

Dementia Strategy for Wales 2026-2036

A draft strategy of what we want to achieve between 2026 to 2036

December 2026

Overview

Welsh Government is publishing a new draft Dementia Strategy (2026-2036) for public consultation. This will replace the previous <u>Dementia Action Plan</u>, published in February 2018, and subsequent Companion Document in 2021.

The Dementia Strategy aims to improve dementia care and support across Wales. We have been clear that we intend to co-produce this new strategy, and that we will take the time necessary to meaningfully engage partners and people with lived experience throughout. This document is therefore intended to provide the opportunity for people to have early engagement in the content of the document. The findings of this engagement will inform our final strategy in 2026.

How to respond

Please respond by completing the online form or completing this questionnaire and sending it to: Email:

mentalhealthandvulnerablegroups@gov.wales

If you intend to respond in writing, please send completed forms to: Mental Health and Vulnerable Groups, Welsh Government, Cathays Park, Cardiff, CF10 3NQ. When you reply, it would be useful if you confirm whether you are replying as an individual or submitting an official response on behalf of an organisation and include:

- your name
- your position (if applicable)
- the name of organisation (if applicable)

Further information and related documents large print, Braille and alternative language versions of this document are available on request.

Having your own discussions

We understand that there are lots of groups that may want to discuss the strategy and respond to the consultation. To support these discussions, we have created an engagement pack with ideas and information on how to feedback. Please contact:

mentalhealthandvulnerablegroups@gov.wales

UK General Data Protection Regulation (UK GDPR)

The Welsh Government will be data controller for Welsh Government consultations and for any personal data you provide as part of your response to the consultation.

Welsh Ministers have statutory powers they will rely on to process this personal data which will enable them to make informed decisions about how they exercise their public functions. The lawful basis for processing information in this data collection exercise is our public task; that is, exercising our official authority to undertake the core role and functions of the Welsh Government. (Art 6(1)(e))

Any response you send us will be seen in full by Welsh Government staff dealing with the issues which this consultation is about or planning future consultations. In the case of joint consultations this may also include other public authorities. Where the Welsh Government undertakes further analysis of consultation responses then this work may be commissioned to be carried out by an accredited third party (e.g. a research organisation or a consultancy company). Any such work will only be undertaken under contract. Welsh Government's standard terms and conditions for such contracts set out strict requirements for the processing and safekeeping of personal data.

In order to show that the consultation was carried out properly, the Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. If you do not want your name or address published, please tell us this in writing when you send your response. We will then redact them before publishing.

You should also be aware of our responsibilities under Freedom of Information legislation and that the Welsh Government may be under a legal obligation to disclose some information.

If your details are published as part of the consultation response, then these published reports will be retained indefinitely. Any of your data held otherwise by Welsh Government will be kept for no more than three years.

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- to require us to rectify inaccuracies in that data
- to (in certain circumstances) object to or restrict processing
- for (in certain circumstances) your data to be 'erased'
- to (in certain circumstances) data portability
- to lodge a complaint with the Information Commissioner's Office (ICO) who is our independent regulator for data protection

For further details about the information the Welsh Government holds and its use, or if you want to exercise your rights under the UK GDPR, please see contact details below:

Data Protection Officer Welsh Government Cathays Park Cardiff CF10 3NQ

Email: dataprotectionofficer@gov.wales

The contact details for the Information Commissioner's Office are:

Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

Telephone: 0303 123 1113 Website: https://ico.org.uk

Contents

Introduction	6
The principles for consideration across the strategy	8
Priority areas for the next dementia strategy	9
Section A: Risk reduction and prevention in dementia	10
Section B: Raise awareness and understanding of dementia	.12
Section C: Improving dementia diagnosis, treatment, care and suppo	
Section D: Supporting unpaid carers of people living with dementia	33
Section E: Supporting the Workforce	35
Section F: Supporting dementia research and innovation	39
Section G: Suitable governance and accountability arrangements to ensure the strategy is delivered.	.43

Introduction

Our previous <u>Dementia Action Plan</u> (DAP) was published in February 2018. The plan set out a clear vision for Wales to be a dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities. In recognition of the challenges of the Covid 19 pandemic we refreshed the plan, alongside our national Dementia Oversight of Implementation and Impact Group (DOIIG), and a subsequent <u>Companion Document</u> was published in 2021.

This was the first dementia plan for Wales and to ensure we learnt lessons from its implementation we commissioned an <u>independent</u> <u>evaluation</u>. The COVID-19 pandemic had a significant impact on the research timeline for the evaluation due to disruption and delays in arranging and undertaking interviews with stakeholders including a focus to ensure people with lived experience of dementia were involved. We delayed its publication to ensure that we were able to obtain this feedback.

The evaluation concluded that the plan had positively transformed the dementia landscape in Wales and advanced person-centred care and support in a number of areas. However, it also recognised that "there remains some way to go" to optimise care and support for people living with dementia and unpaid carers. This provided us with a series of recommendations which are informing our work on preparing the current strategy.

We have engaged widely to encourage as many people as possible to be actively involved with this work and this included undertaking an online questionnaire in 2024 to gather views about the key areas we should focus on in the successor strategy. This resulted in over 400 responses, and these findings have also informed this consultation document.

Throughout this process we have continued engagement with a broad range of stakeholders and crucially people with lived experience who have shaped these proposed priorities. Two external task and finish groups have also been established to advise on both the content and governance arrangements supporting the successor plan and have been instrumental in developing this work so far.

We have been clear that we will develop this new strategy in partnership and that we will take the time necessary to meaningfully engage partners and people with lived experience throughout. This document is therefore intended to provide the opportunity for people to have early engagement on the content and the themes that will be included in the final strategy. Our final document will also provide further detail on how it aligns with other key government strategies and will provide more detail on the expected outcomes and commitments.

What do we mean by dementia?

For the purposes of this consultation, we have used the World Health Organisation's definition of dementia which states: 'Dementia is an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour, and that interfere significantly with a person's ability to maintain the activities of daily living'.

Alzheimer disease is the most common form of dementia and may contribute to 60–70% of cases. Other major forms include vascular dementia, dementia with Lewy bodies, and a group of diseases that contribute to frontotemporal dementia. The boundaries between different forms of dementia are indistinct and mixed forms often coexist.

<u>Alzheimer's Disease International</u> reported in 2020 that over 55 million people worldwide living with dementia in 2020. This number will almost double every 20 years, reaching 78 million in 2030 and 139 million in 2050.

To indicate the scale in Wales <u>a 2024 report by the Alzheimer's Society</u> and <u>CF</u> states that 51,000 people are living with dementia in Wales and this is expected to increase to 70,000 by 2040.

Our vision for our next dementia strategy.

Wales will be a nation where people living with dementia are respected, supported, and empowered to live independently and with dignity in their communities. We envision a society where stigma is not accepted and an increased awareness of dementia, supports people living with dementia and their families to live and socialise in inclusive and compassionate communities, that will empower people to live independently and with dignity in their communities through diagnosis, care, and treatment. Achieving this vision requires a united, crossgovernment and multi-agency effort, grounded in the voices and experiences of those living with dementia. Together, we will build a future where rights are upheld, support is person-centred, and no one faces dementia alone.

The principles for consideration across the strategy.

We want to ensure that our next dementia strategy focuses on the things that matter most to people. These principles will help everyone involved understand the things that guide our actions and decisions and so we have developed a set of principles below that will inform our work.

Person-centred: Offering care and support which is coordinated and individualised, whilst ensuring that people are empowered, included in decision making and treated with dignity, compassion and respect.

Rights-based approach: Supporting people to recognise and develop their own strengths and ability to make informed decisions about their own health and care. Ensuring that care and support is provided in a way that respects, protects and fulfils the rights of individuals, and fully considers the specific rights some groups have, for instance disability rights.

Co-production: A way of working whereby people with lived experience and practitioners work together as equal partners to plan and deliver care and support.

