

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [dyfodol ymarfer cyffredinol yng Nghymru](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [the future of general practice in Wales](#)

GP49 : Ymateb gan: | Response from: Alzheimer's Society Cymru





**Alzheimer's
Society
Cymru**

Gyda'n gilydd, byddwn yn cynnig help
a gobaith i bawb sy'n byw gyda dementia
Together we are help & hope
for everyone living with dementia

Russell George MS
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By email: SeneddHealth@senedd.wales

Friday, 28th March 2025

Dear Chair,

Alzheimer's Society response to the Senedd Health and Social Care Committee inquiry into the future of general practice in Wales

Alzheimer's Society Cymru welcomes the opportunity to respond to the Health and Social Care Committee's inquiry into the future of general practice in Wales.

Alzheimer's Society is the UK's leading dementia charity, working towards a world where dementia no longer devastates lives. We do this by giving help to those living with dementia today and providing hope for the future. We provide direct dementia support services, fund research, and campaign for change to improve the lives of people living with dementia in Wales, England, and Northern Ireland.

This consultation response focuses on the vital role of GPs in enabling access to an early and accurate dementia diagnosis. It covers the need to increase awareness of dementia, particularly the benefits of diagnosis, in primary care settings. It also highlights the need to address regional variation in access to diagnostic services and the delays people can face in getting a diagnosis.

This is because diagnosis has a wide range of benefits: it unlocks access to care, support and treatment, and can help people to live independently for longer. Alzheimer's Society has commissioned research to demonstrate the increasing scale and cost of dementia in the UK, and how improving access to an early and accurate diagnosis can generate cost savings and economic benefits while alleviating pressure on the wider health service.

Our wide-ranging evidence provides insights into the scale of dementia in Wales. We estimate there are 51,226 people living with dementia in Wales, with prevalence due to increase by 37% to 70,000 by 2040.¹ The total cost of dementia in Wales is projected to increase from £2.27 billion to £4.62 billion by 2040.²

Dementia accounts for 918,000 primary care contacts in Wales per year, set to increase in line with rising dementia prevalence: by 2040, an additional 336,100 primary care contacts will be needed for people living with dementia.³ These stark figures highlight the need to make dementia a priority. GPs can play an important part in making this happen, as they are often the first point of contact for those who have concerns about their memory.

The importance of an early and accurate diagnosis

An early and accurate diagnosis enables access to care, support and treatment which is vital in helping people with dementia to better manage their condition. Accessing diagnosis and treatments can help to reduce healthcare utilisation and delay the expensive, intensive care required for the more severe stages

¹ Alzheimer's Society and Carnall Farrar (2024). [The Economic Impact of Dementia - Module 1: Annual Costs of Dementia](#) (p 33).

² Alzheimer's Society and Carnall Farrar (2024). [The Economic Impact of Dementia - Module 1: Annual Costs of Dementia](#) (p 38).

³ Calculated using data from Alzheimer's Society and Carnall Farrar (2024). [The Economic Impact of Dementia. Module 2: Dementia's contribution to health metrics.](#) (p 32).

of dementia.⁴ In turn this can provide savings on long-term care costs⁵ for individuals and the healthcare system.⁶ However, on average, people live with dementia for 3.5 years before receiving a formal diagnosis, indicating that there are various barriers to getting diagnosed.⁷

Recent modelling commissioned by Alzheimer's Society suggests that savings of between £10,489 and £52,783 per person could be generated where nursing home admission can be delayed through effective management and treatment of Alzheimer's disease.⁸ This cost saving is shared by people living with dementia, who can expect to save £10,100 in their lifetime if they are diagnosed early enough to take treatment at the point when it can have the maximum impact.⁹

However, Welsh Government data shows that the national diagnosis rate is only **56%**, resulting in nearly half of people living with dementia being left without the benefits a formal diagnosis brings.¹⁰ There is also significant regional variation in diagnosis rates across Wales. Welsh Government data shows that Powys has a 46.9%¹¹ diagnosis rate whereas the diagnosis rate in Cardiff and Value University Health Board is 64.3%.¹²

Perception of dementia amongst GPs

GPs play a key role in the dementia diagnosis pathway, referring patients to Memory Assessment Services (MAS) or other specialist services following an initial consultation to enable a formal diagnosis of dementia. Research shows that 77% of people report seeing a GP as part of their dementia diagnosis journey.¹³ So, it is important that GPs are aware of the benefits of a formal diagnosis and are equipped with the knowledge and understanding of dementia required to ensure an early and accurate diagnosis, including via referral to specialist services.

