



**IECHYD A GOFAL GWLEDIG CYMRU**  
**RURAL HEALTH AND CARE WALES**

## **Working towards a Dementia Friendly Ceredigion**

- *a review of existing support and activities for People living  
with Dementia in Ceredigion and their carers*

January 2025

(Updated October 2025)

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## Glossary of terms

The below are common abbreviations used from the start and throughout this report for ease of reference:

AFC – Age Friendly Community  
AFI – Age Friendly Initiative  
AHP – Allied health Professionals  
ARCH - A Regional Collaboration for Health  
CCC – Ceredigion County Council  
CPSB – Ceredigion Public Services Board  
DEEP - Dementia Engagement & Empowerment Project  
DFC – Dementia Friendly Community  
DFD – Dementia Friendly Design  
DFI – Dementia Friendly Initiative  
DFWSG - Dementia Friendly Wrexham Steering Group  
HDdUHB – Hywel Dda University Health Board  
LMIC – Low-Middle Income Countries  
MIC – Middle Income Countries  
MWJC – Mid Wales Joint Committee  
NGO – Non-Government Offices  
ONS – Office of National Statistics  
PHW – Public Health Wales  
PLWD – People Living with Dementia  
PNA – Population Needs Assessment  
RHCW – Rural Health and Care Wales  
WHO – World Health Organisation  
WWCP – West Wales Care Partnership  
WWRSP – West Wales Regional Skills Partnership

# 1. Introduction

There are currently more than 55 million people with dementia in the world (World Health Organisation, 2023), with nearly 10 million new cases being identified each year. Moreover, Alzheimer's Research UK predict that the number of people living with dementia in the UK will rise to over 1.1 million by 2030.

In 2022, the West Wales Regional Partnership Board noted that there was an average of 6,884 people over the age of 65 living with dementia in West Wales, 1,322 of these residing in Ceredigion. These figures are predicted to rise to 10,897 in West Wales, with 1,993 people anticipated to be living with dementia in Ceredigion by 2035. There is therefore a known and concerning number of people with dementia living in Ceredigion, with projections unanimously predicting significant increases over the coming years. Ceredigion's elderly demographic also indicates that the proportion of dementia sufferers in the county are significantly higher than in areas whereby there is a younger resident demographic.

This report seeks to scope current provision in dementia support in Ceredigion, be it that which is provided to people living with dementia (PLWD), their family and / or their carers. Furthermore, the report will consider examples of best practice in the delivery of dementia support from an international perspective, ending with recommendations on how to further develop current provision to make Ceredigion an aspirational dementia friendly county.

## 1.1 Background

The Rural Health and Care Wales (RHCW) Work Programme for 2024 / 2025, approved by the Mid Wales Joint Committee (MWJC), set out an intention to review the support provided to PLWD across Mid Wales and their carers. As such, in March 2024 RHCW submitted an application for UK Shared Prosperity Funding to conduct a seven-month project that would work with PLWD and carers in Ceredigion to gain feedback on their experiences and needs, in addition to scoping existing provision and undertaking an international literature search for identification of models of best practice in dementia support that are being applied elsewhere.

Unfortunately, the original application submitted in March 2024 was not successful, albeit that a modified 4-month revised proposal was accepted in August 2024 that enabled a curtailed version of the original project to be undertaken between September and December 2024. This report chronicles the outcome of the revised project.

Due to the shortened timescales, the revised project focussed solely on undertaking research into mapping existing provision of support in Ceredigion that was available to PLWD and their families / carers as at December 2024, and identification of models of best practice in the delivery of dementia support that could be adopted in Ceredigion. The scoping process included an analysis of available literature, grey



of which is considered to be Pen Dinas in Aberystwyth (Driver, 2021; CCC, 2024). Ceredigion is also home to 8 castle sites and 4 county rivers: Aeron, Rheidol, Teifi and Ystwyth (CCC, 2024).

The topology of Ceredigion lends itself to having a large proportion of agricultural workers and also visiting tourists, with a number of regular tourists choosing to re-locate to Ceredigion at retirement. Both of these aspects have implications for dementia, which is prevalent amongst older populations and less likely to have early diagnosis in farming communities. Access to green / blue spaces, which Ceredigion has in plenty, can have however a proven positive impact on health and wellbeing.

## **2.2 Public Services and Employment**

The county town of Ceredigion is Aberystwyth, which is the most highly populated town in the county and serves as the primary administrative capital, housing both Local Authority and Welsh Government office bases. Aberaeron is the secondary administrative hub of CCC and there are a further 5 main towns within the county: Cardigan, Lampeter, New Quay, Newcastle Emlyn and Tregaron.

The county is served by 40 Primary Schools, 7 Secondary Schools (CCC, 2024), with both the University of Aberystwyth and University of Wales Trinity Saint David (Lampeter) also located in Ceredigion. Additionally, the county also has the further education institution Coleg Ceredigion, which a constituent college of Coleg Sir Gar, with sites located in Aberystwyth and Cardigan.

Ceredigion has 1 District General Hospital, Bronglais, in Aberystwyth, 1 (non-inpatient) Community Hospital based in Tregaron and 2 Integrated Care Centres in Aberaeron and Cardigan, all of which are managed by Hywel Dda University Health Board (HDdUHB). Additionally, the county also has two Centres for Independent Living: Penmorfa in Aberaeron, which is open to the public, and Felinfach in Lampeter, which is not publicly accessible.

The Welsh Government, via its Stats Wales portal (<https://statswales.gov.wales>) reports that 10,800 people in Ceredigion are employed in the public sector, with a further 25,800 in the private sector (Stats Wales, 2024). This shows that 29.6% of the population are public sector employees, compared to the Wales national percentage of 30.9% and UK percentage of 24%. There is however a high number of micro enterprises in Ceredigion, driven by the tourism and agricultural industries. The overall employment rate for Ceredigion as at end of December 2023 is reported as 70.1%, with an unemployment rate of 3.5% and economic inactivity of 26.8%. (ONS, 2023).

## 2.3 Demographics

In the last census (ONS, 2021), the population of Ceredigion stood at 71,500, showing a fall of 5.9% when compared to the 75,900 residents reported in the 2011 census. As a comparison, the total population of Wales grew by 1.4% over the same period, increasing by 44,000 to 3,107,500.

Population change in Ceredigion: Census 2011 to Census 2021

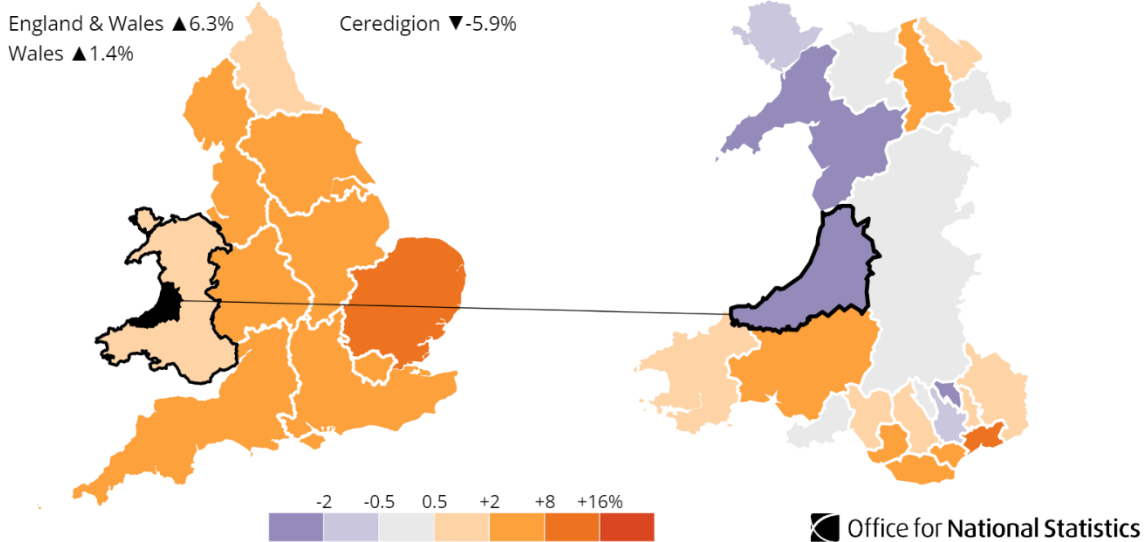


Fig.2: Population change in Ceredigion: Census 2011 to Census 2021 (ONS, 2023)

Furthermore, Ceredigion was recognised as the joint second-least densely populated local authority area in Wales, with Powys taking the top accolade.

Other statistics to note when comparing figures from the census undertaken in 2011 and that undertaken in 2021, reported in January 2023, include the following:

- The average age of a resident in Ceredigion in 2021 was 47, showing an increase of 5 years when compared to the 42-year average recorded in 2011; residents of Wales as a whole had an average age of 42 years old (ONS, 2021); *the average of residents in Ceredigion is therefore 5 years older than the national average age (47 years old versus 42)*
- The number of people aged between 65 - 74 years old in Ceredigion in 2021 rose by just over 18% (+1,500 people); *Ceredigion therefore has a growing elderly population*
- The number of people aged between 35 and 49 years of age fell by just over 20% (-2,600 people); *Ceredigion has a decreasing number of people in the 35-49 year old age range*
- The percentage of Welsh speakers in Ceredigion fell slightly from 47.3% in 2011 to 45.3% in 2021 (-3,300 people)

- There was a small rise of 1% in the number of people who owned their own home in 2021 compared to 2011, from 67.6% to 68.6% respectively
- The number of couples in households in Ceredigion without children rose from 17.9% to 18.3%, going against the regional trend of a slight fall from 17.2% to 16.5%; similarly, the number of couples with dependant children showed a drop from 15.9% to 14.2%
- The percentage of people providing up to 19 hours unpaid care in Ceredigion dropped from 7.5% in 2011 to 5.3% in 2021; there was a rise however in the percentage of people providing between 20-49 hours of unpaid care (from 1.6% to 2%) and a small increase in those providing over 50 hours of weekly care (from 3.1% to 3.2%); *unpaid carers in Ceredigion are providing increasingly more hours of care*
- The proportion of Ceredigion residents who identified as disabled and limited saw a small increase from 10.9% to 11.5%, this being the second-largest percentage point in Wales for this category, making Ceredigion the fifth-highest proportion county with disabled and limited residents
- Unemployment in Ceredigion reduced from 2.3% in 2011 to 1.8% in 2021, with the number of retired residents showing a significant increase from 24.9% to 27.7%; *the percentage of older, retired people in Ceredigion is increasing*
- 48% of Ceredigion residents described their health as “very good” in 2021, showing a slight increase from the 2011 figure of 47.8%: the figure for “good” health rose from 31.8% to 32.8%
- In contrast, the figure for “very bad” health remained static at 1.3%, whilst the percentage of those experiencing “bad” health fell from 4.8% to 4.2% (2011 versus 2021 statistics respectively)

In summary, the census shows that Ceredigion is a sparsely populated county, with an ageing demographic and an increasing number of retired elderly people. The number of residents described as disabled and limited is also increasing, as is the potentially associated number of hours of unpaid care provided by family and friends to those in need.

Other statistics to note can be found in CCC’s Through Age Wellbeing Model strategy 2021-2027, which was approved by the full Council on 21<sup>st</sup> October 2021. The strategy forms a key part of CCC’s Corporate Strategy and illustrates the main priorities for delivery of services that will enhance “the social, economic, environmental and cultural well-being for the people of Ceredigion” (CCC, 2021).

In terms of demographic profiling of the residents of Ceredigion, the stark statistics of particular note for this report is the predicted 27% increase in people aged over 65 that will be living in the county by 2039, and an increase in number of the PLWD from 1,381 in 2021 to 2,021 by the year 2035 (CCC, 2021).

# CEREDIGION NOW AND IN THE FUTURE

In 2020 the total population in Ceredigion was **72,695** including **11,318** students.

Current population projections suggest that the total population of West Wales will rise to **425,400** by 2033, with a rise in those aged over 65 years from 88,200 in 2013 to 127,700 by 2033.

**Over half (58.5%) of Ceredigion's population speak Welsh, a 6% increase from the year ending September 2009.**

The population of people aged over 65 living in Ceredigion will increase by **27%** by 2039.

There are **3,444** active third sector organisations (above the national average of 3,330)

The percentage of children receiving care and support with substance misuse problems in Ceredigion is 5% (below the Wales average of 7.5%).

**Child poverty** in Ceredigion has increased by more than **3%** since 2014.

**By 2033 the proportion of the population between 0-14 years in Ceredigion will reduce to 15% and 15 –24-year-olds will also reduce to 11%.**

There is an expected significant rise in the numbers of people aged 65 and over with a learning disability from 395 in 2021 to 463 in 2035.

Ceredigion has a lower number of looked After Children (LAC) than the national average. Care and support needs span a wide range from universal, through early intervention, multiple needs and remedial intervention.

**The predicted number of people aged 0 - 17 that will have a disability according to Disability Discrimination Act definitions in Ceredigion in 2035 will be 1006.**

**1381**

people known to be diagnosed with Dementia in 2021, this figure is predicted to rise to 2021 by 2035.

Life expectancy in Ceredigion is good at 80.5 years for males and 84.1 years for females, both of which are above the national averages for males and females respectively.

The region attracts high levels of inward migration of people over 65. The level for Ceredigion is 29% migration rate with 85% of these being over 65.



Fig.3: Ceredigion Now and in the Future (CCC, 2021)

## 3. Dementia

This section will consider dementia, looking at how the name has been derived and its meaning, dementia prevalence, diagnosis rates and costs associated with dementia care, all of which impact Ceredigion.

The term dementia derives from the Latin root “demens”, which means being “out of one’s mind”, with the term dementia having been used since the 13<sup>th</sup> century in this context. It wasn’t until the 18<sup>th</sup> century that dementia was first reported as a medical term (Assall, 2019), albeit that the term was applied broadly to a range of psychiatric and neurological conditions that had psychosocial consequences, despite the Greeks postulating a cerebral origin. In the 19<sup>th</sup> century, people with dementia were recognised as patients that required medical care from specialists that were referred to as “alienists”.

