

# A new dementia action plan for Wales



**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



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# Dementia has a huge impact on society and the NHS

Wales needs to make dementia a priority. Dementia is the leading cause of death in Wales and England,<sup>1</sup> and one in three people born today in the UK will develop dementia in their lifetime.<sup>2</sup>

Dementia is caused by diseases, such as Alzheimer's, that damage nerve cells within the brain. Despite common misconceptions, dementia is not a normal part of ageing. It is a progressive, terminal, and currently incurable condition and its impacts can be devastating.

Though Welsh Government estimates there to be 42,000 people over the age of 65 living with dementia in Wales, our estimates suggest the total number could be as high as 51,000.<sup>3</sup> This figure is set to rise by 37% to almost 70,000 people by 2040.<sup>4</sup>

Dementia puts significant pressure on our health and care services and on society as a whole:

- Dementia costs Wales £2.3 billion today, rising to £4.6 billion by 2040.<sup>5</sup>
- Dementia accounts for 918,000 primary care contacts in Wales per year. This is only set to increase with the increasing prevalence of dementia and by 2040, an additional 336,100 primary care contacts will be needed for people living with dementia.<sup>6</sup>
- 1 in 6 hospital beds in the UK is currently occupied by a person with dementia.<sup>7</sup>
- Dementia accounts for 410,000 bed days annually in Wales and by 2040 this will have increased to 560,000 by 2040.<sup>8</sup>
- As dementia severity progresses, health care utilisation mostly increases, particularly in non elective inpatient, primary care and community care.<sup>9</sup>

1 Office of National Statistics (2023). *Deaths registered in England and Wales in 2022*.

2 Office of Health Economics (2015). *Estimation of Future Cases of dementia from Those Born in 2015*. P3.

3 Alzheimer's Society and Carnall Farrar (2024). *The economic impact of dementia. Module 1: Annual costs of dementia*. P33.

4 Ibid.

5 Alzheimer's Society and Carnall Farrar (2024). *The economic impact of dementia. Module 1: Annual costs of dementia*. P38.

6 Calculated using data from Alzheimer's Society and Carnall Farrar (2024). *The economic impact of dementia. Module 2: Dementia's contribution to health metrics*. P32.

7 Alzheimer's Society and Carnall Farrar (2024). *The economic impact of dementia. Module 2: Dementia's contribution to health metrics*. P11.

8 Calculated using data from Alzheimer's Society and Carnall Farrar (2024). *The economic impact of dementia. Module 2: Dementia's contribution to health metrics*. P11.

9 Calculated using data from Alzheimer's Society and Carnall Farrar (2024). *The economic impact of dementia. Module 2: Dementia's contribution to health metrics*. P26.



**1 in 3** people born today in the UK will **develop dementia in their lifetime**



Dementia costs Wales **£2.3 billion** today, rising to **£4.6 billion** by 2040



**1 in 6** hospital beds in the UK is currently **occupied by a person with dementia**



Considering the present and increasing prevalence and impact of dementia, this major health issue is not being made the priority it needs to be. The 2018 Dementia Action Plan was intended to run until 2022, but three years later Wales is still without a new plan. We are now expecting a new Dementia Action Plan in November 2025.

The 2018 Dementia Action Plan did represent a significant step forward in dementia policy, placing lived experience at the centre of policy making and committing to ambitious targets to raise diagnosis rates.<sup>10</sup> However, we have seen limited progress over the seven years the plan has been in place.

Alzheimer's Society has worked with clinicians, academics, and people living with dementia and their loved ones to develop three key priority areas for the next Dementia Action Plan for Wales:

- 1. Diagnosis and treatment: Setting ambitious diagnosis rate targets achievable through increased awareness and improved diagnostic capacity to improve access to treatments and interventions.**
- 2. Social care: Ensuring everyone with dementia has access to appropriate care, by requiring all social care workers to undertake mandatory dementia training.**
- 3. Governance and accountability: Ensuring policy is delivered through enhanced accountability, clinical and governmental leadership, and regularly published data.**

Wales urgently needs a new Dementia Action Plan to meet the challenge of dementia now, and in the future.

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<sup>10</sup> Welsh Government (2018). [Dementia Action Plan](#). P16.