Equity of access, experience and outcomes without stigma and discrimination: Across all settings, stages of dementia, and regions, we will focus on:

- Equity of access to information, including that to support brain health and dementia care
- Reducing stigma and misconceptions about dementia.
- Equity of access to other essential services for people living with dementia.
- Promoting equality, diversity, and inclusion in all aspects of care.

Recognising *intersectionality:* Understanding how different aspects of a person's identity—like race, gender, language, sexuality, disability, and more—combine and interact to shape their experiences. This will look at how multiple factors overlap to affect someone's life, taking a personcentred approach rather than focusing on just one aspect at a time

Ensuring **timely and accurate diagnosis**: enabling early access to support and planning.

Taking a **preventative approach** by focusing on brain health, **improving resilience and reducing risk**, but recognising people will

still develop dementia and we need to ensure people are supported to live healthier for longer.

Services will be **integrated and coordinated**, and will foster collaboration across health, social care, housing, and community services and will develop **evidence-based care and support.**

Support for unpaid carers and families will provide emotional support, education and access to respite. We will recognise the rights that unpaid carers and families have, ensuring they are key partners in care and be supported to be involved in care planning.

We will ensure we **develop our workforce**, enabling staff across health, social and voluntary sectors can recognise dementia symptoms, understand the impact of dementia and use this knowledge to deliver compassionate and quality care.

We will support **research and innovation**, including by supporting people living with dementia to be involved in research on causes, care, and potential cures and support innovation in service delivery and care models.

Priority areas for the next dementia strategy.

We have identified a number of areas that we will focus on in the next strategy. These are:

- A. Risk reduction and prevention in dementia.
- B. Raising awareness and understanding of dementia.
- C. Improving dementia diagnosis, treatment, care and support.
- D. Supporting unpaid carers of people living with dementia.
- E. Supporting the workforce.
- F. Supporting dementia research and innovation.
- G. Suitable governance and accountability arrangements to ensure the strategy is delivered

In the following sections we have outlined what we want to include in each one.

Section A: Risk reduction and prevention in dementia

This strategy aims to strengthen the relationship between existing population health work in terms of brain messaging and consider what that work needs to look like when you consider it through a dementia lens.

There needs to be an increased awareness that the risk of developing some types of dementia can be reduced, or the onset or progression delayed, through lifestyle changes.

This section will explain that 'it is never too early or too late' to consider your brain health and that it is necessary to have a public health approach that tackles brain health across every sector, whether that is the statutory sector (for instance health and social care), third sector, business or communities.

Building healthy habits early supports long-term brain health, helping to maintain cognitive function and enhance mental resilience throughout life. But it is 'never too late' as the brain can adapt and change at any age. Learning new skills, engaging socially, and staying mentally active can improve cognitive function even in later life. Small adjustments can positively impact brain health.

The 2024 update to the standing <u>Lancet Commission</u> on dementia prevention, intervention, indicates that nearly half of all dementia cases worldwide could be prevented or delayed by addressing 14 modifiable risk factors across the lifespan.

- Early life: Less education (5%)
- **Midlife**: Hearing loss (8%), High low-density lipoprotein (LDL) cholesterol (7%), Depression (3%), Brain injury (3%), Physical inactivity (2%), Diabetes (2%), Smoking (2%), Hypertension (1%), Obesity (1%), Excessive alcohol (<1%)
- Late life: Social isolation (5%), Air pollution (3%), Visual loss (2%)

These modifiable risk factors can be categorised as below and need to be considered as part of our 'brain health' interventions. We will need to do this in a way that recognises inequalities of access and opportunity.

Promoting Brain-Healthy Lifestyles

This means encouraging physical activity, healthy diet, weight management, alcohol moderation, support mental wellbeing and smoking cessation¹.

Addressing Medical Risk Factors

This means early identification and management of medical conditions such as high blood pressure, elevated LDL cholesterol (bad cholesterol), diabetes, hearing loss, and vision impairment which play an important role in supporting brain health.

By integrating dementia-related strategies with broader chronic disease approaches - including those targeting traumatic brain injury - we can encourage healthier behaviours and create environments that promote long-term cognitive wellbeing.

Enhancing Cognitive and Social Engagement

This includes a focus on keeping your brain active and staying socially connected which can help support your memory and thinking skills as you age. Activities that challenge your mind - like learning something new, solving puzzles, or engaging in meaningful conversations - can help build what's known as 'cognitive reserve'. This is your brain's ability to adapt and keep working well, even as you get older.

Creating Supportive Environments

Supportive, dementia-friendly communities can make a big difference to the lives of people living with dementia. For Welsh speakers, being able to continue to live in a Welsh speaking community can help individuals to remain socially active. This means creating safe and accessible spaces, raising awareness so people understand dementia and know how to help, and encouraging social participation so everyone feels included. It also involves local services—like councils, businesses, charities, and healthcare—working together to meet people's needs. Most importantly, it means empowering people living with dementia to have a voice in decisions that shape their communities.

¹ This will align with other Welsh Government strategies, such as: Tobacco Control Strategy, Health Weight: Healthy Wales, Minimum Unit Pricing and the Mental Health and Wellbeing Strategy

Section B: Raise awareness and understanding of dementia.

This section will explain how our actions to support brain health will enable us to promote evidence-based messages and help people to understand dementia and know how to support those affected.

Our **public health messaging** needs to be tailored to our communities, and we need to ensure that we communicate in languages that are accessible, take account of cultural diversity and ensure that our communication is also accessible for people with hearing and sight loss. Information, services and support need to be provided in line with the Accessible Communication and Information Standards in Healthcare, which have recently been renewed to include a focus on people with dementia, as well as sensory loss, whose first language is not English or Welsh, people with learning disabilities, and people with low literacy.

Making Every Contact Count (MECC) is crucial. Every interaction is an opportunity to offer support, share information, and encourage positive change. By embedding MECC into routine practice, organisations and individuals can play a powerful role in helping people make healthier choices and access the help they need. These moments of contact, however brief, can have a lasting impact.

This complements 'Social prescribing', an umbrella term that describes a person-centred approach to connecting people to local community assets. It can help empower individuals to recognise their own needs, strengths, and personal assets and to connect with their own communities for support with their personal health and wellbeing

For individuals, it can mean getting support to take action to improve their own lifestyle or enhance social engagement, but for a population the benefits can be wide-ranging.

For this approach to work we need to know what 'community assets' we have available. Community assets is a collective term for anything that can be used to improve the quality of community life. This can include community groups, faith groups, Welsh as a community language, interventions and services which could be delivered online or in person, as well as buildings, land or even a person within a community.²

We need to ensure that we are maximising the opportunities these assets provide to improve the messaging of risks and encouraging the

² Public Health Wales and WSSPR (2023) A Glossary of Terms for Social Prescribing in Wales

establishment of supportive environments that can provide significant benefit for people living with dementia and their families.

We will need to explain how we will ensure that our awareness raising utilises these assets when focusing on activities that support our brain health. We will use this information to support our public health messaging on campaigns and the need for us to prioritise health checks.

We want our approach to tackle health inequalities and the impact of the wider determinants of health, through supporting individual behaviour change and tackling issues that matter to them such as finance, transport or housing. We can also use this approach to help address equity of access, by engaging those who will not have otherwise engaged. This will require a cross- governmental approach.

People who are at greater risk of dementia.

Our dementia strategy will be for the whole population, but we will also need to ensure that we have a focus on those populations that we know are at greater risk. We have outlined these below.

Age	Age is the strongest known risk factor. Most people with dementia are over 65, but over 70,000³ people in the UK under 65 also live with dementia, and we know those with young onset dementia may have atypical presentation which can lead to late presentation to services.
Black, Asian and Minority Ethnic groups.	Dementia prevalence is higher in some Black, Asian and Minority Ethnic groups, especially South Asian communities. These groups often face delays in diagnosis ⁴ as often dementia is misunderstood and stigmatised, resulting in barriers to accessing services. They are also often underrepresented in research.
Women	More likely to develop dementia ⁵ , partly due to longer life expectancy and possibly hormonal factors.

