

# West Wales Care Partners (WWCP) Dementia Strategy

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# 1. Background

# Background

- The West Wales Care Partnership (WWCP) brings together organisations from the statutory, third and independent sectors with a remit of integrating and transforming health, care and support in the region.
- A statutory Regional Partnership Board oversees the work of the WWCP.
- A regional Dementia Steering Group sits underneath the RPB and comprises representation from across the Partnership. It provides a mechanism for developing a regional approach to caring for people living with dementia (PLWD) and their families. This Group worked closely with Attain in developing the draft Strategy and will have a key role in taking forward implementation of the next phases of work.
- Welsh Government provides funding through the Integrated Care Fund (ICF) to support the improvement of care and support for PLWD and their families, This funding is managed through the Dementia Steering Group and will be instrumental in delivering agreed priorities within the Strategy.
- Key partners on the WWCP are:



Carmarthenshire  
Association of  
Voluntary  
Services



Pembrokeshire  
County Council



Pembrokeshire  
Association of  
Voluntary Services



Carmarthenshire  
County Council



Ceredigion  
Association of  
Voluntary  
Organisations



Hywel Dda University  
Health Board



Ceredigion  
County Council

# Background

In February 2021, the WWCP appointed Attain to work with partners to develop a regional dementia strategy and service model pathway of care. Alongside this work, we carried out a review of the regional ICF dementia projects which provided a steer as to what services should continue to be funded, as well as an indication of any additional initiatives that should be undertaken during 2021/22. One priority area was for Attain to develop a business case for the introduction of a dementia wellbeing connector which is based on best practice and an intrinsic role within the WW Dementia Wellbeing Pathway.

The context for this work includes:

- Increasing focus worldwide on dementia and its impact on health and social care systems; prevalence is increasing year on year, mainly due to people living longer, particularly in high income economies.
- To clarify its dementia strategy, In February 2018, the Welsh government published the 'Dementia Action Plan 2018-2022'.
- The vision is 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 March 2021, Improvement Cymru published the All-Wales Dementia Care Pathway of Standards. This work, directed by the requirements of the Dementia Action Plan for Wales, is overseen by the Welsh Government Dementia Oversight Implementation and Impact Group (DOIIG).
- The twenty standards have been designed to be dynamic by responding to evaluation and supporting evidence. They sit within four themes: **Accessible, Responsive, Journey, Partnerships and Relationships Underpinned by Kindness and Understanding.**
- The standards have been co-designed over the past two years with over 1800 people ranging from people living with dementia to voluntary sector organisations to practitioners across Wales and the UK. The standards have captured the needs across regions and have been aligned NICE guidance using the Improvement Cymru Delivery Framework and it is anticipated that work will focus on developing a two-year Delivery Framework Guide for the Welsh regions covering the period April 2022 – March 2024.

Prior to the implementation of the Framework, Attain has co-designed this 5-year strategy with colleagues, people living with dementia and their carers across West Wales. The high-level strategy also provides a programme governance structure and the foundation on which to fund services which is in line with the Improvement Cymru Delivery Framework.

# Project requirements and activities

This slide outlines the project requirements, the outcomes from the work undertaken and key actions.

## The Ask:

### 1. Overarching Dementia Strategy and Delivery Plan

- Facilitate co-production of a regional dementia strategy with stakeholders, PLWD and their carers
- **Develop a sustainable model and associated delivery plan for the strategy in the medium to longer term**, deployment of existing and future funding streams to support this and accounting to Welsh Government and other stakeholders on delivery and impact
- **Consider future regional programme ownership** and leadership requirements to implement and deliver the dementia strategy
- The dementia strategy and associated delivery plan needs to be considered in the context of **changing demographics across the region**, the long-term impact of COVID-19 on people with dementia and evidenced impact of existing workstreams

### 2. Development of a business case for the dementia case manager role

- In line with All Wales dementia standards and the Health Board's recently developed palliative and end of life care strategy, develop a business case for the dementia case manager role

### 3. In respect of the above tasks, Attain have been required to:

- Work with a range of national and regional stakeholders, including Improvement Cymru, system leaders, service managers, clinicians and practitioners, elected and independent members and users and carers as appropriate
- Produce high quality proposals and reports to a range of audiences

## Attain have:

### 1. Overarching Dementia Strategy and Delivery Plan:

- Produced a report following a review of national and international best practice
- Worked with colleagues to develop a **regional strategy, vision and service model pathway based on best practice**
- This strategy includes a **proposed programme and governance structure** which fits with the Welsh Government and Regional structures
- The strategy includes a summary of **current and future population demand and prevalence**. Information relating to the impact of COVID-19 upon those with dementia is not available at this stage
- Stakeholders have identified that COVID-19 has impacted timely diagnosis due to late presentations and inability to access assessment services

