include:**

- The call for a referral and diagnostic pathway, which is consistently used and monitored across Wales.
- A call for GP's to have education about the benefits of an early diagnosis, including the impact of delaying a diagnosis.
- A key point of contact that can provide appropriate and tailored information and support for people affected by dementia from the point of being referred for a diagnosis of dementia.
- Support services for people affected by dementia to be open to people going through the diagnostic pathway, to prevent crisis situations when a diagnosis is received, including pre and post diagnostic counselling for all people affected by dementia.
- People affected by dementia to be aware of their rights as an individual and how these rights can support any needs that may arise in relation to finances, respite and employment.
- Peer support groups and user involvement opportunities to be recognised as forms of valuable support for people affected by dementia and for them to be resourced and sustained across Wales.
- A roll out of information and support hubs across Wales, to ensure engagement and support for the general public and people affected by dementia in both urban and rural areas across Wales.
- Carers and wider family support networks to be recognised in their own right and for their needs to be assessed and supported by adopting a person centred approach.
- Respite services for people affected by dementia, including their carers and wider family support networks to be flexible and not limited to residential care. To consider an age specific or ability based approach, where respite is relevant to the age and abilities of the individual.

- Dementia friendly communities to be sustained as a way to raise awareness and help break down stigma, but for the approach to be refined and based on local need, including the involvement of people affected by dementia to inform and make decisions on what constitutes as a dementia friendly community.
- Mandatory education about dementia for all (schools, businesses to name a few), but as a priority target for all staff in health, social care and the third sector – dementia is everyone's business. Including, knowledge on symptoms related to dementia that aren't solely related to memory including sensory needs such as hearing, taste, smell and sight.
- A holistic support plan, where support is informed and given by therapies such as speech and language, nutritionists, occupational therapists and psychologists.
- Dementia awareness, support and information to be inclusive of people from the BAME, LGBT+, and other seldom heard groups, including better engagement to understand their needs and priorities.
- A palliative care and end of life care pathway to be established for people affected by dementia. Palliative care should be offered, explained and given to PAbD at point of diagnosis.

**Our next step** is to send a report to the Welsh Government highlighting the findings from each of the consultation events and opportunities. This report will influence the first draft of the Wales Dementia Strategy, which will be released in January 2017. The first draft of the dementia strategy will be open for consultation for twelve weeks. Alzheimer's Society in Wales will continue to work with DEEP and both have already planned consultation events and opportunities to ensure the active and meaningful involvement of people affected by dementia.

If you are a person affected by dementia from Wales who would like to be involved in the next stage of consultation events and/or opportunities please contact:

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