Following advances in neuropathology, Alzheimers, as a form of dementia, was first identified by Dr Alois Alzhiemer, a German psychiatrist and neuropathologist, in 1906. Dr Alzheimer had been documenting the symptoms of one of his patients since 1901 (Auguste Deter), which included memory loss, language problems and unpredictable behaviour. When Auguste passed away in 1906, Dr Alzheimer examined his deceased patient’s brain and observed two distinct abnormalities – unusual clumps (now recognised as amyloid plaques) and tangled bundles of fibres (neurofibrillary tangles), which led to the foundation of the pathological hallmarks of Alzheimer’s disease. Presentation of his findings at a medical conference in Tubingen, Germany in November 1906 marked the first time that the symptoms and brain pathology of dementia had been presented to the medical community and led

to identification of Alzheimer's, which is now recognised as the most common form of dementia (Alzheimer's Society, 2024).

It was however only as from the 1960s that further significant advances were made in the diagnosis, recognition and treatment of dementia, with recognition of the disease as a major neurocognitive disorder coming to the fore.

A significant sea change in attitudes towards dementia occurred in 2004, with this being postulated as originating in Japan before spreading across the globe in subsequent years. Prior to 2004, the Japanese word "Chiho" (imbecility, madness) was applied to dementia, however in 2004 this was changed to "Ninchi" (cognitive disorder), with this shift linked with a rising awareness of dementia and its societal impact.

More recently, Dementia UK defines the term dementia as "an umbrella term for a range of progressive conditions that affect the brain" (Dementia UK, 2023). It is defined by the NHS as a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning. There are however many types of dementia, with Alzheimer's disease and vascular dementia making up the majority of cases.

### **3.1 Dementia in Ceredigion**

The Well-being of Future Generations (Wales) Act 2015 and the Social Services and Well-being (Wales) Act 2014 require the production of both Population Needs Assessments and Wellbeing Plans in order to highlight and target the priority needs of local populations. In Ceredigion, the Population Needs Assessment is produced by the West Wales Regional Partnership Board (WWRPB) and the Wellbeing Plans are produced by the Ceredigion Public Services Board (CPSB).

The WWRPB 2022 Population Needs Assessment (PNA) set out a series of key messages and areas for improvement regarding dementia care and support for the West Wales region, this consisting of the local authority areas of Carmarthenshire, Ceredigion and Pembrokeshire, which makes up the footprint of Hywel Dda University Health Board (HDdUHB). The PNA identified over 30 genetic, medical, lifestyle, cultural and societal factors that impact the risk of cognitive decline differently, depending on gender, with a greater risk in women than in men.

In 2022, the WWRPB reported 578 people as having been diagnosed with dementia by their GP in Ceredigion, with an estimated further 512 undiagnosed, giving an estimated total prevalence in the county of 1,090 of PLWD. More worryingly, 2040 projected figures quoted by the West Wales Care Partnership and Attain in their Dementia Strategy report in 2022 were for 863 diagnosed and 760 undiagnosed cases of dementia in Ceredigion, giving a total of 1,623. Whilst these figures are less than the 2,021 cases predicted by 2035 by CCC in its Through Age Wellbeing Model

strategy (2021), they remain high and provide a warning for the need to prepare and provide adequate services for a substantial increase in number of PLWD in Ceredigion.

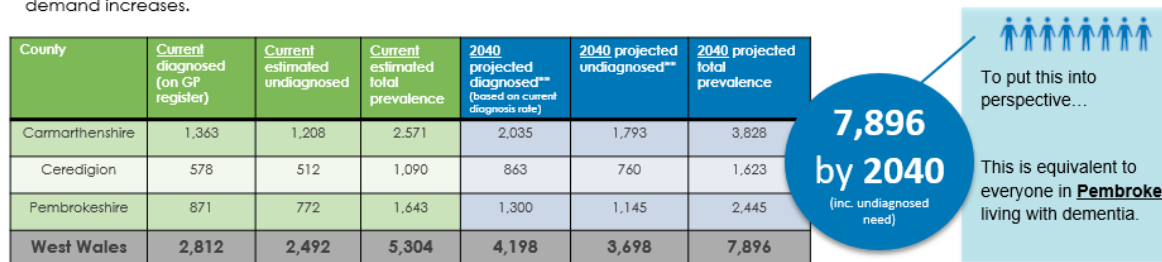
## Population projection of those with dementia in West Wales



**1 in 6**  
 Alzheimer's Society UK estimates dementia affects one in six people aged 80+. West Wales records show 1 in 10 people over 85 with dementia.

Alzheimer's Research estimates that the diagnosis rate\* is 53% across Wales, suggesting a **current** unmet need across Hywel Dda of 2,400 patients

The table below shows ALL diagnoses of dementia on the West Wales GP register **forecasted forward**, factoring in the increase in over 85s and an estimate of undiagnosed need. Data on waiting lists was not available but it is important to find ways to monitor this as demand increases.



WWCP Draft Dementia Strategy February 2022

\*The diagnosis rate is the diagnosis percentage compared to the estimated actual prevalence  
 \*\* projection is based on the diagnosis rate remaining the same as current, this is a strictly 'Do Nothing' scenario

Fig.4: Population projection of those with dementia in West Wales (WWCP & Attain, 2022)

In its PNA, the WWRPB identified gaps and areas for improvement to better support PLWD across West Wales, as outlined below:

- Continuing to improve awareness, identification and diagnosis of dementia, including onset of dementia in younger people
- Ensuring timely diagnosis and access to appropriate care and support
- Improving co-production of services by including PLWD
- Increasing diagnosis rates in non-specialist community settings by:
  - Improving training and awareness of new evidence-based best practice dementia models within primary care, based on the Good Work Framework
  - Supporting GPs, allied health professionals (AHPs) and nurses to make assessments
  - Improving quality of referrals into specialist care for those requiring it
- Developing more consistent rights-based person-centred care and support
- Continuing improvements in community support, training and help for PLWD to discuss their diagnosis, navigate/co-ordinate services, to build resilience and maintain balance across all aspects of their life
- Ensuring equal access to physical health services and treatment for PLWD
- Ensuring advance care planning and end of life care is fully embedded in wider inclusive, person-centred care and wellbeing planning

- Improving research into dementia by involving care homes in the region in current research opportunities
- Continuing the development of a “hub” or single point of contact approach for PLWD to access information and support

Whilst the Wellbeing Plan for Ceredigion 2023 – 2028 (CPSB, 2023) makes no direct mention of dementia prevalence in Ceredigion, many of the ambitions and recommendations stated potentially have benefits for PLWD, specifically those in relation to improvements in the environment, accessibility, community wellbeing initiatives, improvements to connectivity and social prescribing.

### 3.2 Diagnosis Rates of Dementia

Prior to the Covid-19 pandemic, dementia was cited as the leading cause of death in England and Wales (Senedd Cymru, 2023), with 3,530 deaths in Wales recorded as being as a result of dementia in 2021. Almost twice as many women as men accounted for those 3,530 deaths; 1 in 8 female deaths and 1 in 15 male deaths having been classified as being caused by dementia (Senedd Cymru, 2023).

Stark figures issued by the Senedd in 2023 predicted that by 2040 there would be a 70% increase in the number of older people in Wales who will be living with dementia. Recognising this urgent need to support PLWD, the Welsh Government’s Dementia Action Plan 2018-2022 provided £9M to support the RPBs in Wales to deliver better integrated services for PLWD. One of the key initiatives from the Plan include a drive for earlier diagnosis, in order to better prepare and support those in need.

Diagnosis of dementia is, in the main, conducted by memory assessment units; all health boards in Wales have memory assessment services that work to diagnose dementia. In addition to the original £9M funding, a further £3M in funding was allocated to RPBs in 2022 by the WG to specifically better support people during and after the assessment and diagnosis process. In May 2022, the WG stated that “improving timely diagnosis remains a priority for the Welsh Government and the new funding for diagnostic services will be monitored by officials to ensure that we are able to see the impact of this funding in timely access to services”, stating also that “timely and accurate dementia diagnosis and recording is crucial to provision of the right care and support”.

Despite the WG’s endeavours to improve early diagnosis of dementia, the Alzheimer’s Society Cymru stated that the data for diagnosis of dementia in Wales was “incredibly bad” in 2022 and urged health boards to improve dramatically. There have been calls to establish a National Dementia Data Observatory in Wales which has yet to come to fruition, however health boards in Wales are required to report on their diagnosis data as a key quality matrix.

Extracted Welsh Government (WG) data for the period 2020 – 2023 shows that HDdUHB, which covers the counties of Pembrokeshire, Carmarthenshire and Ceredigion, reported a minor increase in diagnosis rates of dementia in relation to health board population, rising from 1.53% in 2020 to 1.59% in 2023.

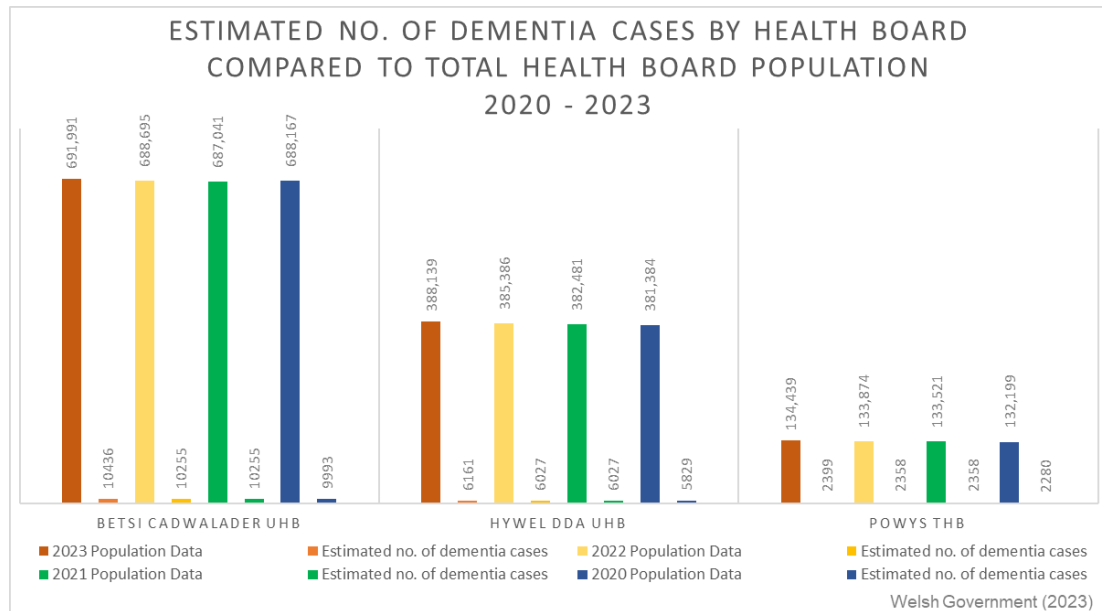


Fig. 5: Estimated Number of Dementia Cases per Health Board 2020 – 2023 (WG, 2023)

The national drive to improve diagnosis rates of dementia in Wales (Dementia Action Plan for Wales 2018 – 2022, WG, 2018) outlines the intent to “continue to implement the recommendations from the memory assessment service national audit and set targets for health boards to increase diagnosis rates by at least 3% a year”.

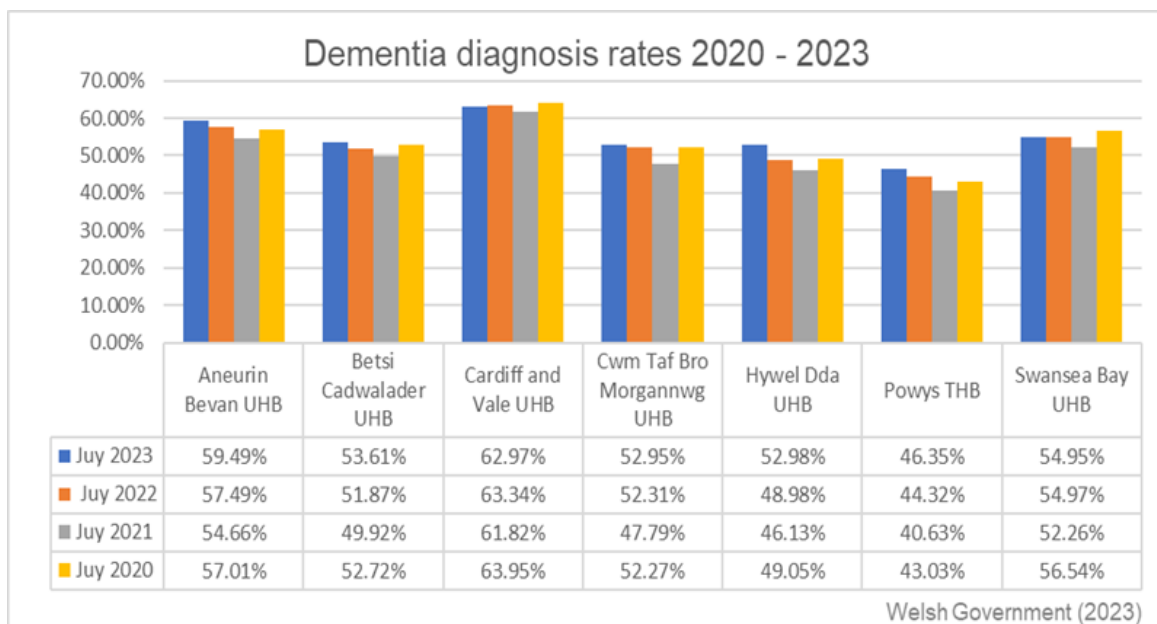


Fig.6: Dementia diagnosis Rates 2020 – 2023 (WG, 2023)

Analysis across all 7 Wales' health boards shows that the targeted annual 3% increase in diagnosis rates for dementia is generally not being met, albeit that HDdUHB almost achieved the 3% target in the period July 2021 - July 2022 and has increased its diagnosis rate by 4% over the period July 2022 - July 2023. Diagnosis rates will have been impacted however during the pandemic period and may have skewed the figures significantly during 2020 - 2021 in particular.