There are various barriers in primary care that need to be addressed to improve access to an early and accurate diagnosis,¹⁴ including reticence to provide a diagnosis amongst GPs and MAS,¹⁵ and stigma associated with dementia.¹⁶

Research shows that GPs consistently cite lack of education and support, poor availability of secondary or support services, and time constraints as barriers to diagnosis at primary care.¹⁷ We have also identified low awareness of the benefits of a diagnosis as an additional barrier to referral.

Alzheimer's Society research into attitudes to dementia in primary care in England, Wales and Northern Ireland has shown **that nearly a fifth (18%) of GPs** believe that there is little benefit in a diagnosis of

⁴ Alzheimer's Society & Carnall Farrar (2024). [The Economic Impact of Dementia - Module 4: Impact of early Diagnosis and Treatment](#) (p 8).

⁵ Prince M, Comas-Herrera A, Knapp M, Guerchet M and Karagiannidou M (2016). [World Alzheimer report 2016: improving healthcare for people living with dementia: coverage, quality and costs now and in the future](#). Alzheimer's Disease International (ADI) (2016), London, UK; Chief Medical Officer's Annual Report (2023). [Health in an Ageing Society](#) (p 145).

⁶ Alzheimer's Society & Carnall Farrar (2024). [The Economic Impact of Dementia - Module 4: Impact of early Diagnosis and Treatment](#) (p 19).

⁷ Aldus, C, F., Arthur, A., & Dennington-Price, A et al. [Undiagnosed dementia in primary care: a record linkage study](#), National Institute for Health Research, Health Services and Delivery Research, 2020; 8(20), (p xvii).

⁸ Calculated using data from Alzheimer's Society and Carnall Farrar (2024). [The Economic Impact of Dementia. Module 4: Impact of earlier diagnosis and treatment](#). (p 18).

⁹ Alzheimer's Society and Carnall Farrar (2024). [The Economic Impact of Dementia. Module 4: Impact of earlier diagnosis and treatment](#). (p 19).

¹⁰ Welsh Government (2024). [General Practice Disease Registers: Interactive Dashboard](#)

¹¹ Ibid.

¹² Ibid.

¹³ Walnut Unlimited (2024). [Alzheimer's Society Personal Experiences of the Dementia Journey – The True Picture](#) (p 27).

¹⁴ Alzheimer's Society (2023). [Improving access to a timely and accurate diagnosis in England, Wales and Northern Ireland](#)

¹⁵ GSR Research (2023). [Evaluation of the Dementia Action Plan 2018-2022: Interim Report Summary](#) (p 3).

¹⁶ Moore, V., & Cahill, S., (2013). [Diagnosis and disclosure of dementia--a comparative qualitative study of Irish and Swedish General Practitioners](#), Aging Ment Health. 2013;17(1):77-84

¹⁷ Koch, T., Illiffe S., (2010). [Rapid appraisal of barriers to the diagnosis and management of patients with dementia in primary care: a systematic review](#), BMC Fam Pract 2010; 11:52

dementia as an incurable, progressive disease.¹⁸ This contrasts with research indicating that **97% of people living with dementia** saw benefits to getting a diagnosis.¹⁹

Research also indicates a lack of confidence among GPs in diagnosing dementia, with **21% of GPs** reporting that they have not got the tools or expertise to make a diagnosis, and **14% reporting** that they are not confident in differentiating dementia from other conditions.²⁰

While **61% of GPs** surveyed reported being confident in identifying the early signs and symptoms of dementia, only **46%** reported that they feel well equipped to support and manage patients presenting with possible dementia.²¹ There is also a lack of clarity amongst GPs around referral, with **21%** of GPs surveyed highlighting a lack of clarity around when to refer, and **12%** reporting a lack of clarity around where to refer.²² On top of this, primary care staff who see a clear benefit in diagnosing dementia refer a significantly higher percentage of their patients than those who do not see a clear benefit (69% vs 61%).²³

This demonstrates the need to raise awareness of the importance of a formal diagnosis of dementia among GPs, in addition to improving understanding and knowledge of dementia in primary care settings. The evaluation of the 2018-2022 Dementia Action Plan notes that people living with dementia reported that they would like to see 'more training for all GP and hospital staff to ensure they have the necessary knowledge and skills to recognise and appropriately respond to the diverse symptoms of dementia and provide person-centred care.'²⁴ This is supported by research indicating that more healthcare professionals (55%) who have access to Alzheimer's Society support services feel well equipped to support and manage patients presenting with possible dementia than those who have not.²⁵

Alzheimer's Society research also found that **only 5% of GPs** surveyed report that they 'very often' diagnose dementia without specialist guidance.²⁶ This compares to **94% of GPs** reporting that they 'always', 'almost always', or 'very often' diagnose conditions with similar symptoms to dementia without the need for specialist guidance.²⁷