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# Priority 1: Diagnosis and treatment

Early and accurate diagnosis and treatment are vital in supporting people with dementia to better manage their condition. Despite this, across the UK, the equivalent of just 1.4% of dementia healthcare costs are spent on diagnosis and treatment, while around a third is being spent on expensive and distressing unplanned hospital admissions.<sup>11</sup> Not having a diagnosis also increases the need for emergency medical care. People with undiagnosed dementia are almost twice as likely to attend A&E than those with a dementia diagnosis.<sup>12</sup>

The next Dementia Action Plan must prioritise access to an early and accurate diagnosis to ensure that people living with dementia can access the treatment and support they need, reducing the impact on our health and care system.

## A diagnosis allows people living with dementia to better manage their condition

Getting an early and accurate diagnosis enables people living with dementia to plan for the future. A diagnosis enables access to care, support, and symptomatic treatment, which helps people to better manage their condition and live independently at home for longer. In his 2023 annual report, Chief Medical Officer for England, Chris Whitty, noted that “this helps to avoid early or unnecessary admission to a care home or hospital, enhancing the quality of life for people with dementia and carers, and providing substantial savings on long-term care costs.”<sup>13</sup>

Without a diagnosis, people who are living with dementia are left to cope alone, missing out on months and sometimes years of treatment, care, and support. In a recent survey commissioned by Alzheimer’s Society, 97% saw benefits to getting a diagnosis.<sup>14</sup>

An early and accurate diagnosis will be even more important when new disease-modifying treatments (DMTs) for dementia become available through the NHS in the future, as well as providing opportunities for people to take part in the research for these drugs.

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11 Alzheimer’s Society and Carnall Farrar (2024). [The economic impact of dementia. Module 1: Annual costs of dementia.](#) P11.

12 Calculated using data from Alzheimer’s Society and Carnall Farrar (2024). [The economic impact of dementia. Module 2: Dementia’s contribution to health metrics.](#) P31.

13 Chris Whitty (2023). [Chief Medical Officer’s Annual Report 2023: Health in an Ageing Society.](#) P145.

14 Walnut (2024). [Alzheimer’s Society Personal Experiences of the Dementia Journey – The True Picture.](#) P25.

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## Wales has the lowest published diagnosis rate at 56%

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## Wales has the lowest published rate of diagnosis in the UK

Diagnosis rates are too low in every part of the UK, but Wales has the lowest published diagnosis rate at 56% – leaving nearly half of people with dementia to cope without the support, care, and treatment a diagnosis can bring. Significant regional variation also means the diagnosis rate is even lower in some parts of Wales, with Powys recording the lowest rate of 46.9%.<sup>15</sup> This is significantly lower than comparable geographies, such as South Yorkshire which records a diagnosis rate of 75.6%.<sup>16</sup>

Welsh Government's 2018 Dementia Action Plan sets a target for health boards to increase diagnosis rates by at least 3% a year from the 53% at which they stood when the Plan was published in 2018.<sup>17</sup> However, diagnosis rates have only increased 3% over the lifetime of the plan, meaning that Wales is around six years behind in terms of improving diagnosis rates.

Unfortunately, many people never get a diagnosis, and those who do get one, often receive it far too late. On average, people go three and a half years after the first onset of symptoms before receiving a diagnosis.<sup>18</sup> A recent Freedom of Information request by ITV Wales revealed that many people are being forced to wait much longer for investigations than the recommended 12 weeks from referral by a GP, with some waiting nearly three years.<sup>19</sup>

## Tackling barriers to diagnosis

There are many barriers to receiving a dementia diagnosis. Low public awareness of the real symptoms of dementia, unchallenged stigma, and mistaken ideas about how useful a dementia diagnosis can be are discouraging people from seeking a diagnosis. According to a study commissioned by Alzheimer's Society, fear of getting a diagnosis and apprehension about speaking to a healthcare professional are preventing many from seeking help.<sup>20</sup>

## Public awareness campaigns to improve awareness and reduce stigma

Many people still believe that dementia is a natural part of ageing, that everyone who has dementia lacks capacity, and that symptoms cannot be treated or managed. These misconceptions can make it difficult for people living with dementia to assert their rights and advocate for their needs.<sup>21,22</sup>

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15 Welsh Government (2024). [General practice disease registers](#).

16 NHS Digital (2025). [Primary Care Dementia Data, January 2025](#).

17 Welsh Government (2018). [Dementia Action Plan](#). P16.

18 Aldus CF, Arthur A, Dennington-Price A, Millac P, Richmond P, Denning T, et al. (2020). [Undiagnosed dementia in primary care: a record linkage study](#), *Health Serv Deliv Res*, Vol 8, Iss 20. P65.