When considering diagnosis figures over the longer term, it must be recognised that increases in diagnosis rates for dementia do not necessarily correlate with the increase in cases of dementia, as early detection rates have been historically low and thus exact comparison is not possible. Dementia is not a new illness and will have affected many people over the past decades, however diagnosis of it has only now come to the fore and statistics for PLWD are therefore skewed somewhat when seeking comparisons of figures over time. The increase in people's life expectancy and growing elderly population figures, the demographic most widely impacted by dementia, also skew proportionate figures, resulting in the fact that direct comparison of rates over time is not possible as the figures do not necessarily accurately present a true reflective comparison.

WG data for disease prevalence by county, by area, shows that as at April 2024 dementia prevalence in both north and south Ceredigion is approximately 1.5%; in both areas dementia is 14<sup>th</sup> on the disease prevalence register of the 17 disease markers.

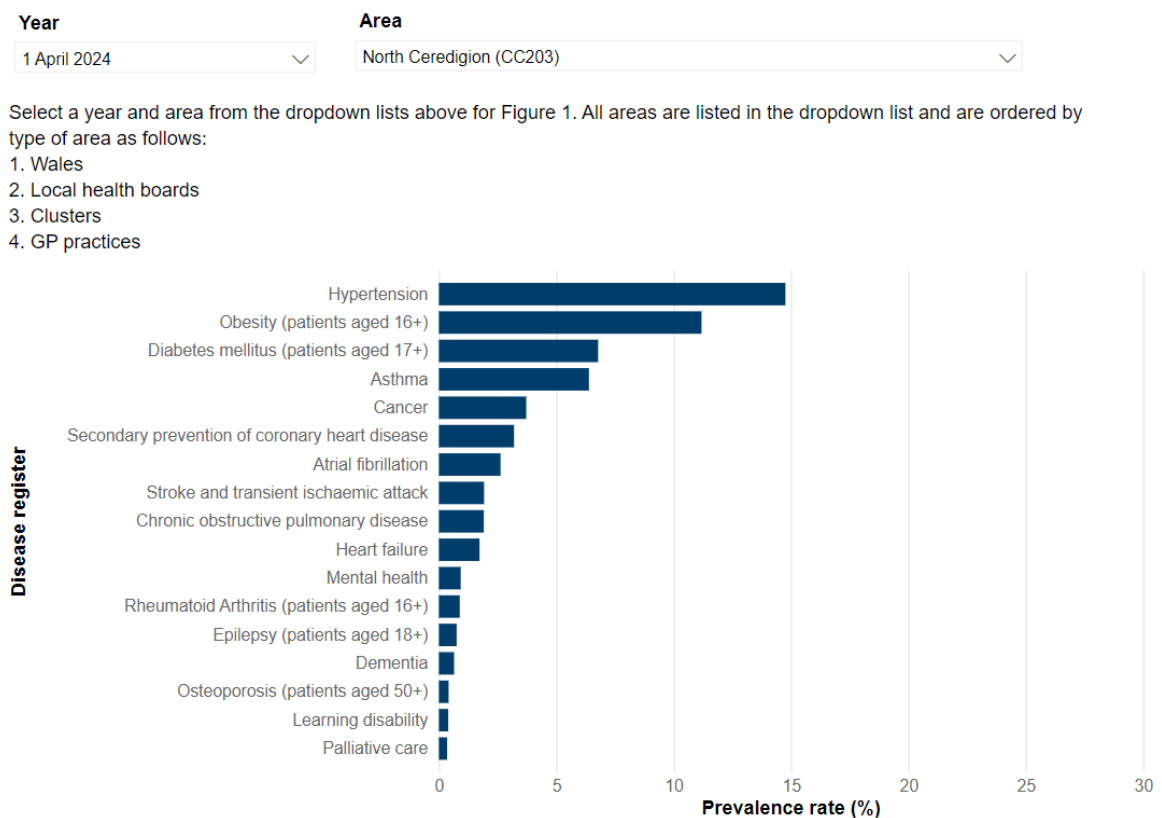


Fig. 7: Prevalence rates by disease register, April 2024 – North Ceredigion (WG, 2024)

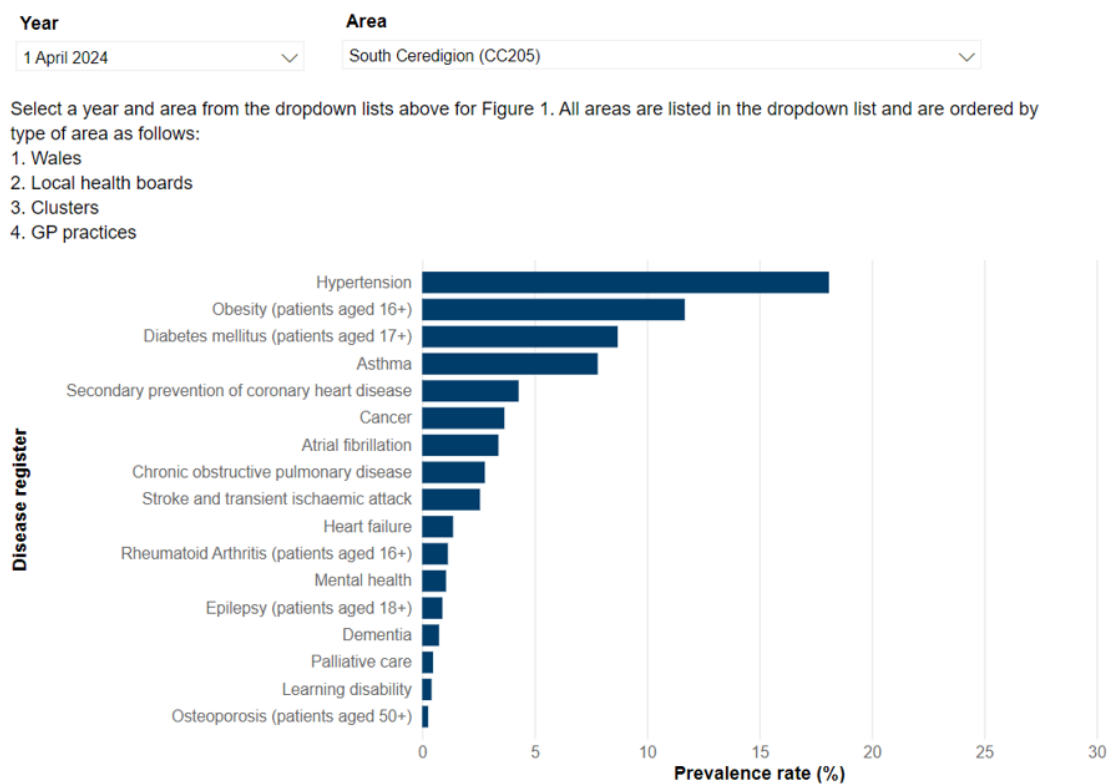


Fig. 8: Prevalence rates by disease register, April 2024 – South Ceredigion (WG, 2024)

### 3.2.1 Barriers to diagnosis rates in rural communities

Under-diagnoses and mis-diagnoses of dementia are identified as significant barriers to accessing timely and therefore more effective dementia treatment and management; this is a theme further developed in a report by an All-Party Parliamentary Group on Dementia, funded by Alzheimer’s Research UK in 2023 (Raising the barriers: An action plan to tackle regional variation in dementia diagnosis in England, 2023). Whilst the focus of this report is England, rural aspects of the report are applicable to Wales and best practice examples of rural communities contained in the report are based in Wales.

Barriers to diagnosis are many and various in nature and are considered in greater depth in the next section of this report. There is a significant concern amongst health professional that, specifically within rural communities, there is a reluctance to seek a dementia diagnosis, alongside a reluctance to provide a dementia diagnosis.

The reasons for this have been associated with a general lack of understanding of the condition, lack of available information, lack of sufficiently skilled local health professionals, weakened links between GPs and specialist teams, and lack of access to dedicated dementia diagnosis and support services i.e. Positron Emission Tomography (PET) scans and Cerebrospinal Fluid (CSF) tests.

Difficulty travelling to appointments, due to poor rural transport networks, and more generally poor infrastructure beyond transport, such as phasing out landline telephones and digital exclusion leading to confusion, all contribute to the barriers faced by people living in rural areas when seeking early diagnosis.

### **3.3 The Cost of Dementia and Dementia Care**

The Alzheimer's Society reports that, in 2024, dementia cost the UK £42.5 billion, with this figure projected to rise to £90.3 billion by 2040 (Alzheimer's Society, 2024); unpaid care and social care account for 50% and 40% of the total cost respectively (Alzheimer's Society, 2024).

The "cost" of dementia in Wales in 2013 was estimated to be £31,300 person per year (The Hidden Cost of Dementia in Wales, 2013), which, when extrapolated to 2024 figures, equates to approximately £42,934 per person per year. For comparison, the estimated societal cost of dementia in India is reported to be around INR 147 billion, the equivalent of £1.375bn (Sinha et al., 2022).

In addition to the direct cost of care and support, other costs associated with dementia have been identified in the literature to include:

- The potential for loss of property, employment, and income streams because of diagnosis for farming communities (Gould et al., 2017)
- Costs associated with future succession planning, Lasting Power of Attorneys and property maintenance or sale costs (Gould et al., 2017)
- Required technological infrastructure investment (Astell et al., 2019; Kohler et al., 2024)
- Costs associated with supportive interventions such as the free "freedom bus pass" (Innes et al., 2016; Alteren et al., 2023)
- Costs incurred by carers leading to undetermined levels of financial burden, with rural caregivers reported as experiencing higher financial difficulties than those living in an urban area (Ward et al., 2021, Roberts et al., 2022)
- Scarcity of financial resources (Phillipson et al. 2016 cross ref Shannon et al., 2019) and central service funding cuts (Dean et al. 2015)

## 4. In Search of Best Practice: a review of the literature

We turned to the literature in an attempt to identify models of best practice relevant to the design, establishment, implementation and evaluation of dementia friendly communities that were happening across the world. As well as seeking to identify models of best practice in the delivery of care and support to PLWD, we also undertook to try to identify barriers to the adoption of best practices, opportunities for improvement, challenges and future development potential.

In addition to undertaking a traditional literature review, a further grey literature review was undertaken to establish whether cited best practices had been, or were being, adopted in Wales, and, more specifically, in Ceredigion. Best Practice examples will follow the thematic review below and are listed in alphabetical order according to country.

### 4.1 Literature Review Methodology

The literature search was undertaken in three stages:

- (i) HDdUHB Medical Library Services, based at Bronglais Hospital, undertook a comprehensive literature database search between 17<sup>th</sup> and 27<sup>th</sup> September 2024, using the search terms below:

- Dementia
- Dementia best practice
- Dementia friendly towns
- Dementia friendly communities
- Dementia friendly regions
- Dementia rural
- Dementia urban
- Dementia inequalities
- Dementia innovation

In total, 671 references were returned from these searches, which were undertaken on the following databases:

- Mediline (n=192),
- Scopus (n=97),
- Embase (n=107),
- Health Management Information (n=57),
- Social Policy (n=218)

The initial review of the returned search listing was then further scaled down by relevance to dementia friendly communities (analysis, development or creation of), urban and rural comparisons, aspects impacting health and wellbeing, such

as outdoor space design, access to activities and technological developments to support wellbeing and health.

At this initial stage, 492 references were rejected as they exceeded the scope of the review, being primarily focussed on clinical, healthcare specific locations and prison environments (n=244), or were identified as duplicates (n=248). The remaining 427 references were selected for further analysis.

- (ii) A desktop search of published articles, papers, media releases (n=36) was undertaken; references outside the scope of this review (n=24) and duplicates (n=1) were removed and the remaining 11 references taken forward for further analysis.
- (iii) An internal review of the available grey literature (n=25) was undertaken between September 2024 and November 2024, which included Strategy and Policy documents, topic specific references and documentation from national Dementia and Alzheimer’s Disease Organisations. These documents were sourced from the Welsh Government, Alzheimer’s Society, Local Authorities, Regional Partnership Boards and other public reporting bodies.

Of the 732 references returned through all searches, 268 were considered outside the scope of this review, 249 duplicates were identified and 9 further references were removed as they were no longer available or had access restrictions applied.

Additionally, for the purposes of this review, references pre-2005 were discarded (n=17), as the focus of the review is to seek current best practices examples to feed into future strategic planning.

After collation of all references of relevance and interest, a total of 189 pieces of literature were taken forward for review as part of the scoping exercise:

| Source                        | Number of references | Texts No Longer Available or Access Restricted | Duplicates | Outside the scope | Pre 2005 texts | Total included in the review |
|-------------------------------|----------------------|--|------------|-------------------|----------------|------------------------------|
| Website searches              | 30                   | 0  | 0          | 24                | 0              | 6                            |
| Media sources                 | 6                    | 0  | 1          | 0                 | 0              | 5                            |
| Mediline                      | 192                  | 9  | 0          | 92                | 5              | 86                           |
| Health Management Information | 57                   | 0  | 1          | 34                | 4              | 18                           |
| Social Policy                 | 218                  | 0  | 84         | 98                | 8              | 28                           |
| Scopus                        | 97                   | 0  | 73         | 8                 | 0              | 16                           |
| Embase                        | 107                  | 0  | 90         | 12                | 0              | 5                            |
| Grey Literature               | 25                   | 0  | 0          | 0                 | 0              | 25                           |
| <b>TOTAL:</b>                 | <b>732</b>           | <b>9</b>                                       | <b>249</b> | <b>268</b>        | <b>17</b>      | <b>189</b>                   |

Table 1: Literature Review Summary

It is worth noting that in seeking to identify models of best practice, RHCW reviewed papers from national and international sources, however only English language texts were included in the review and it is acknowledged that this may have led to the exclusion of a small number of papers.

Full details of all reviewed documentation are included in the Bibliography at the end of this report.

