

Consultation Response

Draft Strategy – ‘Together for a Dementia Friendly Wales’ 2017 - 22

Health, Social Care and Sport Committee

January 2017

Introduction

Age Cymru is the leading national charity working to improve the lives of all older people in Wales. We believe older people should be able to lead healthy and fulfilled lives, have adequate income, access to high quality services and the opportunity to shape their own future. We seek to provide a strong voice for all older people in Wales and to raise awareness of the issues of importance to them.

We are pleased to respond to the Health, Social Care and Sports Inquiry into the Draft Dementia Strategic Action Plan. Age Cymru welcomes the Welsh Government’s commitment to creating a dementia friendly nation and to promoting the rights, dignity and autonomy of people living with dementia.

Dementia support workers

We welcome the action on p26 that states that ‘*every newly diagnosed person with dementia is offered access to a dementia support worker or equivalent.*’ Last year, Age Cymru was commissioned by the Older People’s Commission to carry out interviews with people living with dementia and their carers across Wales¹. Interviewees told us that they would value access to a single point of contact to support them to navigate the often complex interface between health, social services and community based third sector provision. Daily contact with so many agencies can prove extremely stressful. A dementia support worker can provide the extra support needed to reduce the pressure on people living with dementia and their carers and families.

Although we welcome the role of the dementia support worker, it is important to note that this post can only be effective in areas where there are services in place to signpost people with dementia and their carers to. P24 states that a key role of the dementia support worker will be to signpost people with dementia onto ‘*appropriate information and local facilities.*’ However, access to activity groups or dementia cafes is becoming increasingly scarce.

In response to this, the document does state that ‘*health boards and local authorities will work with local communities and third sector organisations to encourage them to open up their*

services so that people with dementia, their families and carers can participate' (p30). We would like to clarify the intent on this point. For example, is there evidence that people with dementia are being turned away from community and third sector services? Training would need to recognise the needs and behaviours of two people with dementia are never the same.

Access to services

People living with dementia and their carers have told Age Cymru that there is a need for more befriending and respite services that respond to the needs of individualsⁱⁱ. However access to befriending projects in Wales is already scarce and evidence shows the situation is likely to get worse. For example, In Swansea a volunteer led befriending project that has been funded by the LA for over 10 years, is due to close by the end March of 2018 if not before.

Long standing issues with the short term funding of dementia services can leave people feeling vulnerable and isolated when a service is withdrawn. There is a pressing need to develop a national strategic approach to the funding of dementia services. For people with dementia, their families and carers, the lack of access to community based support services can have a devastating impact on their quality of life. Additionally, health boards and local authorities need to ensure that the knowledge and expertise of third sector organisations and people living with dementia are utilised in the design and planning of any new service to ensure it is suited to individual need.

Training for carers

P26 mentions *'opportunities for carers' education about dementia should also be taken via formal courses run by organisations such as Carers Trust, Crossroads or Alzheimer's Society.'* Given the points raised in the section above, we would welcome more information on how these courses will be funded and rolled out nationally to ensure all carers have equal access to the service.

Engagement

There is a lack of reference throughout the strategy of the importance of involving people living with dementia in the design and planning of services that affect them. Without this engagement people living with dementia will continue to feel that they are expected to fit in with the delivery patterns of formal services rather than the services being designed to meet their individual needs.ⁱⁱⁱ One of the performance measures (p52) is that *'all memory services to involve people with dementia and carers in feedback and service development.'* This should be extended to include services delivered by local authorities and the third and private sectors.

People with protected characteristics

The draft strategy states that people from the Black African-Caribbean and South Asian UK population have a higher risk of developing both dementia and early onset dementia (p21 and p23). Although the document does propose an action for *'health boards and local authorities to develop actions to increase access for individuals who have protected characteristics'* (p28), there is no performance measure to monitor the effectiveness of any new initiatives. Given the documented evidence that shows that BME people with dementia present to dementia services later when their condition is more severe^{iv}, increasing uptake of services to BME populations should be viewed as a priority and allocated a performance measure.

Furthermore, the proposed review of Population Assessments (p21) should ensure that it includes an assessment of levels of need (including dementia) amongst BME communities.

End of life care

The document states although dying at home is the wish of most people, hospital often ends up being the 'default option.' As many people with dementia end their lives in care homes, the strategy should include a section on the need to ensure that care homes have policies and protocols in place that allow people to die in their place of residence.

High level performance measures

- It is important to note that none of the performance measures listed on pages 51 – 52 require local authorities or health boards to monitor or measure how the strategy will impact on the lives of people living with dementia, their families and carers. We believe it is important to measure outcomes as well as inputs.
- Also, point 7, p51 states the strategy will measure the numbers of carers being offered a support plan, but with no mechanism in place to monitor the impact and delivery of the plan, an increase in the number of plans is meaningless.
- We question whether the target of a 3% per annum increase in the number of people formally diagnosed with dementia is sufficiently ambitious, but welcome the measure relating to the receipt of a diagnosis within 12 weeks.
- Age Cymru is pleased to note the reference to the need to ensure access to independent advocates on p43, but believe access to advocates should be included as a performance measure.
- Performance measure 5, p51, relates to '*staff who come into contact with the public being trained in an appropriate level of dementia care.*' Age Cymru would like clarification that this will include all clinical staff working in within environments where people receive care, treatment or support.

ⁱ Older People's Commission for Wales (2015) *Dementia – more than just memory loss*.

ⁱⁱ Older People's Commission for Wales (2015) *Dementia – more than just memory loss*.

ⁱⁱⁱ Older People's Commission for Wales (2015) *Dementia – more than just memory loss*.

^{iv} By Jo Moriarty, Nadira Sharif and Julie Robinson Black and Minority Ethnic People with Dementia and their Access to Services. (Review date 2014) Available online: <http://www.scie.org.uk/publications/briefings/files/briefing35.pdf>