19 ITV (2024). [Patients in Wales waiting nearly three years for a dementia diagnosis](#).

20 Walnut (2024). [Alzheimer's Society Personal Experiences of the Dementia Journey – The True Picture](#). P28.

21 All Party Parliamentary Group on Dementia (2019). [Hidden no more: Dementia and disability](#). P6.

22 Parker, M. et al. (2020). [Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia](#) *International Psychogeriatrics*, Vol 32, Iss 5, pp 611-634.

Seeking help for dementia-related symptoms often depends on a person's awareness and knowledge of dementia.<sup>23 24 25</sup> Denial or minimisation of the symptoms from the person with dementia or the family caregiver, or a reluctance of the family to get a diagnosis due to the implications for the future, are also barriers.<sup>26 27 28 29</sup> Social networks make a big difference: people who live alone or are in a hospital or care home are less likely to recognise symptoms.<sup>30 31 32</sup>

Low awareness of symptoms of dementia, and poor understanding of the condition itself, can result in misperceptions and stigma. Research commissioned by Alzheimer's Society surveying 3,500 people with experience of dementia showed that stigma is a huge issue for people living with dementia<sup>33</sup> and acted as a barrier to diagnosis. When asked 'How does it make you feel to live with symptoms of dementia?' 43% of respondents answered that they felt stigmatised and 25% said they felt ashamed.<sup>34</sup> In a primary care survey Alzheimer's Society commissioned in 2023, 29% of practice nurses cited stigma and denial as a barrier to referral and diagnosis.<sup>35</sup>

Public awareness raising campaigns are proven to improve awareness and understanding, reduce discrimination and remove societal barriers to improving care and support. Such campaigns achieve short term change by raising awareness and knowledge of specific conditions and symptoms, access to diagnosis pathways and increasing referrals to primary and secondary care.<sup>36</sup>

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23 Alzheimer's Society (2023). [Improving Access to a Timely and Accurate Diagnosis of Dementia in England, Wales and Northern Ireland](#).

24 Gove D et al. (2021). [The Challenges of Achieving Timely Diagnosis and Culturally Appropriate Care of People with Dementia from Minority Ethnic Groups in Europe](#), International Journal of Geriatric Psychiatry, Vol 36, Iss 12.

25 Devoy S and Simpson E. (2016). [Help-Seeking Intentions for Early Dementia Diagnosis in a Sample of Irish Adults](#) Ageing and Mental Health, Vol 21 Iss 8.

26 Alzheimer's Society (2023). [Improving Access to a Timely and Accurate Diagnosis of Dementia in England, Wales and Northern Ireland](#).

27 All-Party Parliamentary Group on Dementia (2023). [Raising the Barriers: An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England](#).

28 Aldus C F et al. (2020). [Undiagnosed Dementia in Primary Care: A Record Linkage Study](#). Health Services and Delivery Research, Vol 8, Iss 20.

29 O'Malley M et al. (2019). [Receiving a Diagnosis of Young Onset Dementia: A Scoping Review of Lived Experiences](#) Ageing and Mental Health, Vol 25, Iss 1.

30 Alzheimer's Society (2023). [Improving Access to a Timely and Accurate Diagnosis of Dementia in England, Wales and Northern Ireland](#).

31 All-Party Parliamentary Group on Dementia (2023). [Raising the Barriers: An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England](#).

32 Alzheimer's Society (2023). [Hospitals and Care Homes Increasing Access to a Dementia Diagnosis](#).

33 Walnut (2024). [Alzheimer's Society Personal Experiences of the Dementia Journey – The True Picture](#). P45.

34 Walnut (2024). [Alzheimer's Society Personal Experiences of the Dementia Journey – The True Picture](#). P14.

35 Bryter UK (2023). Bryter UK (conducted a 15-minute survey between February and March 2023, commissioned by Alzheimer's Society. The sample consisted of 200 general practitioners and 70 practice nurses from Wales, Northern Ireland, and England).

36 COI (2012). [Evaluation of the bowel cancer awareness pilot in the South-West and East of England: 31 January to 18 March 2011](#). P106.