In this report, analysing the literature and seeking to identify best practice examples in the delivery of care to people living with dementia has focussed on the creation of dementia friendly communities, with strong communities being an asset of rural areas such as Ceredigion. This section has therefore been structured to consider the following:

- Dementia friendly communities
- Barriers to achieving dementia friendly communities
- Overcoming the barriers and challenges
  - Education, Training and Awareness Raising
  - Transport and social and health connectivity.
  - Role of, and Impact on caregivers
  - Rurality
  - Built environment design and outdoor spaces.
  - Enhancement of assistive technologies
  - The move away from biomedical models of care to community / person centred care models

## **4.2 Dementia Friendly Communities (DFCs)**

With increases in the rates of dementia that are being diagnosed, and with predicted ongoing increases associated with longevity and more people living until old age, there have been multiple attempts to address the care needs and provision of support for PLWD. One such initiative that is growing in popularity is the development of whole communities, or societies, that cater for the needs of PLWD, their families and their carers. As rural Mid Wales is rife with strong communities, and the thrust of health and care services now moving to community-based provision (Welsh Government, 2018), it is important that we consider how best to utilise a community-based approach as part of the analysis.

There does not appear to be a single model or template for a DFC, however the literature does seek to define what is meant by dementia friendly and dementia friendly communities (Williamson, 2016; Lin, 2017; Silverman, 2021). In most instances, the Alzheimer's Disease International definition (2016) of a DFC is most widely adopted:

*“A dementia friendly community can be defined as a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential”*

In 2017, the WHO defined a dementia friendly society, as an alternative to a dementia friendly community, as being able to provide “an inclusive and accessible community environment, with enhanced opportunities for participation, health and safety for all people, to ensure a good quality of life and dignity for people with dementia and their families”.

Four essential factors have been identified as key elements to developing DFCs:

- 1) Providing training, education and awareness-raising about dementia
- 2) Active inclusion and involvement of PLWD (and the communities they live in)
- 3) Encouraging and supporting partnerships, networks and collaborations
- 4) Securing and sharing resources for developing dementia-friendly communities

*(Williamson, 2016)*

A 2018 study strove to correlate the design of age friendly communities (AFCs) and DFCs, based on “principle” and “domain” characteristics (Shannon et al., 2018). The intent was to encourage collaborative development of age friendly initiatives (AFIs) and dementia friendly initiatives (DFIs), rather than developing these in parallel, for the benefit of all (Scher, 2018; Turner & Cannon, 2018).

| Characteristics        | Dementia-friendly communities   | Age-friendly communities  |
|------------------------|---|---|
| Origin of the concept  | In 2012, the World Health Organization recognised dementia as a public health priority and noted the intersection of health and social inclusion in contributing to the well-being of people with dementia (World Health Organisation & Alzheimer's Disease International, 2012)  | World Health Organization active ageing framework (World Health Organisation, 2007)   |
| Focus                  | Increasing understanding and reducing the social stigma related to dementia by awareness raising. Empowerment of people with dementia by recognition of their human rights and their abilities. Supporting people with dementia to participate in living normal lives for as long as possible (Alzheimer's Disease International, 2016)   | Supporting people to age actively through accessible “policies, services, settings and structures” (World Health Organisation, 2007, p. 5)  |
| Principles and domains | There are four key principles of dementia-friendly communities, the inclusion of people with dementia and care partners during development, communities that facilitate accessible and appropriate activities that are not segregated and have physically accessible spaces and places, organisations and services that adopt a dementia-friendly approach including having appropriately trained staff who know how to interact with people with dementia and collaborative partnerships across organisations working to achieve dementia-friendly communities (Alzheimer's Disease International, 2016) | There are eight overlapping domains relevant to age-friendly communities, and these are outdoor spaces and buildings, transport, housing, social participation, respect and social inclusion, civic participation and employment, communication and information and community support and health services (World Health Organisation, 2007) |

*Fig. 9: Principles of DFCs & domains of AFCs (Shannon et al., 2018)*

The literature evidences many attempts to expand and clarify the characteristics of a DFC intervention, in that they:

- 1) Support community awareness of dementia
- 2) Provide dementia training for health and community organisations
- 3) Support PLWD to remain living at home
- 4) Enable access to timely-diagnosis and to adequate and affordable home health care
- 5) Facilitate dementia-specific recreational and social programs,
- 6) Incorporate age and dementia-friendly environmental features such as legible signage to help people with cognitive impairment navigate their community safely
- 7) Provide inclusive public transportation such as accessible bus stops
- 8) Ensure the availability of respite care for caregivers

*(Alzheimer's' Australia, 2014; City of Burnaby, 2017; Wu et al., 2019; Diaz et al., 2022)*

A step towards the realisation of a more collaborative and unified approach between AFC and DFC developments is reported in one 2023 study. In the post study evaluation of a DFC implementation scheme, it was identified that key community stakeholders had subsequently become members of the AFC action team, incorporating DFC initiatives via a subcommittee (Scher et al., 2023).

Regardless of the route of implementation – via AFC or DFC initiatives - the focus on engagement with, and participation of, PLWD is evidenced across the literature, with calls for PLWD to be consulted, particularly when determining what a DFC should look like (Williamson, 2016; Wu et al., 2019; Hung et al., 2021; Jiminez et al., 2021; Craig et al., 2023; Thijssen et al., 2024).

“Nothing about us, without us” is a borrowed statement from the Disability Movement, coined in 2017, which aligns PLWD to those with protected characteristics for the purposes of diversity and inclusion in decision making, policy, planning and DFC development for, and by, PLWD (Wolfe, 2017). PLWD however remain outside the protected characteristics. One study went further, reporting that the lack of inclusion of PLWD in defining what “dementia friendliness” and DFCs are conflicts with the “explicit need for inclusivity” (Fletcher et al., 2023).

It is important to note that whilst a DFC is generally seen as an enabler to allow PLWD and their carers to remain engaged in their community, well into the disease (Bergeron et al., 2023), in other regions of the World the development of DFCs is associated with being simply a way to make up for the shortage of care for PLWD in families and communities, where familial care of the sick and elderly is a Government requirement (Wang et al., 2024).

The literature also acknowledges the challenges associated with engaging with and ensuring participation of PLWD in DFC development processes, unless they have a care partner (Dean et al., 2015; Heward et al., 2017), with other studies reporting that on occasion the care partner speaks on behalf of the person living with dementia in the decision-making process (Heward et al., 2017; Portegijs et al., 2020).

There are of course inherent cultural differences inferred in much of the (international) research reviewed, with a study in Nanjing reporting PLWD as being “recipients of services” and not stakeholders (Wang et al., 2024), despite the body of research that exists supporting a more inclusive base on which to build a DFC.

One factor to consider with the establishment of a DFC, or series of DFIs, is the long term ongoing sustainable support available for PLWD and their carers (Marshall et al., 2018; Thijssen et al., 2023; Grogan et al., 2024). Stakeholders in the development and sustainability of DFCs almost without variation advocate the incorporation of networks and collaborations, including “informal support networks, networks co-ordinated by dedicated teams or individuals, formal stakeholders steering groups or governing bodies including local councillors, MPs, mayors, businesses and public bodies” (Williamson, 2016), with recommended models bringing communities together to help create inclusive environments in order to promote active and healthy ageing (Herbert et al., 2019; Bergeron et al., 2023).

### 4.3 Barriers to achieving Dementia Friendly Communities

The key challenges identified in the literature to the development of DFCs focus on:

- (i) **Stigma**: stemming from lack of understanding, impacting social inclusion and healthy ageing (Benbow & Jolley, 2012; Lion et al., 2015; Williamson, 2016; Marshall et al., 2018; Hung et al., 2021; Rewerska-Jusko & Rejdak, 2020; Krier et al. 2023)
- (ii) **Lack of self- acceptance and reluctance of PLWD to ask for and / or accept help**, also the family and friends of PLWD, who may feel embarrassed or ashamed, and carers who struggle to support PLWD under their care (Morgan et al., 2014; DiGregorio et al., 2015; Forbes et al., 2018; Williamson, 2016; Phillipson et al., 2019; Bergeron et al., 2023)
- (iii) **Environment: Physical surroundings** (Williamson, 2016; Gould et al., 2017; Hicks et al., 2021; Diaz et al., 2022) and **atmospheric environment** (Fletcher et al., 2023)
- (iv) **Resources**; both technological and physical resources, including information and advice provision and support pre- and post-dementia diagnosis (Williamson, 2016; Smith et al., 2016; Roberts et al., 2022; O’Connell et al., 2024)

- (v) **Policy, health, and social care services challenges** due to location and availability (Williamson, 2016; Windle et al., 2021; Köhler et al., 2024)
- (vi) **Governance** of DFC and DFI implementation, specifically the need for community buy-in (Williamson, 2016; Grogan et al., 2024) and the removal of unconscious bias through continual critical internal review (Grogan et al., 2023)

Additional challenges associated with the lack of social cohesion within the communities include:

- (vii) **Changing demographics**, especially in rural communities (Wiersma et al., 2016; Shannon et al., 2019; Morgan et al., 2019; Hicks et al., 2021; Bergeron et al., 2023)
- (viii) **Lack of funding security** to fully sustain DFC interventions were also highlighted (Szymczynska et al., 2011; Palmer et al., 2019; Bergeron et al., 2023)
- (xi) **Lack of availability of community transport** and other transport issues such as cost, availability, long distances to be covered, confusing timetables and signage were also identified as barriers to DFC (Neville et al., 2018; Roberts et al., 2022; Shatnawi et al., 2023)

These challenges are further considered in this literature review when looking at the means by which to overcome the issues raised.

#### **4.4 Overcoming Barriers and Challenges**

There were multiple ways listed in the literature in which communities can tackle challenges to becoming dementia friendly. This section of the report has categorised 7 of the main thematic challenges and noted how these can be addressed and overcome:

- Education, training and awareness raising
- Transport: social and health connectivity
- The role of and impact on caregivers
- Rurality
- Built environment design and outdoor spaces
- Enhancement of assistive technologies
- Moving from biomedical models to community / person centred care models

#### 4.4.1 Education, Training and Awareness raising

By far the most common requirement to creating a DFC, cited in the literature, is the need for education, training and raising of awareness of dementia. This should include identification of symptoms of dementia and the positive impact that community support can have for PLWD and their carers.

Education across age and professional boundaries, to inform a community-led change in perception of dementia, is seen as fundamental to the establishment and maintenance of DFCs, providing supportive and healthy environments in which people can grow old with dignity and respect and reduce stigmatisation (Smith et al., 2016; Hung et al., 2021; Pozo Menendez et al., 2022; Krier et al., 2023; Lizuka et al., 2024).

A number of studies also noted the need for increased clinical education for medical teams supporting PLWD, particularly in rural environments (Ahmed et al., 2010; Forbes et al., 2012; Saunders, 2013; Morgan et al., 2014; Alzheimer's Society, 2017; Hayden et al., 2023) and the removal of "prescribed diagnosis" (Swaffer, 2014), whereby PLWD are convinced to give up the lifestyle that they had previously enjoyed upon diagnosis, leading to a perception of deficit in diagnosis (Swaffer, 2014).

In assessing clinical education in India, the integration of geriatric research, the definition of geriatric services, noting health problems of aged populations, prevention measures and outlining the National Program for Healthcare of the Elderly into all Indian undergraduate medical training and education programmes was reported as not only good practice, but critical to the development of a DFC. This included multi-dimensional aspects of community medicine, psychiatry and medicine at postgraduate level, in order that all levels of education include dementia friendly community considerations (Sinha et al., 2022).

In undertaking this review, RHCW established that within Ceredigion, Aberystwyth University is incorporating dementia friends and dementia awareness training in all their undergraduate nursing training courses, with all nursing students undertaking a Dementia Friends awareness session. The University is currently engaged in mapping of the Higher Education District Nursing (HEDN) curriculum and the Good Work framework to ensure that all undergraduate nursing students are suitably trained in caring for PLWD and their carers at the point of registration.

Currently, this training takes the form of a two-hour workshop, which covers Dementia Friends, and two one-hour sessions in year one: 'what is dementia?' and 'caring for a person living with dementia.' In year two, there are more in-depth sessions related to both the pathophysiology of dementia and working with

challenging behaviours. In year three, there is some simulation training of working with someone who is confused.

Aberystwyth University also offers a Lifelong Learning module which is open to the public and existing students: A Toolkit for Supporting Someone with Dementia (XK19005); staff are proactively encouraged to attend other dementia training and awareness raising workshops.

Also within Ceredigion, Coleg Ceredigion has confirmed that the concept of Dementia Friends and the associated principles are incorporated into teaching methods, with students actively encouraged to become Dementia Friends as part of their personal and professional development; this type of initiative aligns with the development and promotion of dementia-friendly communities.

Within Coleg Ceredigion's Level 3 Health & Social Care programmes, students study the condition and explore various approaches to dementia care, including the understanding of the progression of dementia, person-centred care and strategies to support individuals living with dementia and their families. The college also places a strong emphasis on experiential learning, with Virtual Dementia Bus Training offered to all students. This interactive training offers invaluable insights into the lived experiences of individuals with dementia, fostering greater empathy and understanding.

A key aspect of the suggested education focuses on the language used for and around dementia, which can often be contentious and based on symptoms rather than a real understanding of the condition (Rahman & Swaffer, 2018). It has also been argued that the term "dementia friendly" itself is associated with a sense of loss or "deficit" rather than focusing on what is still possible (Rahman & Swaffer, 2018). One suggestion for addressing this suggests reframing the term "dementia" to be "reementia", which changes the focus onto what remains not what is lost (Kitwood, 2008 & 2019). Referring to "familiar places and friendly faces" is also cited as better reflecting the ambition of "everyday, in everyway" (Marshall et al., 2018).

Formal training for organisations and services, most commonly the Dementia Friends and Dementia Friends Champion schemes (Fletcher et al., 2023), is also viewed as a positive intervention across the literature, from use in shops and businesses (Williamson, 2016), amongst the farming community and agencies working with that community (Gould et al., 2017) and in churches (Schmidt et al., 2023).

Supportive staff and members of the community are identified in the literature as being essential in helping people with dementia engage in their communities (Wiersma, 2008; Smith et al., 2016). In addition, schemes such as the Red Knot (FOTON Belgium, 2014), the Purple Angel Campaign (Wrexham, 2014), the Orange

Army (Tokyo, 2019) and adoption of the Alzheimer's Forget-me-not emblem that provide assurances to PLWD of dementia friendly support within shops, services and everyday businesses on the High Street are quoted as good practices.