### 2. Development of a business case for the dementia wellbeing connector role:

- Carried out a desktop review on best practice in dementia case co-ordination/management and average case load level
- Developed a business case with input from the WWCP dementia steering group members

### 3. Stakeholder engagement:

- Attain have worked with multiple stakeholders across the region people living with dementia (PLWD) and their carers and front line staff. All West Wales Care Partners have been fully engaged and very supportive in the development of this strategy

## Key Recommendations

### 1. Implementation of strategy and dementia wellbeing pathway

- Once the strategy is formally approved by the WWCP, socialise the recommendations of the strategy, and the dementia wellbeing pathway to ensure that it is owned by colleagues, PLWD and their carers across West Wales
- A communication plan should be developed to run for the life of the strategy
- WWCP to adopt the proposed governance structure and recruit a Regional Dementia programme manager
- A full business case should be developed to take forward the establishment of the dementia wellbeing connector role
- The strategy, vision and service model pathway should be reviewed once information is available regarding the impact of COVID-19 upon those with dementia and their carers
- The waiting time for diagnosis should be reviewed and monitored; solutions should be found to address long waiting times, including the codesign and development of the regional dementia diagnosis pathway and the MAS offer should be reviewed in line with the All Wales Dementia Care Pathway Standards.

### 2. ICF Dementia Plan:

- The strategy recommends that a review be undertaken of ALL initiatives currently funded by the ICF, including evidencing outcomes, align funding to implement the strategic priorities, and ensure any new way of working is fully resourced
- Develop a regional strategic and co-ordinated approach to supporting carers – consider top slicing the dementia ICF funding to enhance the carers' element so ensuring continuation of services, supporting those who are caring for people living with dementia

# What is Dementia and symptoms?

Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning. There are many different causes of dementia, and many different types. People often get confused about the difference between Alzheimer's disease and dementia. Alzheimer's disease is a type of dementia and, together with vascular dementia, makes up the majority of cases.

## Symptoms of dementia

Dementia symptoms may include problems with:

- Memory loss thinking
- Speed mental sharpness and quickness
- Language, such as using words incorrectly, or trouble speaking
- Understanding
- Judgement
- Mood
- Movement
- Difficulties doing daily activities

People with dementia can lose interest in their usual activities, and may have problems managing their behaviour or emotions. They may also find social situations difficult and lose interest in relationships and socialising. Aspects of their personality may change, and they may lose empathy (understanding and compassion). A person with dementia may see or hear things that other people do not (hallucinations). Because people with dementia may lose the ability to remember events, or not fully understand their environment or situations, it can seem as if they're not telling the truth or are wilfully ignoring problems. As dementia affects a person's mental abilities, they may find planning and organising difficult. Maintaining their independence may also become a problem. A person with dementia will usually need help from friends or relatives, including help with making decisions.

The symptoms of dementia usually become worse over time. In the late stage of dementia, people will not be able to take care of themselves and may lose their ability to communicate.

# What Causes Dementia and what are the different types?

## What causes dementia?

The causes of Alzheimer's and related dementias can vary, depending on the types of brain changes that may be taking place. While research has found that some changes in the brain are linked to certain forms of dementia, in most cases, the underlying causes are unknown. Rare genetic mutations may cause dementia in a relatively small number of people.

Although there is no proven prevention, in general, leading a healthy lifestyle may help reduce risk factors that have been associated with these diseases.

## What are the different types of dementia?

Various disorders and factors contribute to the development of dementia. Neurodegenerative disorders result in a progressive and irreversible loss of neurons and brain functioning. Currently, there are no cures for these diseases.

The five most common forms of dementia are:

- Alzheimer's disease, the most common dementia diagnosis among older adults. It is caused by changes in the brain, including abnormal build-ups of proteins, known as amyloid plaques and tau tangles.
- Frontotemporal dementia, a rare form of dementia that tends to occur in people younger than 60. It is associated with abnormal amounts or forms of the proteins tau and TDP-43.
- Lewy body dementia, a form of dementia caused by abnormal deposits of the protein alpha-synuclein, called Lewy bodies.
- Vascular dementia, a form of dementia caused by conditions that damage blood vessels in the brain or interrupt the flow of blood and oxygen to the brain.
- Mixed dementia, a combination of two or more types of dementia.



# The link between Frailty and Dementia

There is a very close link between frailty and dementia.

“Frailty is a state of increased vulnerability to poor resolution of homeostasis following a stress, which increases the risk of adverse outcomes including falls, delirium and disability. It is a long-established clinical expression that implies concern over an older person’s vulnerability and prognosis. This is shown diagrammatically in figure 1, in which an apparently small insult (e.g. a new drug; “minor” infection; or “minor” surgery) results in a dramatic and disproportionate change in health state: from independent to dependent; mobile to immobile; postural stability to falling; lucid to delirious. The dependency oscillations observed in frail older people has been referred to as “unstable disability” to reflect the often marked changes in functional ability that are familiar to practitioners working with older people.” Source: Andrew Clegg Lancet. 2013 March 2.