## Case Study: The ‘Understand Together’ public awareness campaign in Ireland

Two surveys in 2016 and 2018 evaluating the impact of the nationwide ‘Understand Together’ public awareness campaign in Ireland assessed the use of a comprehensive public health approach to increase public awareness and knowledge of dementia risk factors. These studies identified an increase in awareness of recent advertising on dementia amongst key cohorts of the population, including amongst those in rural areas and lower socio-economic groups. There was also positive correlation between awareness of advertising and intention to engage with the diagnosis pathway.<sup>37</sup>

**Above:** Social media collateral promoting the ‘Understand Together’ campaign in Northern Ireland

### Improving clinical awareness

In 2023, Alzheimer’s Society commissioned market research across Wales, England, and Northern Ireland to understand attitudes to dementia in primary care. This research showed that almost a fifth of GPs still believe that there is little benefit in a formal diagnosis of dementia.

The same research showed that GPs who see a clear benefit in dementia diagnosis refer a significantly higher percentage of patients than those who do not see a clear benefit (69% vs. 61%).<sup>38</sup>

Only 46% of GPs surveyed felt well equipped to support and manage patients presenting with possible dementia symptoms and the vast majority (over three quarters) highlighted that they would find information and materials on how to support people living with dementia helpful.<sup>39</sup>

Amongst practice nurses, there is a need for more information specifically on diagnosis, with 90% of practice nurses highlighting that they would find more information on the signs and symptoms of dementia particularly useful.<sup>40</sup>

It is clear that misperceptions exist among health care professionals, resulting in discrimination and stigma surrounding dementia which will have a clear impact on an individual’s choice and ability to secure a diagnosis. The new Dementia Action Plan needs to prioritise upskilling healthcare professionals, giving them the tools and support they need to diagnose and support people living with dementia and increasing confidence and understanding in the health and care workforce to raise diagnosis rates and optimise post-diagnostic support.

<sup>37</sup> Hickey Dr. D (2019). [The impact of a national public awareness campaign on dementia knowledge and help-seeking intention in Ireland](#). P19.

<sup>38</sup> Bryter UK (2023). Bryter UK (conducted a 15-minute survey between February and March 2023, commissioned by Alzheimer’s Society. The sample consisted of 200 general practitioners and 70 practice nurses from Wales, Northern Ireland, and England).

<sup>39</sup> Ibid.

<sup>40</sup> Ibid.

## Addressing poor diagnostic capacity

Absolutely vital to improving dementia diagnosis rates in Wales will be improving diagnostic capacity. Currently, a positron emission tomography (PET) scan or cerebrospinal fluid (CSF) test is required to evidence Alzheimer's disease pathology to confirm eligibility for new disease-modifying treatments. But only half (50.7%) of memory services say they can refer patients for CSF tests<sup>41</sup> and only 2.1% of patients seeking a diagnosis ever have specialist investigations.<sup>42</sup>

The UK has the lowest number of PET and magnetic resonance imaging (MRI) scanners per capita among the Group of 7 (G7) countries, and Wales has a lower scanning capacity than even the UK average. There are 1.05 PET scanners per million population in England, compared to 0.73 PET scanners per million population in Wales.<sup>43</sup> We are far behind comparable nations, and need rapid and fundamental upscaling of our diagnostic capacity by investing in the tools and workforce required to diagnose more people early and accurately.

The 2023 Spotlight Audit in Memory Assessment Services also notes that despite admissions to services increasing by 130% per week since 2009, staffing levels have not matched this increase.<sup>44</sup> This must be addressed to tackle long waiting times for diagnosis.

**Only half (50.7%) of memory services say they can refer patients for CSF tests and only 2.1% of patients seeking a diagnosis ever have specialist investigations**

## Case study: The Blood Biomarker Challenge

Wales needs to be future proofing by preparing for implementation of new diagnostic techniques that can support early and accurate diagnosis. Alzheimer's Society is working on the Blood Biomarker Challenge, a £5 million award that hopes to revolutionise dementia diagnosis in the UK. In collaboration with Alzheimer's Research UK and the National Institute for Health and Care Research (NIHR), it will pilot the use of dementia blood tests in the NHS and could bring these blood tests to the NHS within five years. The NHS in Wales needs to be ready for these innovations.



**Above:** Professor Vanessa Raymont, who leads one of the research teams which make up the Blood Biomarker Challenge.

<sup>41</sup> Royal College of Psychiatrists (2024). *National Audit of Dementia. Spotlight Audit in Memory Assessment Services 2023/24. Appendix Documents II – V.* P43.

<sup>42</sup> Royal College of Psychiatrists (2024). *National Audit of Dementia. Spotlight Audit in Memory Assessment Services 2023/24. Appendix Documents II – V.* P30.