One study reported that education can lead to a reduction in the need for PLWD to *"use humour as a means by which to avoid judgement and to anticipate and prevent embarrassment in others"*, resulting in reduced instances of self-withdrawal from society (Ward et al., 2021), as well act as a tool to facilitate social cohesion (Bergeron et al., 2023).

Intergenerational interventions are also considered essential to raising awareness of dementia and fostering ongoing dementia friendly community support, with two examples of best practice cited in Scotland:

- the "Promoting Excellence" scheme in West Dunbartonshire, and
- the Bishopbriggs Academy's "Community Action Project"

Both schemes are aimed at engaging children, the elderly and PLWD in social history discussions on lives well-lived, as well as in art and craft activities. The Bishopbriggs Project went further, with a "youths on bikes" scheme, which involved young people visiting older people in the community on their bikes, with input from a local cycle co-operative and the establishment of local dementia cafes (Williamson, 2016).

The literature also reports that carers should have education and training courses made available to them, to assist in their preparation for caring for PLWD and enhance their caring skills throughout their care journey, so that they are able to provide the best support possible for their loved ones (Saunders, 2013; Bauer et al., 2019; Gibson et al., 2019).

#### 4.4.2 Transport: Social and Health Connectivity

Transport and travel are noted by the Alzheimer's Society as one of 10 key areas of intervention that can make communities dementia friendly (WHO, 2007; Sinha et al., 2022). With the lack of access to transport cited frequently in the literature as a barrier to social and health connectivity, more especially in rural communities where there are often inadequate public transport networks (Scharf et al., 2007; Doheny et al., 2013; Emler et al., 2012; Novek & Menec, 2014; Neville et al., 2018).

Lower population density and the geographical location of rural communities was also highlighted in the literature as posing additional challenges in terms of both financial and time costs, leading to discrepancies in resource allocation and attendance at health and social activities (Szymczynska et al., 2011; Palmer et al., 2019).

The impact of lack of transport on the elderly, who have no choice but to travel long distances for appointments for dementia treatment, is reported in the literature as simultaneously time and cost inefficient, leading to increased potential of anxiety for what were relatively short appointments. It was noted also that this could be just in relation to the first stage of treatment and most likely the same individuals would be required to make equally long journeys for further tests, scans and follow-up appointments (Krutter et al., 2020; Longstreath et al., 2022; Hayden et al., 2023).

Some studies showed that PLWD who were still able to drive may feel compelled to do so, due to the reduced level of physical effort required when compared to more active forms of travel such as walking and cycling (Musslewhite and Shergold, 2013), poor public transport infrastructure and lack of alternatives (Stasiulis et al., 2020).

One participant, vocalising the Swaffer (2014) perception of deficit, stated that the enforced cessation of driving, as a result of his dementia diagnosis, severely curtailed his social activities - *"the biggest thing that I am unable to do since losing my license is getting to and from my exercise classes and [I've] been unable to get to the library....no longer go shopping, or to church or to visit friends. All parts of my life are affected because I am not able to drive"* (Dobbs et al., 2020).

Whilst losing the ability to drive is undoubtedly a loss, which has the potential to impact on the participants long-term health and wellbeing, there remains however tangible safety concerns relating to PLWD who may wish to continue to drive, due to a reduction in reaction time, difficulty in making reactive decisions and the reduced ability to drive for an extended period or at night because of the dementia condition (Ward et al., 2021). A supportive DFC transport intervention has the potential to address this deficit, which could include community transport cars, or lifts from neighbours as part of a localised support scheme.

The literature highlights other significant health and safety concerns regarding transportation to social and health appointments specifically for people with dementia, including the ability to reach a bus stop safely due to risk of injury or getting lost (Burton and Mitchell, 2006), poor or lack of signage (Sinha et al., 2022), confusing bus timetables (numbers and colour coding) (Crampton & Eley, 2013; Giebel et al., 2021), rapid platform changes at rail stations, steep stairs (Innes et al., 2016; Epps et al., 2018), lack of appropriate walkways, hills and inclines, limited weather protection at bus stops (Chen et al., 2020) and poor announcement quality (Peterson et al., 2022).

With wandering frequently reported as a symptom amongst PLWD, concerns have been raised about restriction of movement due to safety concerns (Bantry et al., 2016) and the increase of carer strain as a consequence, leading to increased levels of disclosure to the police of a dementia diagnosis (Ballard et al., 2000) with people

reported missing most commonly from residential settings rather than from care environments (Rowe & Glover, 2001).

In some of the literature, isolation, due to poor social and health connectivity, is noted as a significant factor in the ability of PLWD to benefit from Dementia Friendly Initiatives (DFIs) / DFC interventions, however it is noted that this lack of connectivity could be appeased by improved transport links (Parr et al., 2004).

Whilst no concise method to identify the unmet transport needs of PLWD was identified in the literature, some studies acknowledged the need for further transport needs assessments. In China, it was reported that 30% of older adults in China with dementia had unmet transport needs (Chung, 2006) and in France 41.4% were unable to use public transport at all due to mild to severe Alzheimer's Disease (Lechowski et al., 2007).

Transport in much of the literature features as a barrier for PLWD, however accessibility, either by public transport or due to location, is just as much an issue for service providers delivering home-based care (Chen et al., 2020).

Service providers from Alberta, Canada that were using alternative transportation services aimed at enabling PLWD and their carers to travel more easily reported that:

- 56% of alternative transportation service providers in urban areas offered a door-to-door service, compared to 43% in rural areas
- escorted services were available to 40% of people, split into 44% in urban settings and 37% in rural settings (Dobbs et al., 2010)

A further study noted that in the USA, 23.15% of people cited lack of, or limited access to, transport as the primary factor in curtailment of social activity (Parisi et al., 2017). Social inclusion is improved with the presence of transportation options, enabling relatively stress-free access to social and health activities (McAdam, 2020). Generally, however, this is more easily remedied in urban areas, with the availability of transportation services in many rural communities across the world being considered to be poor.

The literature also evidences the potential for variation in perceptions of transportation. A Taiwanese study reported that 8.3% of PLWD reported unmet transportation needs, of whom 6.7% were family carers for PLWD (Liu et al., 2021).

In contrast, the same study reported that 65% of PLWD considered there to be good transport connectivity, of whom 17.20% were family carers (Liu et al., 2021).

#### 4.4.3 The role of and impact of a dementia diagnosis on caregivers

Caregiver stigma can lead to the withdrawal from society of not only PLWD but also their carers, due to fears of being stigmatised, socially excluded or in some other way being associated with the disease (Alzheimer's' Australia, 2010; Swaffer, 2014; Evans, 2018; Hung et al., 2021); this is highlighted as a significant concern in the literature reviewed.

Acceptance of a dementia diagnosis is widely seen as being a major step towards reducing the stigma associated with the disease for PLWD, their caregivers and the community surrounding the person with the diagnosis (Sinha et al. 2022).

Many studies commend the commitment of carers to supporting PLWD to remain at home for as long as possible, despite high physical and emotional costs to themselves (Shultz et al., 2004; Goodman et al., 2017; Roberts et al., 2022) and the potentially significant financial pressures of care provision (Hung et al., 2021).

It is further reported in the literature that carers provide extensive and intensive, personal and social care for PLWD, leaving less and less time for their own social activities (Shultz et al., 2004; Goodman et al., 2017), and that the level of responsibility on caregivers increases incrementally as the disease progresses, demanding increasing levels of vigilance and availability (Weir et al., 2017); these factors are significant when noting the increasing number of PLWD requiring care, while the number of potential caregivers' declines (Blackstock et al., 2005; Kohler et al., 2024). Of specific concern are carers who themselves have a dementia diagnosis.

Informal care support from family and friends is considered an important aspect of dementia care and to the development of a DFC (Dean et al., 2015), regardless of location, but is of particular importance when formal service provision is reduced or unavailable, such as is the case in some rural communities (Windle et al., 2021).

The unpaid, informal, care burden has been linked in the literature to unmet needs from formal services (Li et al., 2012). Some rural caregivers reported finding it easier than urban-living carers to get help from family and friends but also reported more pronounced feelings of abandonment by family and friends in the community due to stigma (Ehrlich et al., 2015); later studies reported a lack of informal community-led support in some rural areas (Roberts et al., 2022).

A subsequent study reported lower community care costs, as well as lower rates of admission to long-term care in rural compared to urban areas; this was directly attributed to the provision of elevated levels of care within families (Walsh et al., 2021).

The World Alzheimer's Report (2012) "Overcoming the Stigma of Dementia" reported that of the 2,068 UK respondents to the research survey, 83% were carers and only 6% were living with a diagnosis of dementia. In a similar study undertaken in Spain, the differential between carers and carers with a dementia diagnosis themselves was reported as being 3% carers with a dementia diagnosis and 77% being carers (Basch et al., 2012).

Another theme highlighted in the literature is the gender imbalance amongst caregivers, with 97% of PLWD shown to be cared for at home by a family member. Over 70% of these were female caregivers, most commonly daughters or spouses (Slachevsky et al., 2013). In Canada, it was reported that 80% of caregivers are women, providing on average 8.2 hours of support every day and night (Weir et al., 2017).

In a later Chilean study, a reported 1.3M people self-declared as unpaid carers of a relative, 90% of whom were women. The report also noted that caregiving has a significant negative impact on the educational opportunities and future career potential of carers (Jiminez et al., 2021), with available respite being reported as a significant issue (Dean et al., 2015; Heydon et al., 2023) and support for carers being referred to as a much-needed international priority (Windle et al., 2024).

Whilst some research has been undertaken to determine what a DFC looks like from a carer's perspective, this work is limited. Much of the focus is on the perspective of PLWD or that of policy and decision makers.

A review of specific places for carer support highlights that both formal and informal caregivers consider pharmacies to be an important touchstone for people with dementia and therefore valuable locations for the implementation of DFIs (Gilmartin-Thomas et al., 2017). Carers' connections with others, such as family, friends, acquaintances, businesses, service providers, neighbours and / or strangers, impact everyday practices that are core to the lives of carers and their social wellbeing (Silverman, 2021).

Whilst there is no template or requirement for churches to be dementia friendly, or to provide dementia friendly services, they are increasingly recognised as providing an environment that can readily support adaptations to service delivery to support PLWD and their carers. Through adaptations, the delivery of dementia friendly services and the provision of spiritual connection and engagement for people living with dementia, along with supporting their families and caregivers can readily form part of a DFC development (Williamson, 2016; Schmidt, 2023).

Some studies also suggest that religion is a frequently used coping mechanism for rural caregivers (Windle et al., 2021), with it being considered a "welcome haven" (Schmidt, 2023).

A review of the Dementia Actif Wellbeing Programme in North Wales identified that there was a lack of evidence on how social interaction, wellbeing and the value of community assets could be measured to address the needs of PLWD and their unpaid carers. This includes an evaluation of preventative community-based resources to support unpaid carers and reduce the need for admission to acute secondary and residential care, which is key to a sustainable DFC intervention (Davies, 2023).

Early rural research notes that carers felt that living in the country provided a safe space for their relatives due to visibility within the community (Blackstock, 2005): *"mom will take a walk in the field and you know she is in the field; you can see her"*.

The image of rural caregiving is generally portrayed as a positive one, giving rise to the notion of a "rural idyll" (Blackstock et al., 2005); participants in one study believed that rural living was more co-operative and conducive to mutual support than urban living (Innes et al., 2011); having a sense of peace and connection with nature within safe surroundings which are easily navigated was also deemed positive (Hicks et al., 2021). There is a risk however that this idyllic image of rural caregiving may not meet the reality, leading to Marshall et al. (2018) describing living rurally as living in a "beautiful prison", with isolation and loneliness connotations.

Common recommendations from the literature to inform caregiving support and meet carers' needs include training care staff to participate in meaningful activities in their own homes (Forbes et al., 2011), supporting people to remain connected and included in society (Clarke & Bailey, 2016), supporting families to provide meaningful care-giving and maintain a normal life (Ehrlich et al., 2015 / 2017), enhancing existing resources available to carers and families (Gibson et al., 2019) and the development and use of carers checklists for ongoing help and support, including tips for carers and ideas for care home visits (Angel in Gumboots, 2022). These measures would, it is argued, alleviate what Evans (2021) described in relation to her experience of the period after receipt of her husband's diagnosis, as the "terrible silence".

#### 4.4.4 Rurality

Whilst previous sections of this report have touched on the impact of rurality on PLWD and their carers, looking to define rurality in the context of dementia results in a limited response (Morgan et al., 2009). Early research has concluded that there is insufficient information available to develop rural dementia care services that support PLWD and their carers, despite the rising age of rural residents (Scotland) (Innes et al., 2011) and rural communities generally characterised by low population density compared with land mass and a high level of agricultural industries (Marshall et al., 2018).

Rural areas tend to be inhabited by a higher proportion of older people and thus have a higher prevalence of dementia (Gould et al., 2017); the established association between ageing and dementia also means that rural populations are disproportionately impacted by the inaccessibility of services (Morgan et al., 2019).

In 2013, 63% of the Welsh population was reported to live in rural and often remote environments, i.e. populated by <10,000 people (ONS, 2013). As at October 2024, this figure was reported to be 80% (Welsh Government, 2024). Studies report that available support is often urban-focussed and lacks relevance for people who have lived and worked outdoors all their lives. It is perceived as having no connection with the high level of independence, tradition of pride and self-reliance, and the desire for privacy that exists within the farming community (Gould et al., 2017; Evans, 2021). This often also means that PLWD and their carers living in rural communities feel prevented from asking for help (Gould et al., 2017).

The changing demographic profile of rural communities also poses challenges, with younger people moving away and new residents moving in, who may not be so engaged with the community (Innovations in Dementia, 2011), and the influx of newly retired, relatively wealthy incomers leading to the marginalisation of poorer long-standing, older residents (Keating et al., 2013), impacting on social cohesion (Wiersma and Denton, 2016).

Rural communities can act as both barriers and facilitators to community participation, with informal support potentially being provided within communities based on a known need, e.g. help with shopping, cleaning, transportation (Wiersma & Denton, 2016), contrasting with the increased levels of risk associated with the gradual onset of dementia in a farm worker, due in part to lack of succession planning (Gould et al., 2017) for example, which in turn leads to the whole farm declining, resulting in dangerously high levels of safety risk (Marshall et al., 2018).