The evaluation of the Dementia Action Plan outlines that increasing 'dementia awareness training' and understanding of the importance of an early and accurate diagnosis would also help to improve consistency of diagnosis services and ensure that referrals to specialist diagnostic services are routinely offered.²⁸

Waiting times

There is also significant variation in the time between initial GP consultation to diagnosis in Wales, with waiting periods ranging from one month to over three years, according to the 2018-2022 Dementia Action Plan evaluation.²⁹ According to the Interim Evaluation of the Dementia Action Plan, 36% of people surveyed waited for longer than 6 months between an initial appointment with a GP and receiving a formal diagnosis.³⁰ This contrasts with the current national target of a preliminary diagnosis at 12 weeks from the point of referral 'where clinically possible'.³¹

¹⁸ Bryter (2023). Attitudes to Dementia in Primary Care (p 18). (unpublished)

¹⁹ Walnut Unlimited (2024). [Alzheimer's Society Personal Experiences of the Dementia Journey – The True Picture](#) (p 25).

²⁰ Bryter (2023). Attitudes to Dementia in Primary Care (p 17). (unpublished)

²¹ Bryter (2023). Attitudes to Dementia in Primary Care (p 16). (Unpublished)

²² Bryter (2023). Attitudes to Dementia in Primary Care (p 21). (Unpublished)

²³ Bryter (2023). Attitudes to Dementia in Primary Care (p 19). (Unpublished)

²⁴ QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 21).

²⁵ Bryter (2023). Attitudes to Dementia in Primary Care (p 16). (Unpublished)

²⁶ Bryter (2023). Attitudes to Dementia in Primary Care (p 17). (Unpublished)

²⁷ Ibid.

²⁸ QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 22).

²⁹ Ibid.

³⁰ QSR Research (2023). [Evaluation of the Dementia Action Plan 2018-2022: Interim Report Summary](#) (p 3).

³¹ Welsh Government (2018). [Dementia Action Plan for Wales](#) (43).

The Dementia Action Plan evaluation highlights that the 12 week target remains ‘aspirational’ due to the scale of variation and waiting times.³²

Long waits for diagnosis highlight the need to ensure the referral process is efficient and tackle unnecessary delays in the initial stages of the dementia pathway. Alzheimer’s Society support the acknowledgement in the Interim Evaluation Report Summary that ‘continue[d] work [is required] to reduce waiting times for assessment and diagnosis and increase referrals from primary care into specialist dementia services.’³³ We also support the call for the production of ‘standardised tools and guidance’ to help develop ‘a consistent approach to memory assessment’³⁴ and tackle inconsistencies in diagnosis.

Delivery of diagnosis

People living with dementia have stated the importance of **how** a GP delivers a diagnosis.³⁵ The 2025 Dementia Action Plan Evaluation Report outlines the need for patients to be provided with ‘clear and direct information’ about their diagnosis, with ‘expectations for the future’ set at the point of diagnosis.³⁶ Whilst most patients reported receiving leaflets to help navigate services, these have often been described as ‘too long, too generic, or outdated.’³⁷

There is also a need to enhance support for people prior to a formal diagnosis.³⁸ GPs and Memory Assessment practitioners need to ‘put sufficient time and effort into listening’ to patients, ‘conducting tests and assessments, and explaining the diagnosis’ as highlighted in the Evaluation Report.³⁹

Research has also indicated the need to improve delivery and communication of a diagnosis, with 15% of people surveyed disagreeing that healthcare professionals clearly communicated throughout the diagnosis pathway.⁴⁰ In addition, less than half of carers (45%) felt respected by healthcare and social care professionals.⁴¹

This again demonstrates the need for GPs to have appropriate knowledge, skills and training on dementia to meet the needs of people living with the condition. This would help to ensure that a diagnosis is appropriately communicated and managed, thereby improving the patient experience of the diagnosis pathway.

Post-diagnosis support

GPs play an important role in post-diagnosis management and facilitating access to post-diagnostic support, including through conducting annual patient reviews. However, as the Evaluation Report highlights, there are regional inconsistencies and barriers to accessing post-diagnostic support, highlighting ‘the need for more automatic referrals, regular reviews of needs assessments, and the provision of accessible, clear information and support following a diagnosis’,⁴² including for Welsh language speakers.

³² QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 22).

³³ QSR Research (2023). [Evaluation of the Dementia Action Plan 2018-2022: Interim Report Summary](#) (p 5).

³⁴ Ibid.

³⁵ QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 23).

³⁶ Ibid.

³⁷ Ibid.

³⁸ QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 22).

³⁹ QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 23).

⁴⁰ Walnut Unlimited (2024). [Alzheimer’s Society Personal Experiences of the Dementia Journey – The True Picture](#) (p 31).