<sup>43</sup> NHS Wales Joint Commissioning Committee (2024). *Commissioning Policy Proposal: CP50 Positron Emission Tomography.* P31.

<sup>44</sup> Royal College of Psychiatrists (2024). *National Audit of Dementia. Spotlight Audit in Memory Assessment Services 2023/4.* P12.

## NICE-recommended treatments can alleviate symptoms and reduce pressure on the NHS

The substantial impact of dementia on services can only be reduced through early diagnosis and intervention, avoiding hospital admissions, and delaying the need for social care. Early diagnosis and treatment therefore have the potential to reduce the cost of dementia to the NHS, local authorities, and people living with dementia. Recent modelling commissioned by Alzheimer's Society suggests that cost savings of up to nearly £53,000 per person could be generated where nursing home admission can be delayed through effective treatment of Alzheimer's disease with acetylcholinesterase (AChE) inhibitors.<sup>45</sup> A portion of the cost savings can also be felt by the person living with dementia and their family. People with dementia 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.<sup>46</sup>

AChE inhibitors are most effective when combined with non-pharmacological treatments. One of the interventions for which there is most evidence for effectiveness is group Cognitive Stimulation Therapy (CST), which is recommended in the National Institute for Health and Care Excellence (NICE) guideline for dementia. CST is widely regarded as a cost-effective non-pharmaceutical intervention to enhance cognitive functioning and quality of life for people living with dementia without significantly increasing total care costs.<sup>47</sup> A number of studies have found that CST can help the memory and thinking skills of people with mild to moderate dementia.<sup>48,49</sup>

## Systems are not prepared for new breakthrough treatments

2024 saw the approval by regulators of groundbreaking new drugs, lecanemab and donanemab, which can slow the progression of Alzheimer's disease. Both drugs, lecanemab and donanemab, were determined by NICE and the All Wales Medicines Strategy Group (AWMSG) to be too expensive for distribution on the NHS. However, in other conditions like cancer, treatments have become more effective, safer, and cheaper over time, and we hope to see similar progress in dementia, particularly with around 20 drugs in late-stage clinical trials.

With one in three of us expected to develop dementia in our lifetime, the NHS in Wales must prepare to ensure everyone with dementia has access to the best possible treatments as and when they become available. This must include specific investment in the diagnostic workforce and infrastructure needed to ensure that everyone with suspected Alzheimer's disease can access a test to confirm eligibility for treatment at an early stage in their disease progression.

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45 Calculated using data from Alzheimer's Society and Carnall Farrar (2024). [The economic impact of dementia. Module 4: Impact of earlier diagnosis and treatment.](#) P18.

46 Alzheimer's Society and Carnall Farrar (2024). [The economic impact of dementia. Module 4: Impact of earlier diagnosis and treatment.](#) P19.

47 Knapp M, Thorgrimsen L, Patel A, et al. (2006). [Cognitive stimulation therapy for people with dementia: cost-effectiveness analysis.](#) Br J Psychiatry, Vol 188, pp. 574-580.

48 Chen J, Duan Y, Li H, Lu L, Liu J, Tang C. (2019). [Different durations of cognitive stimulation therapy for Alzheimer's disease: a systematic review and meta-analysis.](#) Clin Interv Aging, Vol 14, pp. 1243 - 1254.

49 Woods B, Rai HK, Elliott E, Aguirre E, Orrell M, Spector A. (2023). [Cognitive stimulation to improve cognitive functioning in people with dementia.](#) Cochrane Database of Systematic Reviews 2023, Iss 1.

## Recommendations

In the next Dementia Action Plan, Welsh Government must commit to:

- 1 Setting bold, ambitious, and achievable new diagnosis rate targets, bolstered by:**
  - a. Public awareness campaigns to raise awareness of symptoms, challenge stigma and encourage people to seek a diagnosis.
  - b. Engagement with medical professionals to increase clinical awareness of the importance of a diagnosis.
  - c. Long-term investment in diagnostic infrastructure and workforce.
- 2 Equitable access to appropriate NICE-approved treatments and interventions to reduce the impact of symptoms, and support people to live independently in their own home for longer.**
- 3 Planning to deliver new disease-modifying treatments in line with NICE guidance, as and when they become available.**



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# Priority 2: Social care

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**Fewer than four in ten people who are living with dementia are satisfied with the support they receive**

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## People with dementia don't feel supported