³ <u>https://www.youngdementianetwork.org/about-young-onset-dementia/young-onset-dementia/young-onset-dementia-facts-and-figures/</u>

⁴ ethinic minorities increasing access to diagnosis.pdf

⁵ Sex, gender and dementia - Alzheimer's Research UK

People with learning disabilities	People with learning disabilities ⁶ are more likely to develop dementia than the general population and can have atypical presentations. Dementia may also progress more rapidly in this group due to delayed diagnosis and co-existing health conditions. The risk is particularly high for people with Down's Syndrome.
People experiencing socio- economic deprivation or physical or social isolation	Social isolation ⁷ and lack of community engagement can contribute to cognitive decline. This group can also have reduced access to healthcare, healthy lifestyle options, and cognitive stimulation.

We need to ensure that people can recognise **early signs and symptoms of dementia** and understand the benefits of a diagnosis. By reducing stigma and supporting people to access early advice, assessment, support and treatment it will help people to live longer independently and maintain a higher quality of life.

This will include equipping people living with dementia, their families and unpaid carers with the right knowledge, but also means doing the same for our 'frontline workforce'. This workforce is broad and can include staff in health care, social care, and the voluntary sector

⁶ Learning disabilities and dementia | Alzheimer's Society

⁷ Social isolation and cognitive decline in older adults: a longitudinal study across 24 countries | BMC Geriatrics | Full Text

Section C: Improving dementia diagnosis, treatment, care and support.

Diagnosis of dementia

We need to recognise that getting a formal diagnosis of dementia is a positive step. A dementia diagnosis is important to individuals, their unpaid carers and their families to ensure they have access to information, to enable them to connect with support services, and to plan for future needs. In addition, for Alzheimer's Disease, disease modifying treatments (DMTs) have the potential to slow disease progression. Early diagnosis and early rehabilitation provide opportunities that can support someone to live as well as possible with their condition. As such any diagnosis should include advice on how to maintain quality of life.

Supporting brain health continues to be relevant when you obtain a diagnosis. Early diagnosis can also lead to improved quality of life through social connections, supporting independent relationships, knowledge and peer support. Early interventions and rehabilitation that can help with symptoms, can also lead to a reduction in hospital admissions and can help people to develop strategies and maximise independence.

We therefore need to ensure that we have timely, accurate and personcentred diagnosis of dementia. This will mean having a clear pathway and competence framework in place and will build on existing work ongoing in Wales⁸. To support this work, we will publish more data on diagnosis of dementia to enable us to measure impact.

Key Considerations for Developing a Dementia Diagnostic Pathway

Our dementia strategy will be clear on the components that should be considered when designing diagnostic pathways. This will include;

Tailored, Integrated Pathways: Developing clear, evidence-based pathways that are person-centred and coordinated across primary, secondary, and social care. It will recognise that different types of dementia require distinct diagnostic and treatment approaches.

⁸ Collaboration between Royal College of Psychiatrists, National Collaborating Centre for Mental Health (NCCMH), Alzheimer's Society Cymru, NHS Performance and Improvement, National Consultant Allied Health Professional Lead for Dementia, Dementia Programme Leads and stakeholders across Wales.

Strengthening Services: Enhancing the capacity and capability of services to improve diagnosis and take a broad multidisciplinary approach to improve access, quality, integration, and both pre- and post-diagnostic support.

Improving Diagnostic Outcomes: By focusing on increasing diagnosis rates, improving diagnostic accuracy, and reducing waiting times through streamlined processes and workforce development. This will include an assessment of our infrastructure readiness that will enable us to develop the infrastructure needed to take into account rising prevalence and introduction of potential disease modifying treatments

Simplifying and Standardising Assessments: Ensuring that they are person-centred and promote improvements to diagnosis. To ensure a service that is equitable and of quality for Welsh speakers this should include developing and validating assessments in Welsh.

Early Identification and Referral: Enable early referral from primary care to memory clinics or specialists and support early intervention using validated assessment tools within primary care settings.

Holistic Health Screening: Incorporate physical health checks, relevant blood tests, and available biomarkers to rule out other causes and support accurate diagnosis.

Trauma-Informed Practice: Embed trauma-informed care principles within diagnostic services, drawing on the Trauma-Informed Wales Framework and good best practice examples, including those from other countries such as such as those developed in Scotland.

Psychological and Emotional Support: Include provision for pre- and post-diagnostic counselling and emotional support.

Workforce Training: Ensure all staff involved in supporting people living with dementia are trained in dementia-specific communication, assessment techniques, and person-centred approaches.

Consistent Coding and Documentation: Adopt standardised coding systems such as SNOMED to support accurate recording and classification of dementia diagnoses.

Community and Third Sector Involvement: Recognise and integrate the role of community awareness and third sector organisations in supporting individuals throughout the diagnostic journey and beyond.

Tackling Inequalities in Dementia Care

Addressing inequalities in dementia care is essential to ensure that all individuals, regardless of background or circumstance, have equitable access to timely, accurate, and compassionate support. When developing and delivering dementia services, the following areas must be considered:

Socioeconomic Barriers: People from lower-income backgrounds may face challenges accessing services due to cost, transport, or competing life pressures. Services should be designed to be flexible, and responsive to these needs.

Geographic Location: Rural and remote communities often experience reduced access to specialist services. We need our approach to consider how we bridge these gaps, such as outreach models and telehealth options.

Ethnicity and Culture: Cultural beliefs and stigma can impact help-seeking behaviours. Services must be culturally competent, inclusive, and co-designed with communities to ensure relevance and trust.

Language Barriers: Language differences can hinder communication and understanding during diagnosis and care. Services and support should be offered in Welsh without a person having to ask for it (the Active Offer). Interpretation services and translated materials should be readily available and delivered in line with the Accessible Communication and Information Standards in Healthcare.

Disability and Comorbidities: Individuals with physical, sensory, or cognitive disabilities, as well as those with multiple health conditions, may require adapted assessment tools and tailored support pathways.

Digital Exclusion: As services increasingly rely on digital platforms, it is vital to ensure that those without access to technology or digital literacy are not left behind. Alternative formats and in-person options must remain available.

By thinking about these things when we design and deliver dementia care pathways, we can move towards a more inclusive, equitable system that meets the diverse needs of the population.

Meeting the Needs of Other Language Speakers in Dementia Care

As referenced above, effective dementia care must be inclusive of individuals and available in people's preferred languages. Language barriers can significantly impact access to diagnosis, understanding of the condition, and engagement with support services. To ensure equitable care, services must be linguistically accessible, culturally sensitive, and tailored to individual communication needs.

Welsh Language

Under the Welsh Language (Wales) Measure 2011, individuals have the right to receive services in Welsh. Dementia services must:

- Provide bilingual information, validated, language-appropriate assessment tools, and support materials.
- Ensure availability of Welsh-speaking staff or interpreters, particularly during diagnosis and counselling.
- Recognise the importance of language in identity and emotional wellbeing, especially for individuals who may revert to their first language as dementia progresses.
- Embed the principles of the Welsh Government's "More Than Just Words" framework to promote the Active offer and culturally appropriate care.

We need to make greater progress in providing health and care services for people living with dementia through the medium of Welsh. Receiving services in Welsh is not a choice, it is a clinical need and is fundamental in ensuring the dignity of Welsh speakers. The strategy will consider Welsh language needs during the pre-diagnosis period, at diagnosis and in the long-term care of Welsh speakers. This will involve developing a culture that supports the use of the Welsh language and ensuring that we monitor progress on this.

There is a need to ensure that information being shared is available bilingually and that Welsh-medium materials and resources that exist are shared and used sufficiently. The next strategy will consider further work that needs to be undertaken to enhance our understanding of testing the cognitive ability of bilingual speakers.