There is accumulating evidence from observational studies to support a temporal association between frailty, cognitive impairment and dementia. A prospective cohort study (n=750) of older people without cognitive impairment at baseline reported that frailty was associated with an increased risk of developing mild cognitive impairment over 12 years of follow-up (hazard ratio, HR, 1.63, CI, 1.27-2.08) (1). Increasing degree of frailty was also associated with a faster rate of cognitive decline. An independent association between frailty and dementia has been reported in two large prospective cohort studies. Source: 1. Boyle PA, Buchman AS, Wilson RS, Leurgans SE, Bennett DA. Physical frailty is associated with incident mild cognitive impairment in community-based older persons. *J Am Geriatr Soc.* 2010; 58(2):248–55. [PubMed: 20070417] 2. Buchman AS, Boyle PA, Wilson RS, Tang Y, Bennett DA. Frailty is associated with incident Alzheimer’s disease and cognitive decline in the elderly. *Psychosom Med.* 2007; 69(5):483–9. [PubMed: 17556640]

More recently a study in 2019 on Frailty as a Predictor of Cognitive Disorders: A Systematic Review and Meta-Analysis (*Front. Med.*, 19 February 2019 | <https://doi.org/10.3389/fmed.2019.00026>) Of the 2,210 studies retrieved by the systematic review, 6 relevant studies were included in a meta-analysis. Baseline frailty was significantly associated with an increased risk of geriatric cognitive disorders (pooled OR = 1.80, 95% CI = 1.11–2.92; p = 0.02). Heterogeneity across the studies was significant (I<sup>2</sup> = 79%). The analyses confirmed Cleggs findings that frail older adults were at higher risk of incident cognitive disorders than non-frail elders. Frailty status seems to be most associated with the risk of incident dementia. Frailty may represent a risk factor for dementia and could constitute a novel modifiable target in early cognitive impairment.

Whilst this strategy focuses on dementia, it is important to understand that the principles behind the strategy such as holistic proactive care planning through integrated MDT working, targeting support when it is needed, are all principles that sit behind best practice frailty models. Understanding the relationship between frailty and geriatric cognitive disorders is crucial as this understanding could contribute to new interventions for the prevention and management of both conditions.

# West Wales vision for dementia services

*'Support each person to live well and independently with dementia for as long as possible'*

**Key enablers to delivery:**

- Clear **regional dementia vision, strategy and service model** in line with best practice
- Develop **effective** professional and clinical leadership and **governance** to ensure the service model and **new roles** are designed in line with best practice and **are part of the whole health and social care system**
- Strategic and collaborative **PLWD/carer centred commissioning arrangements**
- Cross-organisational working
- **Collective financial and performance management**
- **Joint commissioning for integrated care**, ensuring **equity of access and provision across West Wales**
- **Optimise the use of estate** - build on localities and **provide support closer to home** e.g. local meeting places/hubs where people can connect
- **Adapting IT** so that it reflects activity and **captures person centred outcomes**.
- **Shared system transformation** programmes and plans
- **Systematic involvement of PLWD and their carers** and community in the **design and development of the new service model**
- New ways of working expanding the capacity of the Good Work training framework and **new workforce roles** e.g. **Dementia wellbeing connector role**
- **Using technology to empower PLWD** and their **carers** and our **staff**.
- **Commissioning** and provision of **primary care services at scale**
- **Interpret population health/social care data, PLWD/family feedback**, design services for networks and **draw in support from wider services**

Specialist dementia care support – in the community and in hospital



Intermediate care to support people at the time of increasing need. We maximise comfort and wellbeing – supporting people in their home if possible



Proactive Care and Care Planning as a multi-disciplinary team. Care is co-ordinated ensuring the right help, at the right time



Prevention, Planning and Education within our communities  
Communities prepared to support and help