Social care can be a lifeline for people with dementia. Social care helps people manage symptoms and be supported at each stage of the condition. Effective social care for people living with dementia takes account of the effects of the condition, including progressive impacts on the ability to communicate, and complexity of needs.<sup>50</sup> Care needs to be person-centred and culturally sensitive, offer cognitive stimulation and take into account the specific needs created by different types of dementia. Appropriate support provided by trained and knowledgeable staff can reduce adverse, costly, and detrimental outcomes such as hospitalisation, carer breakdown and more rapid admittance to care homes.<sup>51</sup>

Care Inspectorate Wales reviewed dementia care homes in 2019 and found that variation they observed in the quality of care for people living with dementia in care homes is dependent on the staff understanding the needs of people with dementia.<sup>52</sup>

A recent Alzheimer's Society survey found that fewer than four in ten people who are living with dementia are satisfied with the support they receive. When asked what would best help to improve their lives, 65% said more care workers who are skilled in caring for those with dementia.<sup>53</sup>

## There is a skills gap in dementia care

High quality dementia training can help staff to understand the evolving needs of the person living with dementia. For people with dementia, well-trained social care staff results in improvements in their day-to-day quality of life. Best practice examples of training have been shown to:

- Provide a healthier and more ethical means of supporting complex needs such as agitation and help reduce the use of physical restraints.<sup>54</sup>
- Reduce inappropriate prescribing of antipsychotic medications and other psychotropic medications.<sup>55</sup>
- Promote better quality relationships and enable culturally competent care<sup>56</sup>

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50 Nuffield Trust (2024). [What needs to improve for social care to better support people with dementia](#). P18.

51 Alzheimer's Society (2024). [Because we're human too](#).

52 Care Inspectorate Wales (2020). [National review of care homes for people living with dementia](#). P10.

53 Walnut (2024). [Alzheimer's Society Personal Experiences of the Dementia Journey – The True Picture](#). P41.

54 Möhler R, Richter T, Köpke S, Meyer G. (2023) [Interventions for preventing and reducing the use of physical restraints for older people in all long-term care settings](#). Cochrane Database Syst Rev. Vol 7, Iss 7.

55 Ballard C, Orrell M, Moniz-Cook E, Woods R, Whitaker R, Corbett A, et al. (2020). [Improving mental health and reducing antipsychotic use in people with dementia in care homes: the WHELD research programme including two RCTs](#). Programme Grants Appl Res, Vol 8, Iss 6.

56 Alzheimer's Society (2024). [Because we're human too](#). P4.

Despite the huge disease burden of dementia on the social care system, many working in social care lack dementia specific training and skills. Though the data is not available for Wales, we do know that only 29% of the care workforce in England have any kind of dementia training.<sup>57</sup> Care Inspectorate Wales reviewed dementia care homes in 2019 and found that training staff in dementia care was one of the challenges they faced, and that training to support care homes could be better arranged and coordinated.<sup>58</sup>

Dementia is a complex illness with numerous types, and it is essential that staff have the knowledge and training to treat people with all types of dementia and the individual needs of people who draw on care. In Wales, the Good Work Framework is the national framework which sets out a rights-based, wellbeing and person-centred approach to dementia education.<sup>59</sup> However, only 38% of services providing dementia care are aware of the Good Work Framework.<sup>60</sup>

All adult care workers must register with Social Care Wales through a qualification or by employee assessment. Registering through a qualification does include some dementia specific outcomes. However, social care workers who enter social care through employer assessment may never undertake dementia training. This route asks that employers support employees in completing the All-Wales Induction Framework within six years of registering.<sup>61</sup> It is not clear how, if at all, this is monitored and considering many staff leave before six years in social care, it is unlikely that the workforce is adequately trained in dementia care.

## **Wales needs mandatory dementia training in social care**

Mandatory dementia training for all social care staff will provide a range of benefits for both those living with dementia and social care workers themselves. By having a workforce trained specifically in how to care for people living with dementia, those living with dementia will receive the most appropriate and person-centred care.

There is a desire amongst staff to undertake training. The Social Care Workforce Delivery Plan 2024-2027 noted that 80% of the workforce are keen to improve their skills and knowledge.<sup>62</sup> Social Care Wales's 2023 survey found there was an "unmet demand for training" indicating a willingness amongst care staff to undergo training and improve their skills.<sup>63</sup> However, a 2023 Social Care Wales survey identified that 40% of care staff felt there were barriers to accessing training at work.<sup>64</sup>

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57 Skills for Care (2024). [The state of the adult social care sector and workforce in England 2024](#). P41.