British Sign Language (BSL)

People who are d/Deaf and use BSL face unique challenges in accessing dementia care. Services should:

- Ensure access to qualified BSL interpreters for all stages of the diagnostic and care pathway.
- Provide dementia information and resources in BSL format, including videos and visual aids.
- Train staff in d/Deaf awareness and communication strategies to support effective engagement.
- Recognise that d/Deaf individuals may experience delayed diagnosis due to communication barriers and stigma and proactively address these gaps.
- Deliver services and support in line with the Accessible Communication and Information Standards in Healthcare.

Broader Language Needs

For speakers of other languages, services should:

- Offer interpretation and translation services throughout the care journey, in line with the Accessible Communication and Information Standards in Healthcare.
- Provide culturally appropriate materials and support that reflect diverse backgrounds.
- Engage with community organisations to co-design services that are trusted and accessible.
- Ensure staff are trained in cultural competence and understand the impact of language on care quality and patient experience.

Assessment and Support for Mild Cognitive Impairment (MCI)

Recognising and responding to Mild Cognitive Impairment (MCI) is a vital component of dementia prevention and early intervention. While MCI does not always progress to dementia, it represents a key opportunity to promote brain health and reduce future risk.

The development of **Brain Health Clinics** should be prioritised to support early identification and intervention for individuals with MCI. This will enable the opportunity for the accurate recording of MCI diagnoses using Read and SNOMED codes which is essential to ensure visibility within health records and enable appropriate follow-up and support.

People living with MCI should be offered a **personalised risk reduction plan** to enable regular monitoring of physical health, mental wellbeing, and cognitive function.

Plans should incorporate:

- Lifestyle advice (e.g. physical activity, nutrition, sleep, cognitive stimulation).
- Peer support and community engagement.
- Signposting to local services and resources.
- Psychological support where appropriate.

Clear pathways must be established to define who is responsible for reviewing individuals identified as 'at risk' and for maintaining and updating risk reduction plans. People identified at risk also need to be able to ask for a review if they show signs of change.

This approach aligns with current Dementia Care Standards.

Post-Diagnostic Support

Post-diagnostic support must be responsive, person-centred, and sustained throughout the dementia journey. Recognising that every person's experience of dementia is unique, services must be designed to meet a wide range of needs, drawing on diverse professional expertise and community resources.

A central element of post-diagnostic support is the **Dementia Connector**—a dedicated, named point of contact who provides continuity of care from diagnosis through to end-of-life. This role ensures:

- A consistent link between the person, their unpaid carers, family members and the wider health and social care system.
- Navigation of support across services, helping individuals and families understand and access available resources.
- Ongoing emotional and practical support, tailored to changing needs over time.
- Coordination of care planning, including making decisions on future care preferences.

Person-Centred Care and Planning

We need to develop tailored care plans that reflect the individual's needs, preferences, and goals, including future care planning to support decision-making if the person becomes less able to communicate.

These care plans will also enable the person diagnosed with dementia to access timely interventions, such as biopsychosocial interventions, psychological therapies, cognitive stimulation therapy, pharmacological treatments, and rehabilitation services to support independence and wellbeing.

The 'Dementia Connector' will be key to accessing other supportive resources such as those offered by allied health professionals (AHPs) and community-based initiatives.

AHPs play a critical role in delivering holistic, person-centred care—supporting individuals with dementia through tailored interventions that promote independence, wellbeing, and quality of life. Their expertise in areas such as occupational therapy, physiotherapy, speech and language therapy, and dietetics ensures that care is not only clinically informed but also responsive to changing needs.

These plans need to be flexible so people can access support at any stage of their diagnosis, including later points when needs may change or intensify. Coordinated working between professionals, services, unpaid carers, and people with lived experience is key to providing collaborative and inclusive care. This should involve the ability to adapt physical and social environments to reduce stress and promote independence.

Any approach to person-centred care must also recognise and support the vital role of unpaid carers. Ensuring they receive timely information, are offered carers assessments, have access to relevant support, and are involved in care planning as equal partners is fundamental to delivering compassionate and effective dementia care.

In Wales, we will do this through the development of the Integrated Community Care Systems (ICCS), ensuring people are connected to wider support networks and resources. This will build on the existing provision that is mandated through the Social Care and Well-being (Wales) Act 2014 such as through information, advice and assistance services and our Integrated Quality Statement for Older People and People living with Frailty

Dementia Treatment and Disease-Modifying Therapies (DMTs)

While there is currently no cure for dementia, treatment options are expanding, and research continues to advance rapidly. It is essential to recognise that treatment encompasses a broad scope—including

pharmacological therapies, rehabilitation, psychological support, and social care interventions—all of which contribute to improving quality of life and maintaining independence. Treatment should be tailored to the type and stage of dementia. There are established treatments for non-Alzheimer's disease dementias, and these should be made available in line with stage of dementia and NICE guidance. Similarly, for Alzheimer's disease dementia treatment should be tailored to the stage of dementia and NICE guidance, ensuring that individuals receive appropriate support at each phase:

- Mild Cognitive Impairment (MCI): People with mild cognitive impairment, whether due to Alzheimer's disease or another cause, can benefit from personalised brain health and risk-reduction plans. For individuals with MCI due to Alzheimer's disease, additional treatment with Medicines & Healthcare products Regulatory Agency (MHRA) approved disease-modifying therapies may be considered where the person meets the specific eligibility criteria for these therapies subject to these treatments being National Institute for Health and Care Excellence (NICE) or All Wales Medicines Strategy Group (AWMSG) approved.
- Mild Alzheimer's Dementia: Individuals with mild Alzheimer's dementia should continue to receive personalised brain health and risk-reduction plans and be offered already available symptomatic treatments for Alzheimer's dementia. For individuals with mild Alzheimer's dementia, treatment with MHRA-approved disease-modifying therapies may be considered where the person meets the specific eligibility criteria for these therapies subject to these treatments being NICE or AWMSG approved. Treatment with disease-modifying therapies should be discontinued once a person progresses to moderate Alzheimer's dementia, as effectiveness beyond the mild stage has not been established.
- Moderate Alzheimer's Dementia: People with moderate Alzheimer's dementia should already have personalised brain health and risk-reduction plans in place and should be receiving appropriate symptomatic treatments. In line with NICE guidance, individuals with an established diagnosis who are already taking one symptomatic treatment may need to be considered for an additional symptomatic treatment for Alzheimer's dementia. Group cognitive stimulation therapy should be offered to people living with mild to moderate dementia.

• Severe or Late-Stage Alzheimer's Dementia: The focus shifts to palliative and supportive care, including palliative rehabilitation and end-of-life care, that acknowledges the rights and wishes of the person. Comfort, dignity, and emotional support become central to care planning. At this stage, individuals should be receiving appropriate symptomatic treatments. In line with NICE guidance, individuals with an established diagnosis who are already taking one symptomatic treatment should be offered an additional symptomatic treatment for Alzheimer's dementia.

There continues to be advances in early detection and treatment. Innovations in biomarker technology are transforming early detection and diagnosis. These include:

- Neuroimaging biomarkers: MRI, CT, FDG-PET, and amyloid PET scans.
- Fluid biomarkers: Cerebrospinal fluid (CSF) analysis and emerging blood-based biomarkers.

These tools help identify individuals at risk and guide treatment decisions, particularly as new therapies become available.

We will continue to be guided by NICE in the development and provision of new treatments. As research progresses, more potential therapies are likely to emerge and we need to ensure we have the infrastructure in place. However, it will be important to ensure we understand the effectiveness and suitability of new treatments across the different types of dementia and that this is clearly communicated.

What is clear is that we need to ensure that services remain flexible and informed, ensuring that individuals living with dementia benefit from the latest evidence-based interventions.

Care and Support.