1. Help for strong communities

2. Help to help yourself

3. Help when you need it

4. Help long term

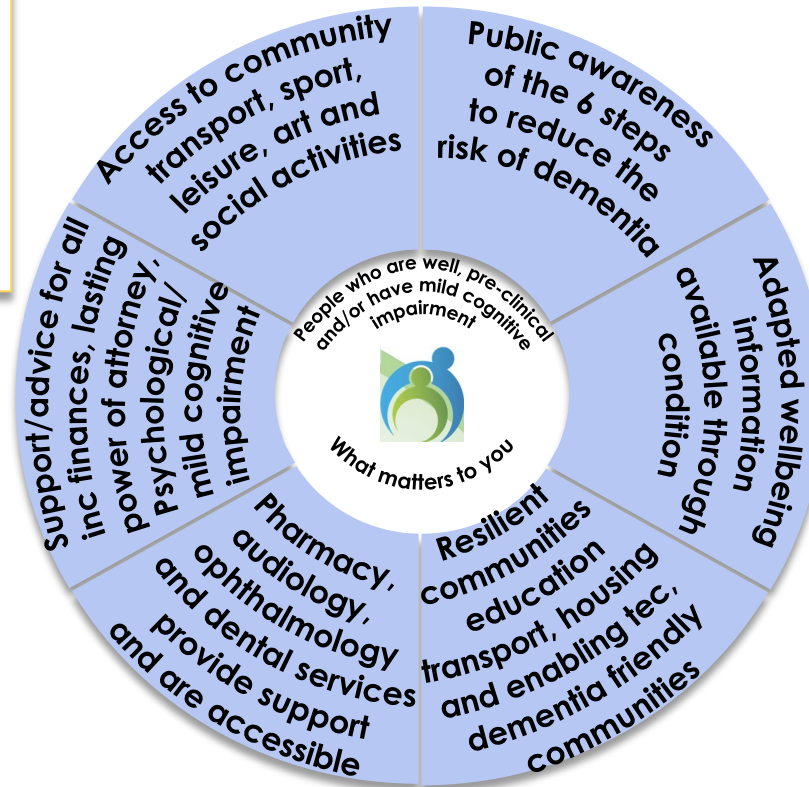
5. Help in hospital

# What good looks like for West Wales – The dementia wellbeing pathway

## Wellbeing, risk reduction, delaying onset, raising awareness and understanding

### **Dementia Statement: Creating dementia friendly communities, making dementia everybody's business**

*We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.*



As a signatory to the Glasgow Declaration (1) the Welsh Government has previously committed to **promote the rights, dignity and autonomy of people living with dementia**. Through the Government's engagement with stakeholders they heard about the positive work of Dementia Action Alliance in developing a **series of statements with people living with dementia and their carers** (2)

**Dementia Statements reflect the things that people with dementia and carers say are essential to their quality of life.** These statements were developed by people with dementia and their carers, and the person with dementia is at the centre of these statements. The "we" used in these statements encompasses people with any type of dementia regardless of age, stage or severity; their carers; families; and everyone else affected by dementia.

**These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights law and are a rallying call to improve the lives of people with dementia.** These Statements recognise that people with dementia shouldn't be treated differently because of their diagnosis.

**We have aligned the dementia statements to the new West Wales Dementia Wellbeing Pathway and the recommendations within the strategy have also been aligned.**

For more information see:

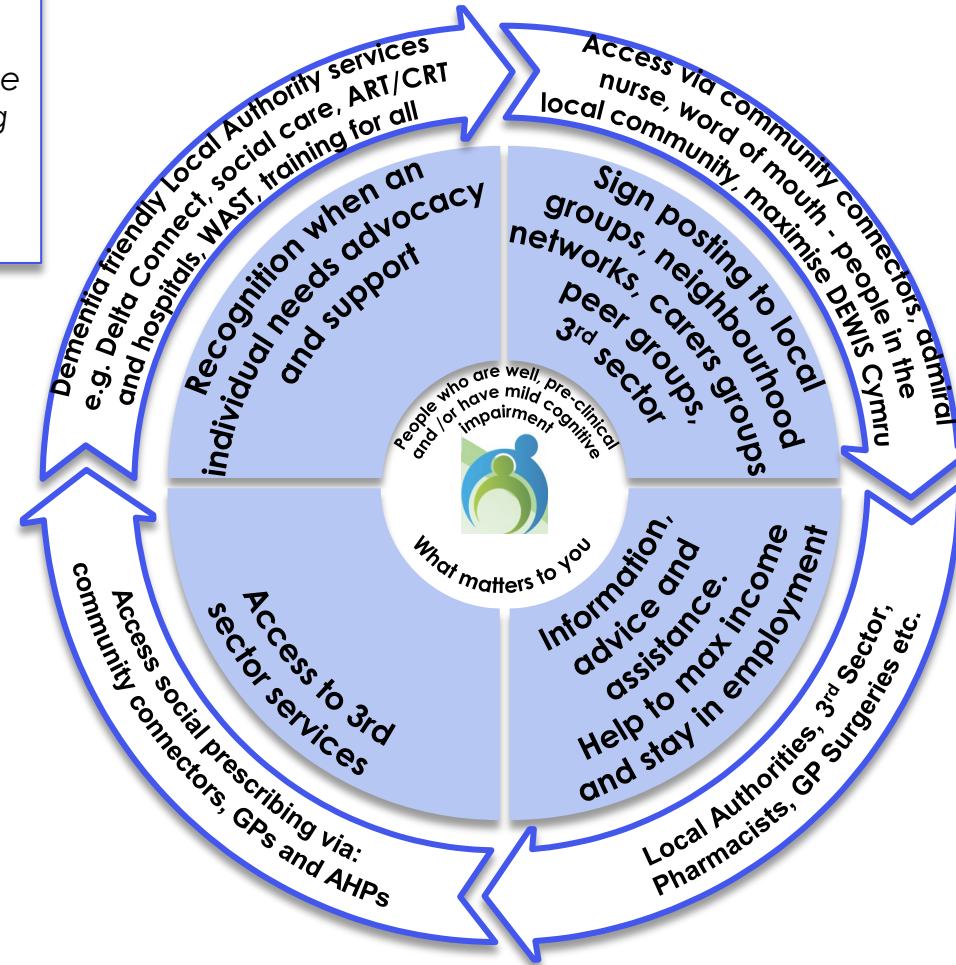
1. <https://link.edgepilot.com/s/67f68721/ecxOvtDsBECT3n7Rjlzvhg?u=https://www.alzheimer-europe.org/Policy/Glasgow-Declaration-2014>
2. <https://link.edgepilot.com/s/8d37d66b/NmKURNiXoUaKCjtzSUIWhQ?u=https://www.dementiaaction.org.uk/nationaldementiadeclaration>