58 Care Inspectorate Wales (2020). [National review of care homes for people living with dementia](#). P11.

59 Care Council for Wales (2016). [Good Work Framework](#). P13.

60 Care Inspectorate Wales (2020). [National review of care homes for people living with dementia](#). P11.

61 Social Care Wales (2023). [Registration changes for social care workers and managers](#).

62 Social Care Wales (2025). [Social care workforce delivery plan 2024 to 2027](#).

63 Social Care Wales (2023). [Social care workforce survey 2023](#).

64 Ibid.



Training can also improve staff retention, with Skills for Care data showing that social care staff who receive regular training have a lower turnover rate than those who do not.<sup>65</sup> High turnover of staff negatively impacts social care, but providing training opportunities can reduce turnover and can increase the likelihood of an individual remaining in the sector.<sup>66</sup> With nearly half of social workers expected to leave the profession in the next five years, increased training opportunities could help retain many of these experienced and vital workers.<sup>67</sup>

Making training mandatory will ensure that dementia patients aren't unfairly penalized by the turnover of social care staff and will support people who draw on social care and their families to feel confident that they will receive the best possible care.

## Recommendation

The next dementia action plan must include:

- 4. A statutory duty for all registered care providers to ensure their care staff undertake dementia training mapped to the standards set out in the Good Work Framework, underpinned by sufficient funding. Local authorities should ensure this training is included as a contractual provision when commissioning adult social care services in Wales.**

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<sup>65</sup> Skills for Care (2024). *The state of the adult social care workforce in England*. P112.

<sup>66</sup> Social Care Wales (2023). *Social care workforce survey 2023*.

<sup>67</sup> Ibid.

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# Priority 3: Governance, accountability, and leadership

Leadership will be crucial to ensure that good policy intentions are translated into real improvements for people who are living with dementia. Political and clinical leaders need to collaborate to construct effective governance arrangements, with clear and transparent accountability structures. This needs to be backed up by better collection, dissemination, and use of dementia specific data to appropriately direct resources to meet the needs of people living with dementia.

## Governance and accountability is vital to ensuring delivery

Effective governance and accountability mechanisms are essential in the delivery of national dementia strategies, underpinned by clear, measurable targets for which specific stakeholders are responsible.

The 2018 Dementia Action Plan set ambitious aims but many of these remain unimplemented. There is a lack of clear ownership and accountability of objectives in the plan. This has led to an absence of centralised leadership for the management and improvement of dementia services, and a lack of strategic approach to delivery. The Interim Evaluation assessing implementation of the 2018 Plan highlighted variation in regional priorities<sup>68</sup>, variable infrastructure<sup>69</sup> and low accountability<sup>70</sup> as barriers to effective implementation. The Interim Evaluation also noted the need for ‘accompanying guidance’ and clarity from Welsh Government around the delivery of key objectives for national bodies, in addition to the appointment of a National Clinical Lead for Dementia to drive implementation.<sup>71</sup>

Given the scale of the challenge of dementia, the next Dementia Action Plan must be ambitious. But these ambitions cannot be realised without leadership and aligned governance and accountability at national and local levels. This will help to ensure consistency and continuity across national and regional dementia pathways, helping to deliver transformation in services and tackle regional variation.

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68 Government Social Research (2024). [Evaluation of the Dementia Action Plan 2018-2022: Interim findings](#). P21.

69 Government Social Research (2024). [Evaluation of the Dementia Action Plan 2018-2022: Interim findings](#). P79.

70 Government Social Research (2024). [Evaluation of the Dementia Action Plan 2018-2022: Interim findings](#). P22. P30. P32.

71 Government Social Research (2024). [Evaluation of the Dementia Action Plan 2018-2022: Interim findings](#). P21.

## Clinical leadership can drive transformation

In Wales, the role of a clinical lead is to offer clinical leadership, advice, input and support on the relevant condition and services across the NHS as a practicing clinician.<sup>72</sup> These leaders support commissioning and transformation of services, development of policy and political accountability, and general efforts to keep the relevant condition at the top of the agenda to deliver the best possible outcomes for patients. Unlike other major conditions, Wales does not currently appoint a national clinical lead for dementia. It is essential this role is introduced to address this lack of parity compared to other areas which do have a clinical lead such as palliative and end of life care; cancer; cardiovascular disease; and diabetes.<sup>73</sup>

England appoints a National Clinical Director for Dementia and Older People's Mental Health.<sup>74</sup> The disparity between clinical leadership structures across the UK nations limits collaboration between clinicians and dementia specialists in the planning and delivery of dementia care pathways. It also limits accountability and improvement in clinical practice, integration between systems and the sharing of good practice to improve the quality of person-centred care.