Person-centred care must be the foundation of dementia care and support, whether it is delivered by health, social care, third sector, or unpaid carers. To achieve this, we must invest in a well-trained, confident, and compassionate workforce that has sufficient capacity and is equipped to meet the evolving and complex needs of people living with dementia. Our workforce development section will go into this in more detail.

The strategy will recognise that there are key principles of personcentred dementia care and support

- Individualised Care: Recognise each person's identity, history, culture, language, values, and preferences. Embed "what matters" conversations into care planning and daily practice.
- **Active Involvement:** Ensure people living with dementia are central to decisions about their health and social care, including advance care planning.
- Continuity of Support: Provide access to dementia connectors
 who act as a consistent point of contact, supporting individuals and
 families through transitions between home, hospital, and care
 settings.
- Accessible Communication: Ensure all information about care decisions is provided in a format that is understandable and meaningful to the person.
- Emotional and Psychological Support: Offer timely access to psychological therapies, and emotional support and psychosocial interventions, recognising the impact of dementia on mental wellbeing for individuals and those that care for them.

By embedding these principles and investing in workforce development, to ensure the provision of evidence-based training, we can ensure that dementia care is not only clinically effective but also compassionate, inclusive, and responsive to the needs of individuals and their families.

Person-Centred Care and Independent Living

Everyone should have access to person-centred care that supports their ability to live independently, avoid unnecessary hospital admissions, and maintain wellbeing. In alignment with the All-Wales Rehabilitation Framework (2022), care should be:

- **Holistic**, addressing physical, cognitive, emotional, and social wellbeing. This includes access to rehabilitation, meaningful activity, and opportunities for social connection.
- Tailored through stepped care models, ensuring support is proportionate and responsive to individual needs.
- Community-based, enabling people to live independently for longer. This is achieved through the involvement of social care, allied health professionals, home adaptations, and assistive technology.
- Collaboratively delivered, with a person-centred approach that brings together health, social care, third sector organisations, and

unpaid carers. This creates a seamless and integrated pathway to living well.

This approach ensures that rehabilitation is not just a clinical intervention but a value-based, inclusive process that empowers individuals and supports their autonomy.

Care and support for people living with dementia must also actively consider and address their **physical health needs**. Many individuals live with multiple long-term conditions, and managing these comorbidities is essential to maintaining overall wellbeing and preventing avoidable deterioration. Proactive and coordinated care can help reduce the risk of hospital admissions and, where admission is necessary, support shorter stays and smoother transitions back into the community through a focus on discharge planning. This includes regular health monitoring, access to rehabilitation, and ensuring that physical health is integrated into dementia care planning across all settings.

Ensuring staff have the time, knowledge and skills to support those with dementia will be part of the future planning and future educational needs.

Inclusive and Context-Aware Dementia Care and Support

Dementia care must be person-centred, but also context-aware—recognising that the setting in which someone lives, their identity, and their community all shape the kind of support they need.

Recognising the setting in which a person lives or receives care is essential to delivering truly person-centred support. Whether someone is at home, in supported accommodation, or in a hospital, the environment influences their needs, preferences, and the type of rehabilitation and support that will be most effective. This means we must think differently about how care is provided—adapting our approaches to ensure they are responsive to the individual's circumstances. The accompanying table highlights key areas to consider across different settings, helping to guide the development of tailored, holistic, and enabling care that supports independence and wellbeing. Welsh speaking individuals living with dementia and their families need clear and accessible information about the extent of Welsh-medium provision in care services, especially in care homes.

Home

Enable independence through home adaptations, assistive technology, and community-based support

Dementia connectors to coordinate care Support access to meaningful social connections (e.g., speech for communication, mobility for outdoor access).

Prison

Recognise unique needs of older prisoners with dementia Provide assessments/diagnostics, adapted environments, and staff training.

Ensure access to healthcare and continuity of care post-release.

Individual with dementia

Care Home

Embed culturally competent, personcentred care in routines and staff training. Promote independence with daily tasks. Encourage meaningful activities and relationships.

Use life story work and reminiscence therapy.

Hospital

In line with hospital charter. Implement dementia-friendly assessments and environments that encourage usual mobility, activity, and social interaction.

Respect language, culture, and heritage Train staff in dementia awareness and communication.

Support timely, coordinated discharge.

Community

Dementia specific and dementia inclusive activities.
Support timely and coordinated care.

Whether someone is living in a rural area, is a woman with caring responsibilities, belongs to a group with specific cultural or health-related needs, or any combination of similar considerations, care must be tailored accordingly, some examples of this are included below.

People with Learning Disabilities

Individuals with learning disabilities, including those with Down's syndrome, are at higher risk of developing dementia, often at a younger age. Diagnosis can be missed if symptoms are mistaken for pre-existing cognitive challenges. Key considerations include ensuring:

- Accessible and meaningful information about dementia risk factors and signs must be available to individuals, care givers and professionals.
- Access to annual health checks that include dementia risk assessment.
- Equitable access to memory services and post-diagnostic support, which will build on previous work in improving psychological support and adaptations within memory assessment services.
- Communication support, that enables behavioural interventions and recognises non-verbal indicators of distress or pain.

Young Onset Dementia (Under 65s)

Young onset dementia affects people typically in their 40s to early 60s and presents unique challenges, such as delayed diagnosis due to busy lifestyles, employment, and family responsibilities. This means that support will need to consider how we can support people to maintain routines, employment, and caregiving roles. This will include peer support networks, legal and financial planning, and access to emotional/psychological support.

Services must be age-appropriate and not default to older adult models.

Women

Women are known to have a higher prevalence of dementia, which is recognised in the <u>Women's Health Plan</u>, and also in many cases can be both the carers and the care recipient.

We need to ensure gender-sensitive approaches to support planning, including emotional wellbeing and social connection.

Rural Communities

Living in rural areas can significantly impact access to timely diagnosis, specialist services, and ongoing support. We need to ensure that we bridge these geographic gaps by working innovatively and considering things such as outreach models and digital solutions.

We also need to consider that people can be more isolated and look at how we can harness available community resources and improve access to transport. This is also true for supporting rural carers, who may have fewer opportunities for respite or peer connection.

Ethnic Minority Communities

Culturally competent care is essential to reduce barriers and improve outcomes:

- Addressing stigma and cultural perceptions of dementia.
- Providing translated and co-produced materials that reflect cultural values.
- Ensuring access to interpreters and culturally sensitive diagnostic tools.
- Training for staff in religious and spiritual considerations.
- Community-based education and outreach to raise awareness and promote early engagement.

Language and Communication in Dementia Care and Support

While the importance of language and communication has already been highlighted in the context of diagnosis, it is equally critical in the ongoing care and support of people living with dementia. Language is not just a tool for communication—it is central to emotional wellbeing, identity, dignity, and safety.

Welsh Language Speakers

As dementia progresses, bilingual individuals often lose their ability to communicate in their second language, with many Welsh speakers reverting to Welsh as their dominant or only language. This has significant implications for care and speaking in one's first language enhances emotional and cognitive wellbeing and is essential for dignity and effective care.

The **Active Offer** must be embedded across all care settings—ensuring Welsh-speaking individuals are proactively offered services in their preferred language, without having to ask. Staff across health, social care, and care homes should be supported to develop and maintain Welsh language skills.

The Welsh language should be central to inspection and quality assurance processes with emphasis placed on the fact that a lack of care through the medium of Welsh can adversely affect the well-being of individuals.

There is a need for Welsh-language dementia resources to support understanding and engagement.

British Sign Language (BSL) Users

For d/Deaf individuals who use BSL, similar principles apply:

- First language communication is vital for emotional wellbeing, safety, and autonomy.
- Services must be tailor-made to ensure individuals fully understand the care and support being offered and feel in control of their decisions.
- There is a clear need for dementia resources in BSL, alongside access to trained interpreters and staff who understand d/Deaf culture and communication needs.