The benefits of living in a rural community for PLWD and their carers reported were:

- enabling PLWD to continue to contribute
- enabling support for PLWD and their carers from the wider community

The detrimental aspects of living in rural communities are reported as being more far reaching, some of which exceed the remit of this review, such as:

- Complex care systems
- Lack of provision affecting continuity of care
- Transportation and travelling
- Cultural sensitivity reflecting lack of awareness of any available services
- Difficulties obtaining a diagnosis
- Challenges providing long-term care and alternative housing options

- Poor service provisions
- Difficulties faced in accessing services and receiving daily home care
- Language barriers for Indigenous or minority language groups

*(Windle et al., 2021)*

A 2022 article by Roberts et al. (2022) identified four methods of enhancing support for PLWD and their carers that could be adopted in rural communities:

- 1) creating supportive rural communities to evidence the possible benefits of living in a rural community
- 2) enabling PLWD and their carers to develop managing and coping strategies to enable them to derive strength and support from the area in which they live and the people with whom they engage
- 3) identifying and seeking to resolve the more detrimental aspects of living in a rural community as outlined by Windle (2021)
- 4) Highlighting and raising awareness of specific difficulties with dementia care services regarding rural communities

*(Roberts et al., 2022)*

To create a sustainable DFC, the literature suggests developing a model which builds on the community connections that already exist in most rural communities, such as informal support networks, networks co-ordinated by dedicated teams or individuals, community steering groups or governing bodies that include local councillors, MPs, mayors, businesses and public bodies as well as PLWD and their carers.

Recommended supportive models that could be adopted by rural communities include the North Wales Dementia Friendly Recognition and Accreditation Scheme, which is used to standardise and promote dementia friendliness within businesses and organisations across the region. In addition, the Dementia Friendly Wrexham Steering Group (DFWSG) and the Bangor University's Dementia Services Development Centre's engagement in research of PLWD and their carers are both good local examples of commitment, with sustainability of outcomes at their heart.

The latter of these models of practice directly addresses point 10 of the 11 areas for improvement suggested in the WWRPB Population Needs Assessment for Ceredigion 2023 – 2028:

- Improving research into dementia, involving care homes in the region in current research opportunities

It is important to note however, as discussed at the start of this review, that there is no “one size fits all” approach to the establishment of a DFC. Engagement with

neighbours and communities can be as important for people who have lived in urban environments for a long time as it is for those from a rural background (Innovations in Dementia, 2011), and a DFC for PLWD living in a remote rural area, about to go into a residential care home, may be very different from that of a person who has had a recent, early diagnosis (Williamson, 2016); it is therefore important to embed a critical review and evaluation process from the outset (Grogan et al., 2024).

Living in rural communities does however present additional demands and challenges for PLWD and their caregivers regarding access to assistive technologies, which have the potential to create equity in service provision. Most notably, the broadband infrastructure to support services is patchy in many rural areas and non-existent in a few of the more remote environments (Marshall et al., 2018).

The Global Research, Innovation and Education on Assistive Technologies (GREAT) initiative identified rural areas as problem areas for access to Digital Assistive Technologies (DATs) in 2018 (GREAT, 2018). Despite this, and other research in the area, little improvement is evidenced in the sustainability and accessibility of the technological infrastructure across Wales and, more specifically, in Ceredigion.

#### 4.4.5 Built Environment design and Outdoor Spaces.

##### Built Environment

Physical space can also act as a barrier to the provision of support to PLWD and their carers (Blackstock, 2005), with environmental considerations impacting social interactions through physical design and technology (Wiersma, 2008; Smith et al., 2016). Studies show that communities themselves can be deemed to be physically and socially hostile places, with inaccessible housing and built environments (Fleming et al., 2017; Bowes & Dawson, 2019).

Identified key navigational pointers that have inspired further research into the navigation skills of PLWD in care settings focus on:

- The size and shape of the corridors within living areas impacted PLWD
- Straight circulation systems enable residents to navigate more effectively
- Numerous shifts in direction interfere with the residents' wayfinding.
- Orientation was improved if the whole corridor could be overseen from any point of the living room.
- Elimination of unnecessary alcoves and wall recesses within the corridor was beneficial
- Orientation of bedrooms was important, based on the stage of dementia the patient had

- Location of additional toilets in the living areas, which were not assigned to a bedroom / person, did not affect orientation

*(Marquardt & Schmieg, 2009)*

Two categories of Dementia Friendly design (Physical and Cognitive) are therefore suggested:

- *Physically friendly* – which includes step free access and availability of elevators
- *Cognitive friendly* - with design focussing more on the colour, brightness, contrasts and volume of design data that is incorporated, e.g. recesses, corridor width etc.

*(Marquardt & Schmieg, 2009)*

One additional feature of good design that is recommended for PLWD is the need for PLWD to have single rooms with their own belongings around them in care settings (Marshall, 2010). This perhaps would not be as appropriate if a married couple were in shared residential care accommodation.

Further attempts have been made to clarify the basic features of good dementia-friendly design, with six key aspects recommended:

- Familiarity of surroundings
- Legibility to aid navigation
- Distinctive design and layout to aid distinction between areas
- Comfort, to ensure PLWD are at ease
- Accessibility to areas PLWD want to go
- Safety measures to allow people to move around without fear of harm

*(Mitchell et al., 2017)*

Subsequent research identifies two principal systems of navigation that are applicable to internal and external environments: path integration (self-motion and cognitive updates) and landmark-based navigation (visual landmarks) (Zhao & Warren, 2015). The impact of landscape changes due to Planning decisions or natural emergencies have also been reported as creating significant wayfinding issues for PLWD.

Enhancing the built environment to improve accessibility by making it easier for people with dementia to navigate public spaces, is seen as crucial to support PLWD (Diaz et al., 2022), with two themes being common in the literature - access to, and accessible of, facilities and environments:

- Accessible toilets at transportation hubs are important for accessibility and acceptability of services; a lack of such facilities can deter PLWD from travel (Crampton & Eley, 2013; Tales et al., 2017; Koreki et al., 2021; Matthews et al., 2022)
- Accessibility of use of public facilities, including toilets, is also an important consideration, including the removal of confusing buttons, improved colour contrast, lighting, reflections and emergency cords (Koreki et al., 2021; Peterson et al., 2022)
- Access to family restrooms at transportation hubs specifically is important if carers are of a different gender to the PLWD (Peterson et al., 2022)
- Access to local leisure, recreation and tourism opportunities (Innes, 2013)
- Access to the arts: galleries, museums, theatre, or involvement in groups for people with dementia to paint, sculpt, sing, dance and act (Innes, 2013)
- Accessibility in physical environments should include maximising visual cues, such as statues and other such landmarks, to aid orientation; this could be in supermarkets, town centres, care facilities or in homes (Innes, 2013; Digby et al., 2014; Smith et al., 2016; Innes et al., 2016; Williamson, 2016; O'Malley et al., 2018)

Interestingly, only one study in this review reported that, with regard to street layouts, more cul-de-sac streets would be better for PLWD, along with traffic light-controlled street crossings rather than zebra crossings or pedestrian "islands" (Smith et al., 2016).

The link between navigation, well-being, behaviour and the design of the physical environment is evidenced in case studies of the many newly-built German nursing homes that have been constructed using therapeutic design techniques (Marquardt & Schmieg, 2009).

Small-scale environments have been reported to hold positive associations with PLWD, leading to a reported reduction in dysfunctional behaviour and improved well-being, including lessened depressive symptoms and improved mood and quality of life (Marquardt et al., 2014).

Large scale spaces on the other hand, such as supermarkets, are associated with noise, crowds, lack of outdoor space, high traffic levels, shiny floors and the fear of falling, with visible police presence (USA study) (Smith et al., 2016).

Whilst the majority of the literature in this area looks at the physical and cognitive aspects of design, one study identifies the need for more work to be done on the impact on PLWD under the 6 key design principles of familiarity, legibility, distinctiveness, comfort, accessibility and safety in regard to the atmospheric approach to creating friendly environments (Fletcher et al., 2023).

All design principles identified as part of this review are equally applicable to PLWD, people with physical impairment and to inclusive Age Friendly and Dementia Friendly Communities (Koreki et al., 2021; Shatnawi et al., 2023).

To improve the landscape of the built environment for PLWD, a series of actions has been identified in the literature that focus on:

- Improving walkability around the community
- Improving access to public transportation hubs or bus stops
- Improving signage for wayfinding and literacy
- Improving navigation tools for public transportation, e.g. public noticeboards with times and stop locations

*(Lanthier-Labonte et al., 2024)*

The Aged Care Quality and Safety Commission's (Australia) fifth standard requires that the residential aged care facility (RACF) "helps consumers to move freely in the environment (including access to outdoor areas)" (Lai et al. 2023); the creation of safe and barrier free residential (care and home) environments is identified as key to not just good dementia friendly design but to better outcomes for PLWD and their carers.

Fletcher et al. (2023) coined the term "blanket of dementia" and noted that supportive communities and cultural events could remove some challenges to PLWD and their carers, or at least offer some respite at busy events through interventions such as:

- installing monitoring facilities
- using electronic security doors
- maintaining sufficient lighting throughout the day
- laying nonslip floor tiles
- installing elevators

*(Fletcher et al., 2023; Wang et al. 2024)*

The concept of having Dementia / Alzheimer's Disease villages emerged in 2009 at Hogeweyk (The Netherlands); these villages are based on person centred care and organisation of the physical, social and health environment to meet the needs of PLWD, with access to weather protected outdoor spaces with sufficient seating central to the design planning (Marquardt & Schmieg, 2009; Krier et al., 2023).

Subsequent studies of dementia and Alzheimer's' Villages across Europe, identified in the European Foundations' initiative on Dementia (EFID) study (2016), all note layout, design and care services as key factors to ensure PLWD enjoy and continue to participate in a community where everyone has a variant of the same condition. It is noted however that dementia village model scientific literature is almost non-existent (Krier et al., 2023), as are qualitative evaluation studies of such models of care.

Three recent examples of good practice with regard to the build environment are outlined below:

- In 2016, Heathrow Airport became the first airport with an exclusive facility for persons with dementia (Pech et al., 2022)
- In 2019, The Foton Center of Expertise in Bruges opened as an "inclusive city" project to make it more suitable for persons with dementia, whereby shopkeepers, police, the public and cultural organisations have been trained to better communicate with people with cognitive impairments (Pech et al., 2022)
- In 2024, Knowl Park House in Mirfield opened as a high-tech, single storey, purpose-built facility for residents living with dementia. The facility was developed as a Centre for Excellence in care and support in collaboration with the DSDC (University of Stirling)

### Outdoor Spaces

Access to outdoor space is widely recommended for people with dementia, with opportunities to access outdoor environments and get in touch with nature and / or animals being evidenced to have a positive impact on activity levels, participation and engagement in activities, with evidenced enhanced motivational levels (Connell et al., 2007; Jarrott & Gigliotti, 2010; Silverman, 2021; Ward et al., 2021; Sinha et al., 2022; Alteren et al., 2023; Lai et al. 2023).

Additionally, walking (or cycling), as active travel and part of healthy ageing, are also considered important for people of all ages and conditions including PLWD (Hunter et al., 2011); research supports the notion that carers and PLWD should be supported in their walking activities for ongoing health maintenance (Silverman, 2021).

In dementia friendly communities, two key characteristics are reported to make a positive difference:

- 1) people in customer facing positions having received training in how to interact with PLWD
- 2) access to, and easy navigation around, outdoor areas, which include quiet places within public spaces (Dean et al., 2015; Smith et al., 2016)

Having green and blue spaces within reach, visible signs of nature, listening for birdsong, plenty of trees, plants, shrubs and flowers in gardens, as well as quiet spaces, are all reported as important for the wellbeing of PLWD and their carers (Smith et al., 2016), aiding with memory recall and contribution to a rich sensory experience (Ward et al., 2021). Additionally, the benefits of outdoor activities such as gardening are evidenced to play a preventative role in helping people with dementia remain at home for longer (Sinha et al., 2022).

Connection with the outdoor environment forms part of a targeted action for social wellbeing in the Wellbeing Plan for Ceredigion 2023 - 2028 (CPSB) and provides some evidence of the embedding of these outdoor requirements and the widening reach from just PLWD to the entire population of the county. This can be seen as a step towards equality of access, if not equity, as modifications to infrastructure to support PLWD and their carers remains a challenge.

**Wellbeing Plan for Ceredigion 2023-2028: Social Wellbeing Pillar**  
*Social, green and blue prescribing, provided by well-coordinated services, to be seen as a normal and accepted referral mechanism for health improvement*  
(CPSB, 2023)

Several studies have also reported a reduction in aggressive and other behaviours when PLWD spend time outdoors, as well as improvements in quality of life, less depressive episodes and better sleep patterns (Lai et al., 2023).

Barriers to the access to, and accessibility of, outdoor spaces focus around three main impacts:

- 1) **Environment impact** – linked to ease of access based on location (Duggan et al., 2008)
- 2) **Fiscal impact** – the cost of developing existing infrastructure (Hunter et al., 2011)
- 3) **Health impact** – dependant on an individuals' physical and cognitive ability to undertake the activity (Duggan et al., 2008; Hunter et al., 2011)

Additional reported barriers include: the weather, need for carer support to access outdoor spaces, lack of interest in going outside and safety concerns (Lai et al., 2023).

Lai (2023) also reported the most commonly suggested solutions to accessing the outdoors as being taking action to:

- flatten surfaces / slopes
- remove large rocks, enabling easier wheelchair access and to mitigate concerns about trips / falls
- add more colour, sensory materials to the garden
- paint guide markers around the edge of the footpath and a larger communal area.

Lai concludes his report by stating that more work is required to embed dementia friendly design in outdoor spaces in order to allay the fears for PLWD and more especially their carers – “for 89% of residents, staff reported that time spent outdoors had some benefit for their agitation and distress, but despite this and the dementia-friendly design, staff were still concerned about falls” (Lai et al., 2023).