# What good looks like for West Wales – The dementia wellbeing pathway

## Recognition, Identification, Support and Training

### Dementia Statement: Each person gets fair access to care regardless of diagnosis

We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.

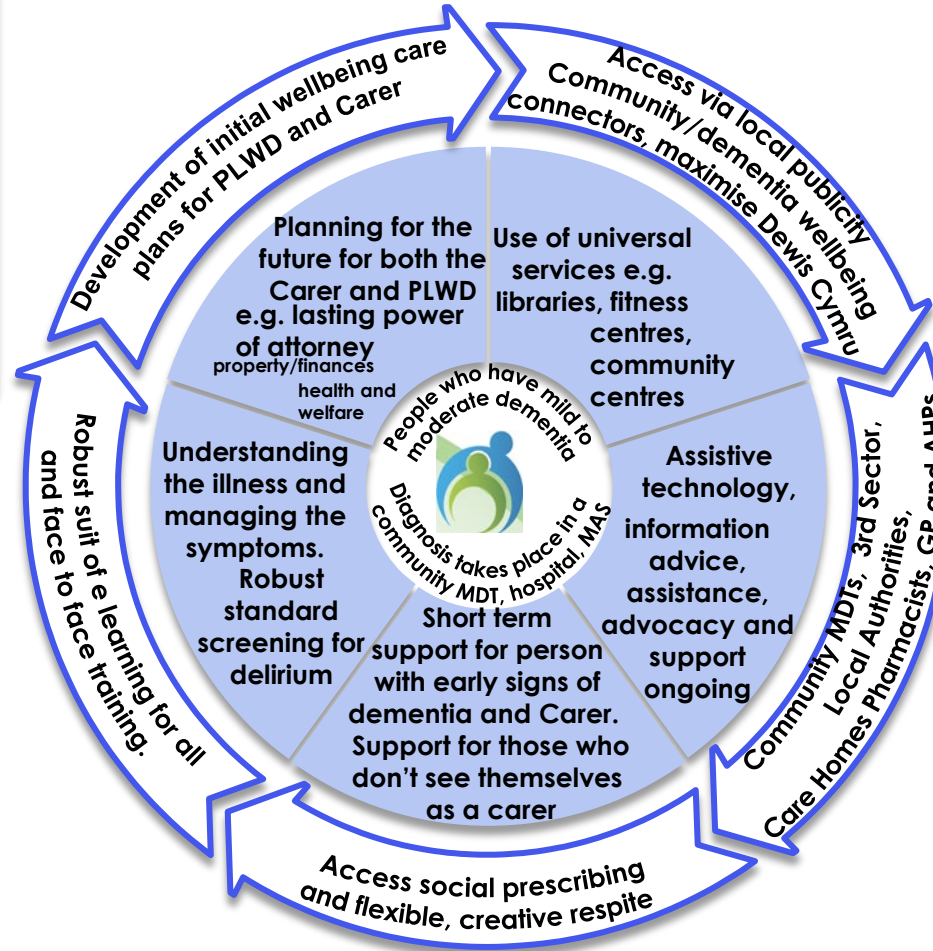


# What good looks like for West Wales – The dementia wellbeing pathway

## Assessment and diagnosis

### Dementia Statement: Each person is seen as an individual

We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