In both cases, care must be person-centred and linguistically inclusive, recognising that communication is a cornerstone of quality dementia support. This means not only offering services in the right language, but also ensuring that materials, assessments, and interactions are culturally and linguistically appropriate.

Tailored Care and Support Across Dementia Types

Dementia is not a single condition but a spectrum of disorders, each with its own progression, symptoms, and support needs. Providing effective care means recognising this diversity and ensuring that services are flexible, inclusive, and tailored to the specific type of dementia a person is living with. Some examples of this are:

Alzheimer's Disease.

This is the most common dementia. Support should focus on delivering person-centred interventions that address the unique needs, preferences, and abilities of each individual. Evidence supports combining pharmacological treatments, with non-pharmacological strategies like cognitive stimulation, physical activity, and social engagement.

Frontotemporal Dementia (FTD)

FTD often affects people under 65 and is characterised by changes in personality, behaviour, and language. It can be particularly challenging for families and carers due to the emotional and behavioural symptoms. Support should include:

- Specialist behavioural and psychological support.
- Age-appropriate services and peer support.
- Education and guidance for carers on managing symptoms.

Dementia with Lewy Bodies (DLB)

DLB presents with fluctuating cognition, visual hallucinations, and Parkinsonism. Individuals may be sensitive to certain medications, making accurate diagnosis and careful management essential. Care should include:

- Multidisciplinary input, including neurology and psychiatry.
- Medication reviews and tailored treatment plans.
- Support for mobility, sleep disturbances, and hallucinations.

Vascular Dementia

Often linked to stroke or cardiovascular disease, vascular dementia can present with stepwise cognitive decline (periods of relative stability punctuated by sudden, significant drops in ability). Managing underlying health conditions is critical. Care should focus on:

- Cardiovascular risk management.
- Rehabilitation and reablement.
- Support for cognitive and emotional wellbeing.

Mixed Dementia

Many people live with more than one type of dementia, most commonly Alzheimer's disease and vascular dementia. This requires integrated care approaches that address the full range of symptoms and health needs.

Other forms of cognitive impairment.

Alcohol-Related Brain Damage (ARBD) is a form of cognitive impairment linked to long-term alcohol misuse. It can result in memory loss, difficulties with planning and decision-making, and changes in behaviour. People with ARBD may be younger and face stigma or barriers to accessing dementia services. Care should focus on:

- Early identification and diagnosis.
- Access to specialist support and rehabilitation.
- Holistic approaches that address physical health, mental wellbeing, and social inclusion.
- Support for recovery and maintaining independence.

Planning for the Future: Advance and Future Care Planning, Palliative and End-of-Life Care

Advance and Future Care Planning

Advance and Future Care Planning (AFCP) empowers individuals by placing their values, preferences, and human rights at the centre of care, ensuring decisions reflect what matters most to them. It reduces unnecessary or burdensome interventions, increases the likelihood of a dignified death in their preferred place, and fosters meaningful reflection on identity, spirituality, and priorities. At the same time, AFCP supports

families by easing emotional burdens and improves the overall quality and coordination of end-of-life care across healthcare systems.

Dementia is a progressive and terminal condition, and as it advances, individuals may lose the capacity to make decisions about their care. AFCP is essential to ensure that people living with dementia can express their values, preferences, and beliefs while they still have capacity, and throughout their care journey.

This includes making advance decisions about treatment, appointing Lasting Powers of Attorney (LPAs), and recording wishes around future care and support. AFCP should be accessible, with reasonable adjustments made to support engagement, and must be informed by the principles of the Mental Capacity Act.

Care and support must be personalised and holistic, guided by the individual's recorded wishes wherever possible. Early conversations about future care, including place of care and treatment preferences, help ensure dignity and autonomy are upheld.

Palliative Care

Palliative care should be introduced **early in the dementia journey**, not just at the end of life. It focuses on improving quality of life, managing symptoms, and providing emotional and psychological support. Key elements include:

- · Collaborative working across health and social care.
- Ongoing review to ensure care remains responsive to changing needs.
- Training for the workforce to deliver compassionate, informed care.
- Support for carers throughout the progression of the condition.

End-of-Life Care

End-of-life care becomes more prominent in the later stages of dementia, often overlapping with palliative care. It should be guided by the Welsh Government's Quality Statement for Palliative and End-of-Life Care and the national service specification for palliative and end of life care, which emphasise dignity, respect, and cultural sensitivity, including the importance of the Welsh language. Key considerations include:

 Early planning for place of care and ensuring necessary support and equipment are in place.

- Symptom management and comfort.
- Support for carers during the final stages.
- Access to bereavement support following the death of a loved one.

Together, these approaches ensure that care remains compassionate, coordinated, and person-centred, even as needs become more complex.

Evidence-Informed Dementia Care and Support

Dementia care and support must be grounded in the best available evidence, recognising that this is an evolving field where new research continues to shape best practice. As our understanding of dementia grows, so too must our approaches to care—ensuring they remain responsive, effective, and person-centred.

There is a hierarchy of evidence that guides decision-making, starting with nationally recognised standards such as NICE guidance, which provide a robust foundation for clinical and care pathways. However, emerging research, lived experience, and innovation also play a vital role in shaping services, particularly in areas where evidence is still developing.

This means that strategies and service models must be flexible and adaptable, with mechanisms in place to incorporate new findings and respond to changing needs. It also requires a commitment across organisation to provide continuous learning, evaluation, and collaboration across sectors to ensure that dementia care in Wales remains at the forefront of quality and compassion.

Section D: Supporting unpaid carers of people living with dementia.

Unpaid carers play a vital role in supporting people living with dementia, often providing complex care over extended periods. Alongside generic information such as access to social prescribing opportunities, benefits and carers rights (including assessments) there should also be dementia-specific support for carers must be comprehensive, culturally sensitive, and accessible. This should include:

- Respite care tailored to dementia, including short breaks and flexible options to support carer wellbeing.
- Psychosocial interventions that are accessible both to people living with dementia and their unpaid carers
- Education and psychoeducation, including skills training and information about dementia progression, communication strategies, and managing behavioural changes.
- Peer support networks play a crucial role in reducing isolation and fostering emotional resilience. These networks provide a safe space for sharing experiences, practical advice, and coping strategies, which can help normalise challenges and reduce feelings of stigma.
- Crisis support pathways to help carers navigate urgent or challenging situations.

Improving communication between health and social care professionals and unpaid carers is essential to ensure carers are well-informed, involved in decision-making, and recognised as integral members of the care team. Local authorities have statutory duties to involve unpaid carers in the assessment and care planning/reviews through the Social Services and Wellbeing (Wales) Act 2014. And Health boards should assure themselves unpaid carers included in the development of care and treatment plans. Welsh Government Discharge Guidance also requires unpaid carers to be included from the earliest stages in individual discharge planning

The Welsh Government's current Strategy for Unpaid Carers, published in 2021, outlines a whole-system approach to recognising and supporting carers across Wales. This outlines the legal rights under the Social Services and Well-being (Wales) Act 2014, including access to a Carer's Assessment and a Carer's Support Plan which are statutory duties.

It also focuses on four national priorities: improving recognition, access to information, support for education and employment, and promoting emotional wellbeing.

A new National Strategy for Unpaid Carers will be published in 2026. This will refresh the strategic priorities for unpaid carers including respite/ short breaks, access to information and carers' needs assessments and support. There will be alignment between the Dementia and Unpaid Carers strategies.

Section E: Supporting the Workforce

Developing a skilled, confident, and compassionate workforce across **health, social care, and the third sector** is essential to delivering high-quality dementia care. We need to ensure everyone in the workforce receives high quality learning and development opportunities.

Dementia training must be embedded as a core component of workforce development, with a strong emphasis on **trauma-informed approaches** that recognise the complex experiences of individuals living with dementia and their unpaid carers.