#### 4.4.6 Enhancement of Assistive Technologies

There are many obstacles affecting access to dementia care in rural communities which do not map neatly onto physical distances but which can be mitigated by the use of technology alongside other social, health and transport networks (Lanthier-Labonte et al., 2024). The supportive use of telehealth in community settings increases opportunities to mitigate the need to travel long distances or “off Country” (Shahid et al., 2011) for improved access to generalist and specialist healthcare (Caffery et al., 2017; Clare et al. 2019) and for caregivers in rural areas.

Connell et al. (2014) state that the “emergence of information and communication technologies (ICT) such as mobile applications (apps), videoconferencing and social media have opened fresh possibilities to address the accessibility gaps in services and social connections”.

Overcoming geographical distances with the use of supportive and assistive technological advancements, leading to widening access to social networks (Williamson, 2016; Clark et al., 2020) is cited as being important for carers and PLWD in the widespread and remote communities in Australia; equally so in other parts of the World (O’Connell et al., 2014; Blackberry et al., 2023).

The importance of developing and establishing assistive or adaptive technologies was highlighted by several countries in the 2016 EDIF study, more specifically the equipment required to enable:

- people to live safely in their own homes
- stay in communication with others
- more controversially GPS systems and mobile phone technologies to enable carers to monitor the geographical location of the PLWD

*(Williamson, 2016)*

One study reported that the provision of dementia support is fragmented and often lacks relevance, stating that current ICT solutions do not address the full range of support requirements of PLWD and their carers to support the whole dementia journey; specifically, the available potential of e-health has not been harnessed for dementia care and there is a more general lack of understanding of how viable business models in this field can operate to alleviate the burden on carers as well as on PLWD themselves (Marceglia et al., 2018).

The development and integration of technology that can follow the patient and caregivers throughout the development of dementia is a key aspect of technological advances in dementia care. The use of greater technological solutions is also aimed at improving care co-ordination between formal and informal caregivers and through Multi-Disciplinary Health Teams, through the integration of existing infrastructures and care models, to reduce pathway care costs that lead to increased efficiencies (Marceglia et al., 2018).

Additionally, the potential for technology to support connectedness in a dementia context (Lindqvist et al., 2018) and in the development of a DFC (Ward et al, 2021), to enable the more traditional notions of neighbourhoods as bounded spaces to be overcome, is well understood (Clarke et al., 2020); all this despite the fact that technology has been identified as a potential barrier for people with dementia (Gaber et al., 2019).

A recommended consideration is that a hybrid method of adoption is made available which combs physical and technological support and promotes the benefit of Digital Assistive Technologies (DATs) for people with dementia and their relatives (Astell et al., 2019; Pappada et al., 2021).

#### 4.4.6.1 E-Learning resources

The adoption of technological innovations for education, training and skills development are also essential to support the use of health technologies, such as the dementia supporter training programs that are widely available in Japan. These training programmes enable practical skills development whilst simultaneously crossing what is termed the technology fear barrier. One Japanese study created VR films to aid education and training amongst medical, convenience

store and other workers, to demonstrate how PLWD are impacted by Visuospatial agnosia (inability to analyse and orient using visual stimuli) and the difficulties experienced using coins for payment. Other technological innovations in this study included "Through the Dementia Lens" (TDL), and simulation training via "Dementia Live" to improve family relationships with the PLWD and increase clinical caregivers' knowledge, empathy and positive interactions with people with dementia (Sari et al., 2020).

iSupport technology for carers of PLWD, particularly in LMIC countries, may be considered a valuable resource, due to the relative ease with which linguistic and cultural adaptations could be introduced; these could potentially provide support in areas where resources and professional support are limited or lacking entirely (Windle, et al., 2025).

Challenges to the use of technology include:

- cultural values about dementia
  - ignorance and stigma
  - concerns about gossip, privacy and interference (Smith et al. 2009; Wiersma and Denton, 2016; Gould et al., 2017; Bauer et al., 2019; Cox et al., 2019; Roberts et al., 2022; Haydon et al. 2023)
- accessing services
  - limited access to GPs who are knowledgeable about dementia (Ahmed et al., 2010; Forbes et al., 2012; Saunders, 2013; Morgan et al., 2014; Alzheimer's Society, 2017; Marshall et al., 2018; Haydon et al., 2023)
  - limited access to memory assessment services (Cahill, 2007; Bradley et al., 2020)
  - limited access to health and social services due to location, lack of public transport, timing and signposting
- technology infrastructure
  - patchy and erratic signal reception and limited broadband connectivity (Tinker et al., 2004; Cahill et al., 2007)
  - lack of local infrastructure to support remote communication (Pugh et al., 2007)

The implementation of DATs has been evidenced to improve levels of care due to digital communication through a reappraisal of healthcare communications (Hellzen et al., 2022), but there are still governance challenges to overcome, which include:

- autonomy for users
- independence of PLWD and caregivers in the use of technology
- decision making strategies

- political support
- financial challenges in implementing DAT in healthcare settings.

(Hellzen et al. 2022)

One study concluded that difficulties in recognising the challenges to implementation of technology for PLWD occur in part due to research studies often being made up of small sample sizes and lacking a control group. The same study also raises concerns regarding short term interventions and lack of effective follow up and evaluation (Hoel, Feunou & Wolf-Ostermann, 2021).

Whilst ethical considerations, medical and social care support requirements, and implementation criteria for DAT to support PLWD within healthcare settings are generally considered to be of paramount importance, restrictive laws that hamper innovation and the lack of funding to support the technological developments and / or technological infrastructure are highlighted as real concerns (Kohler et al., 2024).

The commitment to address technological imbalance across Ceredigion forms part of a targeted action for social wellbeing in the Ceredigion Wellbeing Plan 2023 – 2028:

**Wellbeing Plan for Ceredigion 2023-2028: Social Wellbeing Pillar**  
*Opportunities to be maximised to improve and promote  
the potential of digital connectivity*

(CPSB, 2023)

There are a plethora of E-learning tools, resources and guidance available from various organisations, such as Alzheimer's Societies in England and Scotland (available from mid-2010's), and the Centre for Ageing and Dementia Research (iSupport for carers and PLWD, launched in 2024).

Dementia Friendly Gwent, established in 2022, offers a range of online resources to support PLWD and their carers. It also produces a bi-annual "Coffee morning report", collated by the Gwent Regional Partnership Team, who facilitated a coffee morning that brings together both professionals and citizens from across the region, to share innovation, good practice and look at ways of moving forward to support communities and enhance the lives of those living with dementia in the county.

#### 4.4.7 From Bio-Medical to Community-Led /Person-Centred Care Models

The basic premise is a move from bio-medical models of care for PLWD, which focus on symptoms of cognitive decline, to a person-centric model encapsulating the

lifestyle and habits of PLWD, pre and post diagnosis, which enable continuing participation and engagement in community and social activities.

The impact of travelling long distances for geriatrician appointments can result in anxiety and demonstrates the application of a bio-medical model of care in which dementia knowledge is often seen as specialised and centralised within urban areas; this can result in dementia knowledge and care becoming inaccessible both geographically and culturally for populations in more rural and remote regions (Haydon et al. 2023).

The bio-medical focus on cognitive impairment, progressive cognitive decline and ensuing psychosocial impact affects PLWD and their carers' ability to remain independent, physically active, mentally balanced, mobile and socially engaged, with a healthy and good quality of life, can lead to an increase in falls (Lee et al. 2024). Concisely put, the adoption of a purely bio-medical model focuses on making the person fit the service, regardless of external and personal factors which may serve to deem this inappropriate or detrimental to ongoing health outcomes for the individual.

The first iteration of person-centred care identified through this scoping review is credited to Kitwood (1997); his work is considered to be a turning point in dementia research ("The Person Comes First", revised in 2019 to "The Person Still Comes First" (Kitwood, 1997 & 2019)).

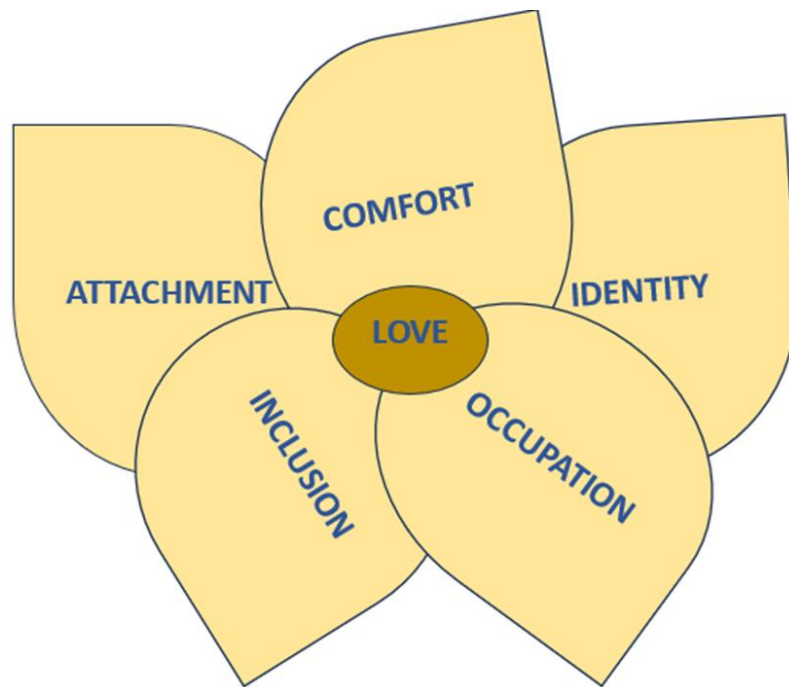
Kitwood conceptualises the person-centric approach in the form of a forget-me-not flower head, an emblem that was not widely adopted by the Alzheimer's Society until 2000 but had pre-existing connections through the Freemasons to dedication and courage in the face of grave danger. The flower as an emblem was first seen in the years immediately following the Second World War, when Freemasons who had survived the war and many of whom had survived concentration camps, wore the flower as a symbol of solidarity. It should be noted that it was not Kitwood however who influenced the decision of the Alzheimer's Society to adopt the emblem, but his work may have contributed to the discussion.

Kitwood's forget-me-not uses the petals of the flower to form the key characteristics of support required by PLWD at a human level: Identity, Occupation, Inclusion, Attachment and Comfort; these elements should form a circle of care around core principle of Love (see next page).

The shift to person rather than medical models of care embraces health care sensitivities associated with religion, gender and cultural traditions, considering also social, political and economic factors that affect health and access to healthcare (Williamson & Harrison, 2010); it focusses on moving services to the person and is guided by the person's individual needs and beliefs. This patient-centred approach

aligns with modern day principles of Value-Based Healthcare and Prudent Healthcare (WG, 2014).

The person-centred model also moves more towards the delivery of services where people are located, through the provision of mobile health units, integrated care centres and community venues, supported by more community-based professional healthcare services, developing the care closer to home ethos outlined in “A Healthier Wales” (WG, 2018).



*Fig. 10: The Person-Centred approach to care for PLWD (Kitwood, 1997 & 2019)*

The literature evidences that PLWD wants to stay in their own homes for as long as possible (Swaffer & Low, 2016; Courtney-Pratt et al., 2018; Tracey & Briggs, 2019; Diaz et al., 2022); this can be facilitated through the adoption of more person-centred care and asset-based approaches to support and care for PLWD and their carers (Rahman, 2017; Courtney-Pratt et al., 2018; Rahman & Swaffer, 2018), enabling them to participate in decision making and discussions, taking into account their cultural beliefs and values (Fazio et al., 2018; Kitwood et al., 2019).

Person-centred approaches include Dementia Friendly Choirs (Harris & Caporella, 2019) and initiatives such as the “Playlist for life”, devised by Sally Magnusson after witnessing the effects of music on her mother, who lived with dementia. Other key factors in a person-centred care approach for PLWD include social prescribing, outdoor connection, arts, crafts, and activity-based gatherings. In fact, anything that enables PLWD to connect with, and function alongside, other people in familiar places, undertaking familiar activities.

Despite the growing support for this person-centred approach to care, however, there remains an inherent culture where the dominance of the bio-medical model can still be evidenced:

*“..a significant number of more traditional health and social care providers identified themselves, and their work, as contributing to the development of 'dementia friendly communities', which raises the question of whether people with dementia are seen as citizens of those communities, as opposed to "patients" or "service users" and which evidences the dominance of the bio-medical model of dementia care and support”.*

*(Williamson, 2016)*

The move away from the bio-medical model of care to a more person-centric approach can be witnessed in Ceredigion, with the closure of Aberaeron and Cardigan Community Hospitals in 2019 and a relocation of multi-disciplinary teams to purposely-built Integrated Care Centres. The closure of the inpatient services at Tregaron Hospital in 2023 and the yet unrealised, albeit planned, vision for the Cors Caron Integrated Care Centre shows a consistency of approach across the county. These actions also comply with the WWRPB Population Needs Assessment requirements to “develop the application of best practice in models of primary care based on the Good Work framework, and to develop a consistent rights-based person-centred approach to care and support” (WWRPB, 2024).

What is potentially lacking currently however is an ongoing, rolling evaluation and critical review of significant service changes in Ceredigion, and beyond, as called for in the literature (Grogan et al., 2024).

#### **4.5 Limitations of the Literature Review**

A number of limitations with the literature search became evident during the review process which do not detract from findings, but should be duly noted, as outlined below:

- The search sought to identify only English language references which means that any research outside the English language criteria is not included in the review; it is noted that the search did, despite this criterion, bring up one reference in Greek and one in Polish, neither of which were ultimately available for review
- Of the selected references, only 5 were related to or produced in Wales and could thus directly inform the research on the experience of PLWD in Wales (2017 n=1) (2021 n=1) (2022 n= 1) and (2023 n = 2)

- The results are limited in terms of the date in which the searches were undertaken, which were September to December 2024

#### 4.6 Summary of Literature Review Findings

From the vast range of literature looked at as part of the review of best practices, it is abundantly clear that engagement with, and **involvement of, PLWD and their carers** in the development of DFCs, DFIs and other support services is seen as critical to their success and sustainability.