## Better collection, dissemination, and use of data

Improved data collection is a critical foundation for enhancing understanding of the dementia pathway and identifying where services can be improved. However, there is a significant mismatch between the scale and urgency of dementia as the biggest killer in the UK, and the huge gaps in dementia-specific data.

The routine collection of national dementia diagnosis data in the UK is reported as being 'very limited' by the World Health Organisation.<sup>75</sup> In Wales, this picture is even worse. Whilst NHS England publishes extensive monthly diagnosis data for England, Wales data is only available once a year and only reports dementia prevalence in those aged over 65.<sup>76</sup> Unlike in England, Welsh data is not available on the type of dementia, assessment received, or on referrals. It is not possible to redesign services and deliver effective pathways with such a limited picture. Better data collection and publication is needed to properly understand variation and allocate resources appropriately. Key information which needs to be published regularly includes:

- All diagnoses data, including dementia type and diagnosis setting (e.g. primary care, acute care, care homes).
- Recording of dementia severity in primary care using a uniform severity measurement tool indicator such as the Mini Mental State Examination.
- Diagnosis waiting times, with as much context as possible to aid understanding of reasons behind variation in waiting times.
- Access to imaging and specialised testing.
- Prescribing data on the use of NICE-recommended medicines.

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72 NHS Executive (undated). [Introducing the new National Strategic Clinical Networks](#). P19.

73 NHS Executive (undated). [Introducing the new National Strategic Clinical Networks](#).

74 NHS England (undated). [National Clinical Directors and Speciality Advisors](#).

75 World Health Organisation (2021). [Global status report on the public health response to dementia](#). P14.

76 Welsh Government (2024). [General practice disease registers](#).



Consistent data on these indicators would enable the sharing of comparative data to help identify and respond to long-term demographic trends, NHS performance and service variation and ensure that progress can be accurately tracked and measured.

## Recommendations

The next Dementia Action Plan must be supported by:

5. **A new, effective, and transparent governance structure for dementia policy in Wales, with clear lines of accountability at national and local level.**
6. **A National Clinical Lead for Dementia in Wales.**
7. **Better collection, dissemination, and use of dementia data to set objectives, track progress and evaluate performance.**

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# Summary of recommendations

Dementia is one of the biggest health challenges facing Wales today. With prevalence due to increase by 37% over the next 15 years, action is needed now to support people living with dementia and reduce the impact of the condition on our health and care systems. Welsh Government must commit to publishing a new Dementia Action Plan in 2025 which prioritises diagnosis, treatment, social care, and implementation. To ensure the next Dementia Action Plan delivers for people living with dementia, Welsh Government must commit to:

- 1 **Setting bold, ambitious, and achievable new diagnosis rate targets, bolstered by:**
  - a. Public awareness campaigns to raise awareness of symptoms, challenge stigma and encourage people to seek a diagnosis.
  - b. Engagement with medical professionals to increase clinical awareness of the importance of a diagnosis.
  - c. Long-term investment in diagnostic infrastructure and workforce.
- 2 **Equitable access to appropriate NICE-approved treatments and interventions to reduce the impact of symptoms, and support people to live independently in their own home for longer.**
- 3 **Planning to deliver new disease-modifying treatments in line with NICE guidance, as and when they become available.**
4. **A statutory duty for all registered care providers to ensure their care staff undertake dementia training mapped to the standards set out in the Good Work Framework, underpinned by sufficient funding. Local authorities should ensure this training is included as a contractual provision when commissioning adult social care services in Wales.**
5. **A new, effective, and transparent governance structure for dementia policy in Wales, with clear lines of accountability at national and local level.**
6. **A National Clinical Lead for Dementia in Wales.**
7. **Better collection, dissemination, and use of dementia data to set objectives, track progress and evaluate performance.**

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**Dementia is the UK's biggest killer, and one in three people born in the UK today will develop the disease in their lifetime. Your support gives people living with dementia help and hope, for today and the future. It is only because of you that we can continue to give vital support to those living with dementia, fund groundbreaking research and campaign to make dementia the priority it should be. Together, we can ensure dementia no longer devastates lives.**

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Alzheimer's Society operates in England, Wales, Isle of Man and Northern Ireland. Registered charity number 296645 and Isle of Man (1128)