Strategic leadership and governance are critical to driving this agenda forward—establishing clear roles and responsibilities, including a strategic function for **Health Education and Improvement Wales** (**HEIW**) and **Social Care Wales**, to lead and support improvements. This work needs to enable staff across health, social and voluntary sectors to recognise dementia symptoms, understand the impact of dementia and use this knowledge to deliver compassionate and quality care, informed by dementia training.

Embedding dementia care and learning opportunities into organisational governance structures will ensure accountability, sustainability, and a culture of continuous improvement across all sectors.

Existing Learning and Development Frameworks

A range of existing frameworks provide a foundation for dementiarelated workforce development across health, social care, and the third sector. This section of the strategy will explore how frameworks such as Good Work, the Allied Health Professionals (AHP) Framework, and the emerging competency framework linked to diagnostic pathways can be aligned to support a whole-system approach. This includes promoting dementia-friendly awareness and recognising how such frameworks can support unpaid carers and people with lived experience.

We will examine how these frameworks operate together, identifying whether they focus on specific specialisms or offer more generic support across roles and settings. As part of this work, we intend to revise and provide supporting materials to enhance the usability of the current **Good Work – Learning and Development Framework**, which is structured around three levels:

- Informed individuals (general awareness)
- **Skilled practitioners** (direct care roles)
- Organisational influencers (leaders and managers)

This work will be co-produced, ensuring that learning materials are relevant, inclusive, and reflective of real-world experiences and needs.

To build a confident, skilled, and compassionate workforce, a dementia learning and development framework should incorporate several key components:

Continuous Professional Development

Starting with a focus on supporting those entering the workforce to start well, with access to foundational training. Continue to promote ongoing learning through vocational and professional development opportunities and encourage reflective practice and supervision to embed learning into everyday care.

Person-Centred Care Competencies

Promote person-centred, compassionate, and competent practice across health and social care. Training should include tools such as "What Matters to Me" to support personalised care planning, and place emphasis on communication skills, empathy, and cultural competence.

Rights-Based and Inclusive Practice

Ensure the workforce understands and upholds the rights of people living with dementia, promoting anti-discriminatory practice. Staff should be equipped with knowledge of legal frameworks, safeguarding responsibilities, and advocacy services to support inclusive care.

Supportive Work Environments

Foster a culture of compassionate leadership, respect, and inclusion. Provide emotional, psychological, and physical support for staff and unpaid carers. Encourage integrated working across disciplines and sectors and promote shared learning and joint care planning to strengthen collaboration.

Workforce Planning and Capacity Building

Effective workforce planning for dementia care must be grounded in a mature, system-wide approach that spans health, social care, and the third sector. We need to consider the following:

Awareness as a Foundation: Building dementia awareness across all sectors is a critical starting point, and schemes such as 'dementia

friends' ⁹ have a key role to play. This ensures that all staff, regardless of role, have a baseline understanding of dementia and its impact.

Awareness needs to be part of the education and training that students within health and social care experience and for that ongoing training and support to employ those skills in day-to-day interactions with patients.

Assessing Current and Future Capacity: Workforce planning must be informed by robust data on current capacity and projected needs, particularly in light of increasing dementia prevalence and the need to improve diagnosis rates. This includes mapping skills, roles and service gaps across regions and sectors. The Welsh Language Standards also place duties on organisations to provide training courses for staff to develop an awareness of the Welsh language.

Integrated and Regional Planning: A coordinated approach is by organisations is needed to understand and address workforce gaps. Regional and integrated planning, such as clinical services plans, integrated medium term plans and the Regional Partnership Board plans, should support demonstrate the delivery of learning and development opportunities that are accessible and relevant across settings.

Recruitment and Retention Strategies: Strategies should be aligned with relevant professional frameworks and recognise the diversity of roles that support people with dementia—whether in part or wholly. Organisations need to ensure these requirements are included in pathways for clinical, care, and community-based roles.

Whole-Pathway Workforce Planning: Workforce planning must span the entire dementia pathway—from diagnosis to end-of-life care—and anticipate future needs, including the capacity to deliver disease-modifying treatments and fostering a culture of research and innovation. A united approach should bring together professionals from all sectors, including the third sector, to ensure continuity and quality of care. Organisations need to ensure that there are sufficient staff to specifically care for those with dementia and also support those patients living with dementia that require treatment and care and support for other conditions.

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⁹ https://www.alzheimers.org.uk/get-involved/dementia-friends

Monitoring and Evaluation: Supporting Workforce Development and Understanding Learning Impact

Effective workforce development in dementia care requires a strategic approach to monitoring and evaluation that not only measures the impact of learning and development but also supports broader actions to strengthen the workforce.

Evaluating Training Impact and Care Outcomes
 Use audit tools and recognised quality benchmarks to assess how training translates into improved care practices and outcomes.

 This ensures that learning interventions are not only delivered but are effective in enhancing the quality of care and professional

competence.

- Embedding Lived Experience in Evaluation
 Incorporate feedback from people living with dementia and their carers to evaluate workforce effectiveness. Their perspectives are essential in understanding how training influences real-world care experiences and whether it meets the needs of those receiving support.
- Broadening Workforce Development Support
 Monitoring and evaluation should also inform wider workforce
 development strategies, including identifying gaps in skills,
 promoting continuous professional development, and shaping
 future training priorities. This includes fostering a culture of
 reflective practice, supporting staff wellbeing, and ensuring
 equitable access to learning opportunities across roles and
 settings.

By aligning evaluation with broader workforce development goals, organisations can create a more resilient, skilled, and person-centred workforce that is responsive to the evolving needs of people with dementia and their unpaid carers. These need to be reflected in organisations' strategies and clinical services plans, as these are developed.

Section F: Supporting dementia research and innovation.

This strategy aims to strengthen the relationship between dementia research and the existing infrastructure in Wales by identifying emerging needs, setting priorities, and addressing gaps where Welsh-specific research is required. To achieve this, it will foster strategic partnerships that leverage both UK-wide and international research where most beneficial, while also building collaborations within Wales to deliver research that reflects local contexts and needs. Developing pan-Wales relationships will be key to sharing learning from ongoing studies and ensuring that research is embedded across health and social care systems. The plan will encourage collaborative work between national bodies such as the UK Dementia Research Institute, Health and Care Research Wales (HCRW), NHS, and NICE, while also engaging third-sector organisations and academic institutions to ensure that research efforts are inclusive, impactful, and aligned with the lived experiences of people affected by dementia in Wales.

A **clear research framework** will be developed to determine when a research gap warrants Welsh-led investigation, and to identify areas where Welsh input is essential to broader UK or international studies.

Central to this approach is the creation of a culture that values research—one that actively communicates its benefits to individuals, families, and professionals, and encourages participation across all communities. We will ensure our updates on the strategy include supporting research, so people can see the benefits of involvement in research projects.

Research Priorities

The development of a research framework will help us to identify key areas where available research or planned research can drive improvements in care, support, and outcomes for people living with dementia. These priorities reflect both unmet needs and opportunities for innovation and evidence-based practice. This work has already started through stakeholder engagement and the development of impact assessments that will accompany this strategy. These emerging research priorities include:

• Young onset and rarer dementias: understanding the unique challenges and care needs of individuals diagnosed at a younger age or with less common forms of dementia.

- **People with learning disabilities**: exploring how dementia presents and progresses in this population, and tailoring support accordingly.
- **People living alone with dementia**: investigating the risks, support mechanisms, and service models that can enhance independence, wellbeing and safety.
- Dementia with comorbidities: including mental health conditions and long-term physical health issues, to better understand complex care needs and integrated approaches.
- Ensuring diversity in research: making sure that we pick up both gender and ethnicity differences in this work.
- Understanding the impact of bilingualism: to ensure care and support is equitable and of quality for Welsh speakers, more research is required how to effectively and correctly assess Welsh speakers/bilingual speakers.
- Post-diagnostic support and care pathways: evaluating what works in the critical period following diagnosis, and how to ensure continuity and quality of care.
- **Unpaid carers**: researching the experiences, needs, and support systems for those providing unpaid care, often under significant emotional and financial strain.
- Equity and access to services: including a focus on early detection and timely diagnosis, to reduce disparities and improve outcomes across communities.
- **Prevention**: including a focus on brain health, improving resilience and reducing risk
- Improvements in palliative and end of life care: considering best practice, models of care, and support systems that ensure dignity, comfort, and person-centred approaches for people with dementia and their families during the final stages of life.