⁴¹ Walnut Unlimited (2024). [Alzheimer’s Society Personal Experiences of the Dementia Journey – The True Picture](#) (p 32).

⁴² QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 25).

The provision of post-diagnosis information can be improved by ensuring that GP practices have a 'dedicated liaison' to signpost to post-diagnosis services and support, which would ensure 'a single point of contact' and enhance continuity of care as recommended by the Evaluation Report.⁴³

This aligns with the vision of the Welsh Government's Dementia Action Plan which commits to introducing Dementia Support Workers as a named contact (connector) to offer support, advice, and signposting throughout the dementia pathway.⁴⁴ However, the Connector, or 'Dementia Key Worker' roles have not been consistently implemented. Only 45% of people living with dementia reported that they had a Dementia Support Worker in place.⁴⁵ Alzheimer's Society therefore support the Evaluation Report's recommendation for the Dementia Connector roles to be consistently implemented across Wales⁴⁶ supported by Welsh Government funding to deliver 'the equivalent of an additional two posts per region' and the work of the Dementia Connector workstream.⁴⁷

Sharing of Good Practice:

The sharing of good practice or possible solutions to identified challenges is also key to improving the consistency of diagnostic practice in primary care settings.

A further recommendation from the Evaluation Report includes the need for stakeholders to work collaboratively with Regional Partnership Boards (RPBs) to share good practice with the aim of developing 'a standardised assessment and diagnostic plan or pathway for Wales' to enhance consistency of practice and identify gaps in service provision.⁴⁸ This would set out a national standard for GPs to tackle inconsistencies in practice as part of developing a more effective diagnosis pathway.

Alzheimer's Society also supports the need to 'develop a national community health clinical pathway' to support GPs in Wales 'with early detection, assessment, and referrals'.⁴⁹ A community health clinical pathway could form part of the specialist guidance for GPs.

We support the Evaluation Report's additional recommendation around the need to explore 'the development of assessment models that can be delivered in community and non-clinical settings where appropriate',⁵⁰ which would also help to tackle barriers to accessing diagnosis services. This is particularly important to increase national diagnosis rates, reduce variation in access to diagnosis services between different regions and increase public awareness of dementia.

Conclusion

With the scale and cost of dementia projected to increase significantly in Wales, it is vital that GPs are able to meet the needs of people living with dementia and their carers.

The current lack of consistency in diagnosis highlights the need to ensure that GPs are more aware of the benefits of an early and accurate diagnosis and have the skills and support to manage the diagnosis process more effectively. This will also help to ensure more consistent assessment and referral routes and tackle unnecessary delays to diagnosis.

This will be dependent on specialist training and the development of a standardised diagnosis pathway to support GPs around diagnosis of dementia, communication, and onward referral as referenced in the Evaluation Report.⁵¹

⁴³ QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 24).

⁴⁴ Welsh Government (2018). [Dementia Action Plan for Wales](#) (17).

⁴⁵ QSR Research (2023). [Evaluation of the Dementia Action Plan 2018-2022: Interim Findings](#) (p 41).

⁴⁶ QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 27).

⁴⁷ Ibid.

⁴⁸ QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 23).

⁴⁹ Ibid.

⁵⁰ Ibid.

⁵¹ QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 23).

Alzheimer's Society Recommendations:

- 1) The Welsh Government must work with stakeholders to raise awareness, knowledge and understanding of dementia amongst GPs, improving perceptions of the benefits of a formal diagnosis to help enable early and accurate diagnosis.
- 2) The Welsh Government must provide adequate investment in diagnosis infrastructure and the specialist workforce required to diagnose more people as the prevalence of dementia increases. This will help to increase national diagnosis rates.

Alzheimer's Society also support the following recommendations as included in the independent Dementia Action Plan Evaluation Report:

- 3) Service providers and GPs to collaborate with Regional Partnership Boards (RPBs) to share good practice with the aim of developing 'a standardised assessment and diagnostic plan or pathway for Wales'.⁵²
- 4) Welsh Government to 'develop a national community health clinical pathway' to support all GPs in Wales 'with early detection, assessment, and referrals'.⁵³
- 5) Dementia Connector (also referred to as Dementia Key Worker)⁵⁴ roles to be consistently implemented across RPBs to provide people living with dementia with a main point of contact throughout the dementia pathway, including for post-diagnosis support services and accessible information.⁵⁵

Thank you for the opportunity to respond to the Committee's consultation and please get in touch if you have any questions about our evidence.

Yours sincerely,

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⁵² QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 23).

⁵³ Ibid.

⁵⁴ QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 13).

⁵⁵ QSR Research (2025). [Evaluation of the Dementia Action Plan 2018 to 2022: main findings and recommendations for future strategies](#) (p 27).