

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC50: Ymateb gan: | Response from: Alzheimer's Society

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Russell George MS  
Chair, Senedd Health and Social Care Committee  
Welsh Parliament  
Cardiff Bay  
Cardiff  
CF99 1SN

Thursday, 25<sup>th</sup> May 2023

Dear Chair,

### **Consultation Response: Supporting people with chronic conditions**

We welcome the opportunity to respond to the first stage of the Health and Social Care Committee's inquiry into supporting people with chronic conditions and are broadly supportive of the key themes selected as outlined in the Terms of Reference.

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia in Wales, England, and Northern Ireland. Our mission is to transform the landscape of dementia to create a society where those living with dementia are supported to live independently in their communities, ensuring that they feel valued and can access quality person-centered care that meets their individual needs.

We are a key partner in developing and monitoring the Welsh Government's Dementia Action Plan and work with NHS Bodies and other stakeholders to improve dementia services through co-production with those with lived experience.

In Wales approximately 50,000 people are currently living with dementia, a figure which is forecast to rise to above 100,000 by 2050.<sup>1</sup> With the number of people living with dementia rising with an ageing population, reduced capacity in healthcare services and a social care system reliant on unpaid carers, we would encourage the Committee to take particular regard of the needs of people living with dementia as part of the inquiry.

As the prevalence of dementia continues to rise, it is vital to treat it as a priority. Previous research has shown that dementia costs Wales £10.6 billion per year, representing an increase of 17% since 2011.<sup>2</sup> With 91.8% of people living with dementia having another health condition<sup>3</sup> and the economic and social cost of dementia rising, it is vital to tackle the barriers preventing access to quality care and support, and raise awareness of dementia as part of public health messaging.

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<sup>1</sup> Senedd Cross-Party Group on Dementia, (2021) *No understanding, No knowledge, No support, Hospital Care in Wales*, p.3: <https://business.senedd.wales/documents/s127656/Report%20from%20the%20CPG%20on%20Dementia.pdf>

Alzheimer's Society, (2015). *Diagnose or disempower? Receiving a diagnosis of dementia in Wales*, p.V: [Diagnose or disempower? \(alzheimers.org.uk\)](https://www.alzheimers.org.uk)

<sup>2</sup> Carers UK and Centre for Care, (2021) *Valuing Carers 2021 England and Wales*, p.9: <https://www.carersuk.org/media/2d5le03c/valuing-carers-report.pdf>

<sup>3</sup> Browne J et al (2017) *Association of comorbidity and health service usage among patients with dementia in the UK: a population-based study*

A key determinant of quality care is an accurate and timely diagnosis. While 91% of people affected by dementia highlight the clear benefits of getting a diagnosis,<sup>4</sup> the diagnosis rate in Wales is approximately 50 per cent having declined during the COVID-19 pandemic. The main barriers to accessing diagnostic services include the lack of awareness of the benefits of a diagnosis, regional variation in the availability of services (particularly in rural areas) and the lack of a multi-disciplinary approach within the workforce. Another key issue is the lack of PET scanners to facilitate quality diagnosis's, with only 3 PET scanners available in Wales.

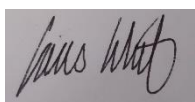
Key systemic issues which must be addressed include the need to collect and publish consistent diagnosis data (including by sub-type of dementia) and the lack of post-diagnosis support proactively offered to service-users and carers, many of whom feel unsupported and isolated after diagnosis. We recommend that the Committee includes a focus on diagnosis rates across conditions as part of the inquiry.

It is essential to raise the diagnosis rate in order to deliver the appropriate care and support to meet the needs of those living with dementia by ensuring fair access to diagnostic services for all regardless of ethnicity, gender, language, or geographical location.<sup>5</sup> Culturally relevant assessment tools and interpreters (including bilingual assessments for Welsh speakers and assessments for those who are deaf or British Sign Language users) should be introduced and made widely available, including amongst individuals from under-represented groups and ethnic-minority communities who often face additional barriers to diagnosis and receive a diagnosis at a later stage when compared to the general population.<sup>6</sup>

The Committee's inquiry provides an opportunity to examine the quality of dementia services in Wales and how to address the underlying barriers to accessing quality care and support to enable people to live well with dementia. With the Welsh Government's refreshed Dementia Action Plan due to be published next year and the increasing prevalence of dementia in Wales, we believe it is a timely opportunity for dementia to be included as a specific topic within the Committee's inquiry.

We welcome the opportunity to contribute to the Committee's inquiry and please do not hesitate to contact us should you have any questions or need any additional information.

Yours sincerely,



**James White, Head of National Influencing, Alzheimer's Society**

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<sup>4</sup> Alzheimer's Society (2022). 91% of people affected by dementia see clear benefits to getting a diagnosis, available online at: [www.alzheimers.org.uk/news/2022-05-16/91-people-affected-dementia-see-clear-benefits-getting-diagnosis](https://www.alzheimers.org.uk/news/2022-05-16/91-people-affected-dementia-see-clear-benefits-getting-diagnosis)

<sup>5</sup> Alzheimer's Society (2023) *Improving access to a timely and accurate diagnosis of dementia in England, Wales and Northern Ireland*, p.5: <https://www.alzheimers.org.uk/sites/default/files/2023-05/alzheimers-society-improving-access-timely-accurate-diagnosis-england-wales-full-report.pdf>

<sup>6</sup> Adelman, S. (2010). *Prevalence and recognition of dementia in primary care: a comparison of older African-Caribbean and white British residents of Haringey*, PhD thesis. University College London