Embedding Research into Practice: To maximise the value of existing and future research, it is essential to embed evidence into everyday practice. This means translating findings into actionable guidance, training, and service design, and ensuring that frontline staff, carers, and people living with dementia benefit directly from the knowledge generated and have the opportunity to be involved. A culture of learning and continuous improvement, supported by research, will help drive sustainable change and better outcomes.

Innovation in Delivery

To improve diagnosis and care for people living with dementia, we must actively support and scale innovative approaches that respond to evolving needs and technological opportunities, such as:

- **Supporting digital innovations**: including virtual clinics, remote monitoring, and assistive technologies that enhance access, continuity, and personalised care.
- **Promoting co-designed solutions**: ensuring that people living with dementia and their unpaid carers are meaningfully involved in shaping services and tools that reflect their lived experience.
- Encouraging new models of care: ensuring that innovative approaches such as precision medicine are considered, and that services are supported to implement these where appropriate.

To strengthen our research efforts, we must invest in **building capacity** and fostering a culture that values inquiry, evidence, and continuous learning. This includes developing research skills among both staff and people with lived experience, recognising their unique contributions to shaping meaningful and impactful studies.

Providing training, mentorship, and practical support enables staff to actively engage in research activities, enhancing their critical thinking and helping to grow the evidence base that informs dementia care. By embedding research as a core component of professional practice, we can ensure that innovation and improvement are driven by real-world insights and robust data.

Central to building a meaningful and inclusive research culture is the active involvement of people with dementia and their carers as **experts by experience**. Their insights are invaluable in shaping research design and delivery, ensuring that studies reflect real-world challenges and priorities. We must also create accessible and engaging ways for the wider public to participate in and understand research—whether through community forums, simplified summaries of findings, or inclusive consultation processes. Importantly, research must reflect the **diverse lived experiences** of those affected by dementia, including underrepresented groups, and align with the identified research priorities to ensure relevance, equity, and impact.

Evaluation and Impact.

To ensure that research and innovation in dementia care leads to meaningful change, it is vital to embed robust evaluation mechanisms. Establishing **core outcome measures** allows us to consistently assess the impact of research across different settings and populations. These measures should capture improvements in **quality of life**, the **cost-effectiveness** of interventions, and the **benefits of treatments and**

service transformation. Leveraging data in this way supports evidence-informed decision-making and helps demonstrate value to stakeholders.

Equally important is the **wide dissemination of findings**—using accessible formats such as webinars, summaries, and community engagement events—to ensure that knowledge is shared, understood, and applied in practice.

Section G: Suitable governance and accountability arrangements to ensure the strategy is delivered.

Effective governance and accountability are essential to delivering a dementia strategy that is inclusive, evidence-informed, and responsive to the needs of people living with dementia. This requires strong leadership, clinical input, multi-agency collaboration, robust oversight mechanisms, and meaningful stakeholder involvement.

Stakeholder involvement is fundamental to the success of dementia strategy governance. Co-production must be embedded within governance structures, ensuring that people with dementia, carers, and staff are actively involved in decision-making processes. Their lived experience brings essential insight and relevance to strategic planning and service delivery.

To enable meaningful participation, appropriate support must be provided, including accessible formats, facilitation, and capacity-building.

In addition, robust feedback mechanisms—such as surveys, forums, and analysis of complaints data—should be used to inform governance decisions and drive continuous improvement. This inclusive approach ensures that services remain person-centred, responsive, and accountable to those they are designed to support.

Leadership Arrangements at a National Level

Strong national leadership is essential to ensure strategic coherence, accountability, and meaningful progress in delivering the Dementia Strategy for Wales. Two key governance structures will be established to provide oversight, expert input, and lived experience engagement.

National Dementia Ministerial Board

The National Dementia Ministerial Board will serve as the central strategic body responsible for guiding the national dementia agenda. Its composition will include Ministers with responsibility for dementia, senior Welsh Government officials, regional leads, NHS Wales, local authorities, dementia charities, advocacy groups, people with dementia and their caregivers, as well as representation for Welsh language and protected characteristics.

Responsibilities of the Board will include:

- Providing strategic direction and oversight
- Monitoring progress and ensuring alignment with national health and social care policies
- Managing risk and considering funding implications
- Establishing task and finish groups to address specific priorities

Dementia Advisory Board

Reporting to the Ministerial Board, the Dementia Advisory Board will bring together a broad range of expertise to inform policy and practice. Its membership will include dementia care experts, Welsh Government officials, third sector, regional leads, researchers, professional bodies, inspectorates, people with dementia and their caregivers, and representation for Welsh language and protected characteristics.

Responsibilities of the Advisory Board will include:

- Providing expert advice and reviewing policy implications
- Ensuring the voices of those directly affected by dementia are heard and considered
- Supporting awareness-raising efforts aligned with the Dementia Strategy for Wales

Once the strategic priorities of the strategy are confirmed, relevant governance arrangements will be aligned and embedded under the appropriate key strategic groups. This will ensure that oversight, accountability, and decision-making structures are tailored to support the delivery of each priority area, enabling coordinated leadership and effective implementation across organisational and partnership levels. This detail will be in the final strategy.

Leadership Arrangements at a Regional Level.

A designated Dementia Lead and a Dementia Programme Board (or equivalent) should be in place to drive strategic implementation at both organisational and partnership levels. These structures should include representation from people with lived experience, ensuring that leadership is informed by real-world perspectives and priorities.

To enable a whole-system approach, governance arrangements must actively involve local authorities, health boards, third-sector partners, and people with lived experience. The mechanism for this collaboration will be through **Regional Partnership Boards (RPBs)**, which will play a

central role in commissioning, engaging, co-producing, planning, delivering services, and allocating resources in line with strategic priorities.

The Dementia Programme Board will be responsible for monitoring progress, identifying and sharing best practice, and addressing barriers to implementation at a regional level. They will be expected to have clear action plans developed and monitored to address identified risk.

Reporting mechanisms must be in place to ensure regular updates to senior managers, organisational boards, and external stakeholders, including the public and regulatory bodies such as Care Inspectorate Wales (CIW) and Healthcare Inspectorate Wales (HIW).

As we develop our governance arrangements, it is essential to ensure alignment with relevant **statutory and regulatory frameworks**. Governance structures must uphold compliance with key legislation, including the Social Services and Wellbeing (Wales) Act, Mental Capacity Act, Mental Health Act, the Equality Act and Welsh Language Standards. In addition, adherence to regulatory standards set by bodies such as NICE, Care Inspectorate Wales (CIW), and Healthcare Inspectorate Wales (HIW) is critical to maintaining quality and accountability. Robust safeguarding policies and procedures must also be in place and actively monitored to protect the rights and wellbeing of people affected by dementia, ensuring that governance supports safe, equitable, and legally sound care delivery.

Monitoring the Impact of the Strategy

To ensure the strategy remains effective, relevant, and responsive to the needs of people living with dementia, robust performance monitoring and quality assurance mechanisms must be in place.

This includes establishing clear Key Performance Indicators (KPIs), including targets for diagnosis, and outcome measures that can be regularly reviewed and benchmarked across services and regions.

Annual updates on progress and impact will be made publicly available, with a focus on how the strategy has improved experiences and outcomes for people with lived experience. These updates should be accessible and inclusive and will incorporate a review to assess emerging needs and ensure the strategy continues to align with evolving evidence and practice.