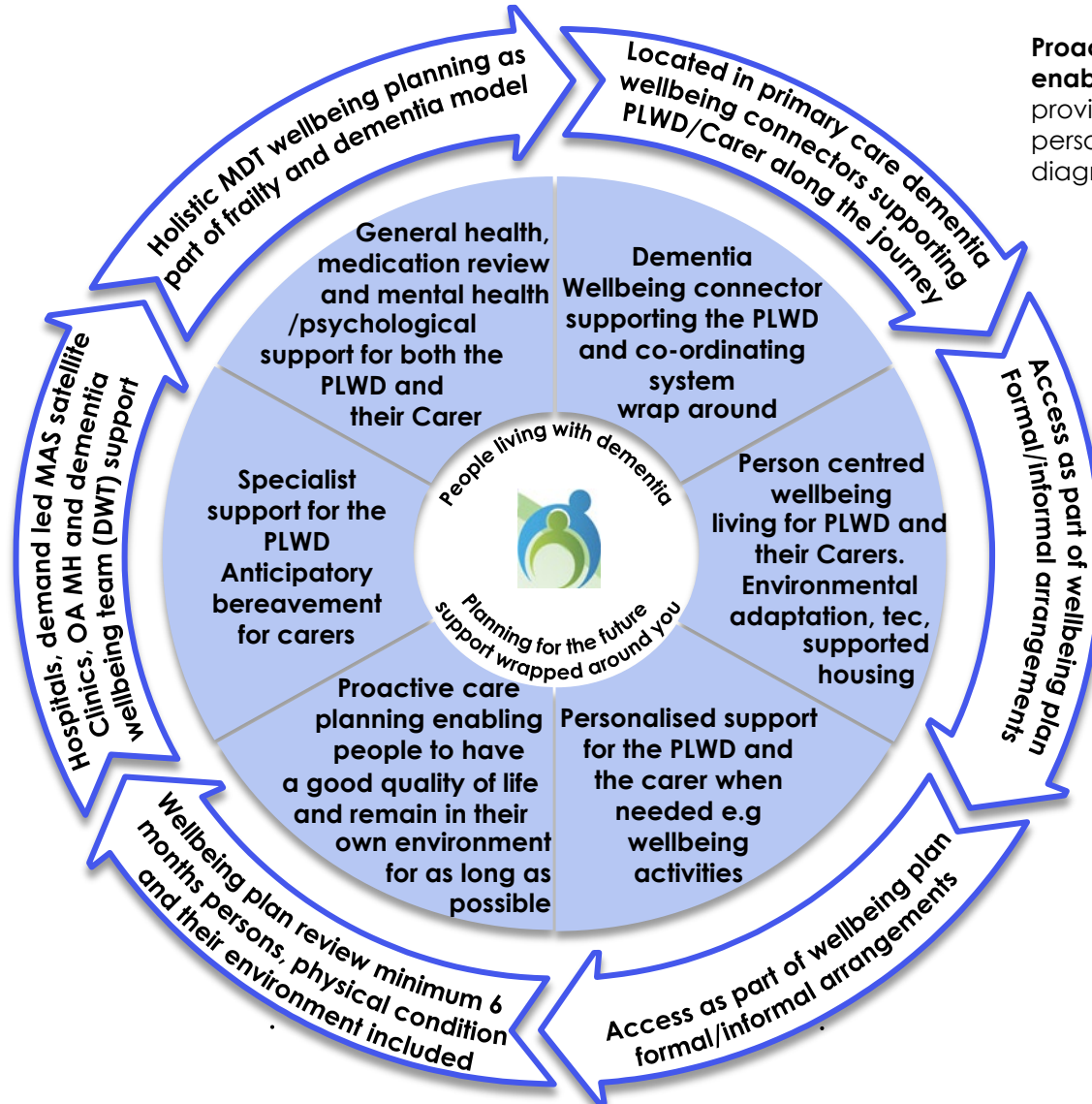


# What good looks like for West Wales – The dementia wellbeing pathway

## Living well with dementia

### Dementia Statement: Care is co-ordinated

We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future. We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.



Proactive care planning through **HOLISTIC** MDT (colleagues enabled to attend virtually) - consistent regional approach, providing stable support and wellbeing plan around the person and where appropriate, their carer, regardless of diagnosis including:

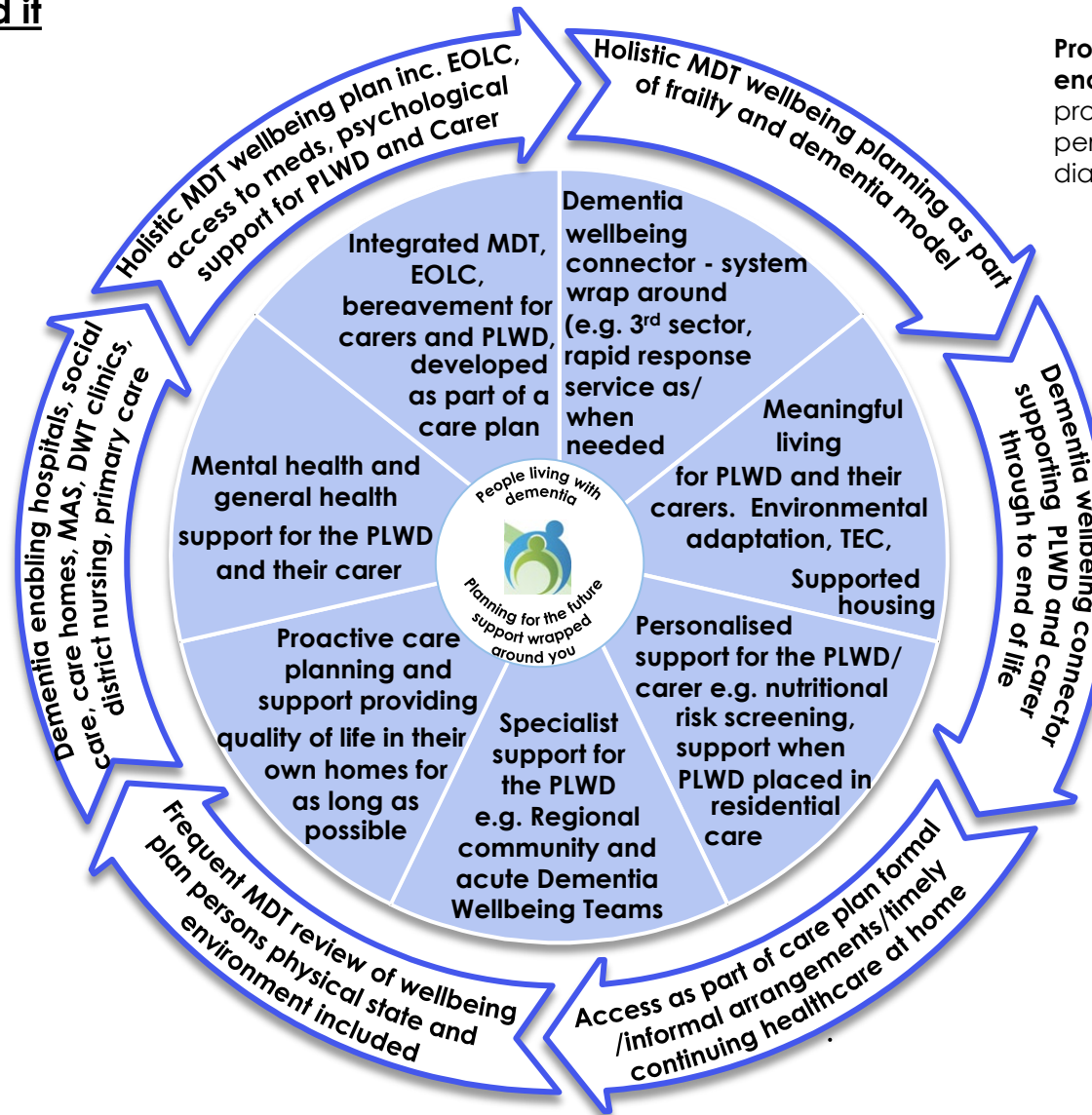
- Dementia wellbeing connector
- GP
- Advocate
- Social care
- District nurse (DN)
- Allied health professionals (AHPs) e.g. OTs, physio, dietetics, speech and language etc.
- Key workers/ assistive technology lead
- Admiral nurse
- Primary care
- 3<sup>rd</sup> sector
- Pharmacist
- Psychologist
- Care homes
- Older Adult mental health
- Adult MH for young onset
- Advice and advice on training as required from DWTs in the community and acute settings
- Secondary care and SPC consultants as required

# What good looks like for West Wales – The dementia wellbeing pathway

## Increased support when you need it

### Dementia Statement: All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.



Proactive care planning through **HOLISITC** MDT (colleagues enabled to attend virtually) - consistent regional approach, providing stable support and wellbeing plan around the person and where appropriate, their carer, regardless of diagnosis including:

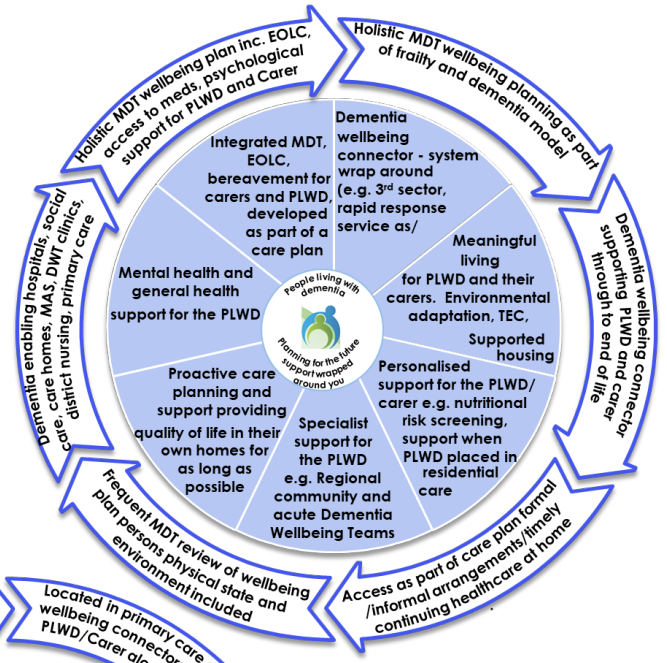
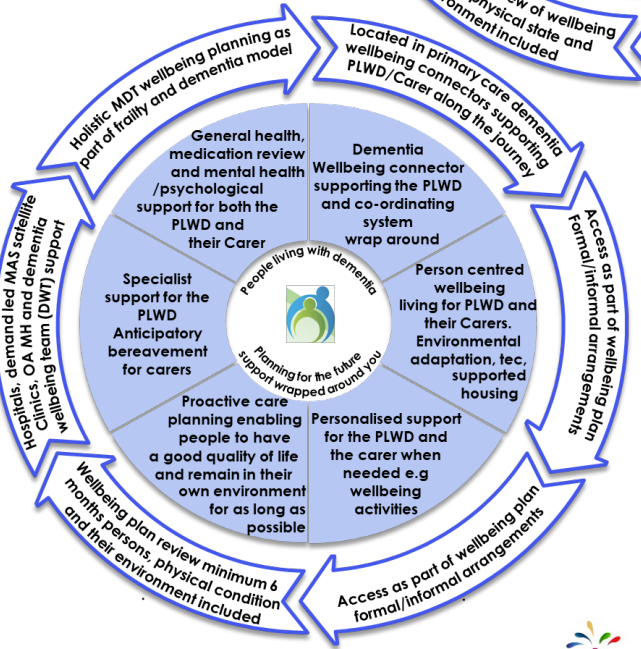
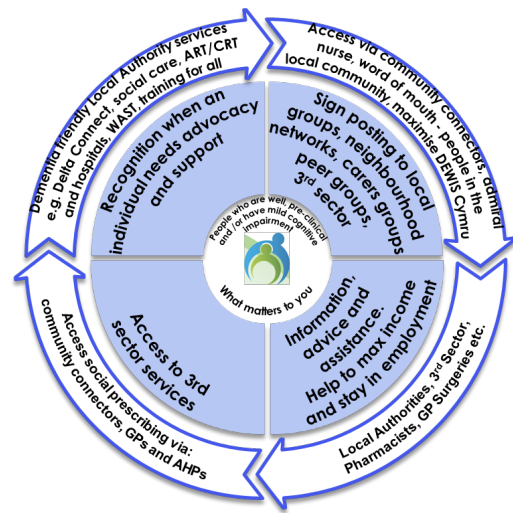
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- Adult MH for young onset
- Advice and advice on training as required from DWTs in the community and acute settings
- Secondary care and SPC consultants as required

Implementation of the Good Work Framework - we need to consider the learning and development needs of everyone who is affected in some way by dementia. This includes people living with dementia, carers, frontline staff, managers, commissioners, regulators, researchers, shopkeepers, next door neighbours etc. Resulting in people who are informed, people who are skilled and people who can act as influencers

# What good looks like for West Wales – The dementia wellbeing pathway

- This pathway places the PLWD and their carer at the centre of service support. It illustrates a new more joined up way of providing services. It is based on best practice and existing services within West Wales.
- The service model should be underpinned with an agreed set of service operating procedures which need to be developed

*Team around the person - support increases with needs  
Experts influencing across the pathway*



Underpinned by communication plan, recognising experts by experience, access to assistive technology etc. Implementation of the Recognition and Good Work Training Frameworks





# Next steps

## Delivering the programme:

- Agree the rationale to continue funding during 2022/23
- Identify resource to set up and manage the programme of work across partners - recruit to the role
- Create a programme plan, prioritise projects and revise timelines to ensure that there is a realistic and deliverable plan in place. Use Workstream Management as the process for delivery
- Identify Workstream SROs to drive work with PMO support; provide ownership and accountability to deliver
- Regular progress updates should be provided at the monthly WWCP Dementia Steering Group

## Implementing the strategy:

- Seek sign off from Integrated Exec Group and Regional Partnership Board, develop communications plan to socialise the strategy so all partners are aware of the direction of travel for dementia services within West Wales.
- Communications plan to cover the life of the strategy, enabling the public to be aware of any new developments in their area
- Update the programme plan with the new service developments required to deliver the dementia wellbeing pathway
- Ensure robust governance is in place to oversee the implementation of the new service initiatives, ensuring all new initiatives take a programme approach reporting progress regularly to the Regional Dementia Steering group

Implementation of the new  
West Wales Dementia  
Strategy

## Contacts

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