Wales has pockets of such practice that have become evident when working through this review, including the use of the CABAN group to participate in and develop research at Bangor University and the Dementia Friendly Wrexham Steering Group, to name but two examples. Other good practice initiatives and activities are however limited, such as use of the well-established and recommended Dementia Engagement & Empowerment Project (DEEP) training and resources, which appears to be limited in Wales, as far as this review has been able to ascertain. These sessions and resources are developed and delivered by PLWD and cover a range of topics from how to engage PLWD in research, how to get the most out of PLWD through group discussion and what to do when things do not work out as planned.

Secondly, the **vast difference in perception and reality of service availability and accessibility between urban and rural communities in Wales** that impact on equity of service and care can be quite considerable. Undoubtedly, rural communities are hampered in ways that urban communities are not. Most notably, this is due to poorer transportation networks and technological infrastructure, contrasted against the increased proportion of PLWD in rural communities as opposed to urban environments. Poor roadways and lack of safe passages along main roads in some communities impacts social inclusion, as does the ability of care services to access patients safely and in a timely manner.

Of increasing concern is the current UK Government proposals (2024) to reduce building control restrictions to stimulate UK economic growth. A knock-on effect of this could be the removal of landmarks and “familiar places,” leading to the potential for wayfinding issues to escalate, with resultant increased confusion for PLWD, as well as a reduction in accessible green and open spaces.

The **increasing cost and resource burden on caregivers** is a significant issue, with the number of PLWD increasing whilst caregivers (without a dementia diagnosis themselves) are decreasing in number. The lack of adequate respite support and the opportunity limiting impact of being a caregiver means that carers are operating at levels of care that could, in other settings, perhaps be considered inadvisable.

The overriding lesson learnt from this review is that change does not come without education and training. The empowerment of communities to educate themselves and others about dementia would lead to increased understanding of the condition; it would encourage engagement with PLWD in social and other activities, with PLWD active participants in expanding education and training on dementia and implications of the conditions not only on individuals but on families, communities and social networks. **An increase in the provision of dementia education and training** is thus a vital step towards healthy ageing for those PLWD now and those who may develop it in the future.

The sea change that started in Japan in 2004 should be allowed to regain its impetus through statutory and non-statutory support, with both financial and other resources needed to redress the imbalances inherent in our current communities specifically regarding **transport, technologies, skilled healthcare professionals and the decline in social and open spaces.**

## **5. In Search of Best Practice: Identified Dementia Friendly Initiatives**

This section sets out to highlight referenced examples of good or best practice that were found in the literature, grouped thematically into categories:

- Dementia Guidance
- Dementia Villages / Residential Establishments
- Dementia Friendly Communities
- Dementia Friendly Worship
- Dementia Friendly Research

### **5.1 Dementia Guidance**

**Dementia Engagement & Empowerment Project (DEEP), UK** – a network of groups led by or actively involving PLWD, aimed at influencing services and policies affecting PLWD and the communities in which they live. There are over sixty groups operating nationally and DEEP sessions are available to employees via the Improving Adult Care Together (IMPACT) centre, based at the University of Birmingham.

**The Scottish Dementia Working Group, Scotland** – provide information sheets and guidance <https://www.alzscot.org/our-work/campaigning-for-change/have-your-say/scottish-dementia-working-group> (accessed 26.11.2024); this is a working group, established in 2001, made up entirely of people with a diagnosis of dementia, who have worked to develop core principles for involving people with dementia in research. This is the first model of its kind found in the literature.

NHS Scotland Wayfinding document (Health Facilities Scotland 2017) - design guideline tools set up for healthcare facilities.

## 5.2 Dementia Villages / Residential Establishments

Several countries noted good practice examples of dementia villages in the literature, with the following examples cited from across the world:

**De Hogeweyk, The Netherlands** – opened in 2009, a forerunner in the field of dedicated dementia villages, and defined as a neighbourhood with local life in which residents are as free as possible to pursue the way of life they had before their admission (Krier et al., 2023). There are places that open to the family and the outdoors that are accessible at any time of the day.

**The Harmonia Village, Dover, UK** - Harmonia Village offers nursing care in six separate houses, each of which looks like a regular residential home, equipped with technology to enable people to be cared for in a safe non-intrusive way 24 hours a day.

**Rochester Harmony House, Respite Centre, UK** - opened in October 2019 as a care facility with a unique concept providing ten beds available for respite care for up to 14 days in a guesthouse setting, which can be pre-booked.

**Greenhouse, Mississippi, USA** - all en-suite bedrooms open directly onto a communal "hearth" space, enabling residents to navigate between their own rooms and the sitting, dining, and activity areas with ease.

**Bellmere, Australia** – opened in 2017 as the World's First Residential Aged Care MICRO TOWN® Community. The community resembles a typical Australian suburban community with seventeen houses located on six streets across two hectares.

**Korongee, Tasmania** - opened in 2020 and mirrors a typical Tasmanian streetscape and the community surrounding it. Each of the twelve small homes is situated in one of four quiet cul-de-sacs which make up the village. Paths meander through connecting the houses to a café, hairdresser, community centre and grocery store.

**Langley Village, Canada** – built in 2019 as the first dementia village in Canada; purposefully built to allow for freedom and quality of life, with every resident in this village having one thing in common: they're all living with dementia.

**Svendborg Demensby, Denmark** - opened in 2016 as the first of its kind in Denmark, modelled after similar villages in the Netherlands, Italy, and Canada. It focuses on stimulating residents and is designed as a genuine village with a city

square surrounded by shops, such as a restaurant, a bar, a hairdresser, a theater, a music library, a wellness salon, where residents can get manicures and massages, an exercise centre and a closed garden. Residents live in communal housing with shared kitchens and living rooms in addition to having their own apartment.

**Dax, France** – this French Alzheimer Village is one of the very few Alzheimer's Villages in the world and opened in 2020, hosting 120 patients and 120 professionals and numerous volunteers. Krier et al. 2023

**Tönbeön am See, Germany** - this dementia village opened in 2014 on the southern outskirts of Hamelin, as the first of its kind in Germany. It is modelled on the Hogeweyk dementia village in The Netherlands. It has four houses, all decorated in assorted colours and themes, offering space for 52 residents in total.

**Bruff, Ireland** – Ireland's first Dementia Village opened in 2018, with three homes to accommodate 18 PLWD. The village contains a community centre and a 40-seat cafe as part of its facilities.

**Villaggio Emanuele, Italy** – an Alzheimer's Village in Rome which faithfully reproduces the Hogeweyk model in the Netherlands, offering an environment suitable for improving the quality of life of the people affected by this serious illness; it provides a stimulating, safe and soothing environment that aims to reproduce, as much as is possible, family lifestyle and ways of life. It adopts an alternative therapeutic approach to the traditional one, so as to effectively preserve the residual cognitive abilities of each resident.

**Il Paese Ritrovato, Monza, Italy** - opened in 2018 as the first Alzheimer's village designed in Italy.

**Kia Ora, New Zealand** – opened in 2017 on the shores of Lake Rotorua. It is classed as a world-leading concept that is just like any other small New Zealand town, in which residents, including those with dementia, do not just exist, but thrive with total freedom within the boundaries of the 1.4 ha village. It is inspired by Hogeweyk's "normal living" principles. The unique design of the village, and the way its residents are cared for, is centred around evidence that suggests familiarity, comfort and stimulation has the greatest impact on overall health.

**Carpe Diem, Kristianland** - Norway's first dementia village, which opened in 2017. The facility is built as a closed village where residents can safely continue to live their lives as normally as possible within secure boundaries. The project is divided into two levels of care, with 136 housing units in shared living arrangements and twenty-two enhanced dementia care units.

**Jura-Dorf, Switzerland** - inspired by De Hogeweyk in The Netherlands, due for completion at the end of 2024, Jura Dorf offers space for 112 people with a dementia illness. In addition to residential buildings, the village-scape includes paths that are similar to streets, squares and seats, with plenty of space for disabled-friendly and obstacle-free movement. In addition to a marketplace, there is a public cafe, a pharmacy, a doctor's surgery as well as a hairdresser's shop.

### 5.3 Dementia Friendly Worship

**Boxborough United Church of Christ, Massachusetts, USA** - holds a quarterly dementia friendly service, with simple, short worship, familiar hymns (first verse only), readings and reflection, held during the week (Schmidt et al., 2023).

### 5.4 Dementia Friendly Communities / Community Initiatives

**Kortrijk, Belgium** – a series of reminiscence walks aimed at getting PLWD out and about. There are 4 5km walks along “slow roads” or promenades which are open for public use, not just for those with dementia. Each route has 2 or 3 key reference points of interest; the walks have been developed in collaboration with the local population and organisations including PLWD (Pozo et al., 2022).

**Age Friendly Manchester, UK** – Valuing Older People Team. Manchester was the first UK city to join the World Health Organization's (WHO) Network of Age Friendly Cities and Communities, committing Manchester to working towards being a better place to grow older. Manchester's Age Friendly programme has an international profile and is seen across the world as an example of good practice and innovation (Spencer et al. 2013).

**Dementia Without Walls Project, UK** - Dementia without Walls was the name given to a programme of projects and initiatives around the UK funded by the Joseph Rowntree Foundation between 2012 and 2015. As well as strengthening the collective voice of people with dementia through the Dementia Engagement and Empowerment Project (DEEP), the Dementia without Walls programme had two main strands of work in which people with dementia were involved:

- Supporting dementia friendly communities in different locations including York, Bradford, Derry-Londonderry and Sutherland.
- Projects to encourage us all to think differently about dementia, including truth telling with people with advanced dementia, positive risk taking, rights and disability, and women's experiences of dementia (Spencer et al. 2013)

Findings from the subsequent evaluation of the Brandford and York initiative, the first of its kind for dementia friendly communities, used a “four cornerstones” approach (place, people, resources, networks) to assess friendly audits of buildings, with findings indicating that:

- The active, meaningful engagement of people with dementia and their families is fundamental
- Communities must engage with, and achieve equity for, all people with dementia, whatever their circumstances
- Practical barriers to inclusion must be addressed if normal lives are to be continued
- The human rights of people with dementia and carers must be recognised and promoted
- Local grassroots community activity is the bedrock of dementia friendly communities, but this activity must be supported by strong strategic planning, commissioning, and leadership
- There is no one template – each community must develop its own approach  
(Williamson, 2016)

**West Dunbartonshire (WD), Scotland** - a partnership of statutory, NGO third and independent sector agencies of the WD community health and care partnerships, WD community and volunteering services and Scottish Care which has developed a local Dementia Strategy with commitments from neighbouring services to meet the needs of all citizens locally, including those with a diagnosis of dementia; began across 22 neighbourhoods and now has a schools programme "Promoting Excellence" to raise awareness, and an Individual, Social and Material (ISM) evaluation tool (Williamson, 2016).

**Bishopbriggs Academy Community Action Project, Scotland** - enables school pupils to undertake dementia informed training and encourages them to participate in intergenerational initiatives supported by the local dementia action team. Once trained, pupils devise initiatives for older people in their community, such as dementia cafes and "Youths on Bikes" (a scheme involving young people visiting older people in the community with input from a local cycle co-op) (Williamson, 2016).

**The Dementia Hwb, Swansea** – a “one stop shop” that has expanded to two permanent sites, plus a mobile unit, delivering a good example of community-led dementia friendly initiatives in action (presented as best practice at the CADR Conference 2023). The Hwb is open 7 days a week between 11am and 3pm, being staffed by volunteers and individuals / professionals from local organisations who support PLWD and their loved ones.

**Dementia Friendly Wrexham Steering Group (DFWSG), Wales** – a group of volunteers with professional or personal experience of dementia that aim to make the county of Wrexham a dementia-friendly community by including the voice of PLWD in all decisions; support PLWD to live well and feel safe in their local communities; offer free dementia friends information sessions and hold events/activities for PLWD, including an annual Wrexham Memory Walk.

DFWSG is part of the North Wales Dementia Friendly Communities Scheme, developed by the North Wales Regional Partnership Board (NWRPB).

## 5.5 Dementia Friendly Research

**The Dementia Services Development Centre (DSDC), Stirling University, Scotland** - world renowned for its work on dementia friendly design, environments and housing.

**Eindhoven University of Technology, The Netherlands** - brings knowledge of intelligent lighting systems to improve physical and mental wellbeing of PLWD.

**“Our people, our places”, UK-Sweden** - one of the largest English-language research projects on the topic of dementia-friendly communities; a UK-Sweden dementia research project funded by ESRC and NIHR, involving a collaboration of 7 Universities (Manchester, Stirling, Liverpool, UCL, Salford, Lancaster, and Linköping in Sweden) and 4 Users Groups that put local neighbourhoods and networks of PLWD and their carers at the centre of their work (Ward et al., 2021 & 2022).

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## 5.6 Other cited best practice from the grey literature

The good practice cited here is taken from **“Raising the barriers: An action plan to tackle regional variation in Dementia diagnosis in England” (2023)**, an All-party Parliamentary Group publication on dementia, funded by Alzheimer’s Research UK. Only the practice specific to Wales is shown below, noting the county identity is not shown in the literature:

- Improving access to a dementia diagnosis in a rural community:

This review of a memory assessment service covers a large and very rural area in one of the largest counties in Wales and was led by Dr Sarah Smith, Leeds Beckett University.

The memory assessments service sits within the mental health team that is led by a consultant psychiatrist, alongside a dementia nurse who co-ordinates the assessment and post diagnostic support, with part-time support from a community psychiatric nurse in the wider team.

The factors that lead to identification of the service as a model of best practice include:

- *Having no central office location* – services are delivered at a range of community venues and with healthcare teams working from home
- The service is aimed at delivering *personalised care, home visits and individual follow-up*.
- Patients are *referred via Primary care surgeries*, following screening by a *practice-based dementia nurse* which includes pre-screen assessment, bloods, heart rate and a brain scan
- *Patient need and preference* determines whether memory assessments are conducted via home visits or at a location identified in the community
- Patients with a diagnosis are offered *immediate post diagnosis support* within the service and referred onto appropriate community connectors and services in the VCSE sector, depending on patient preference and need

## 5.7 Recommended reading and supporting resources

**Contented Dementia by Dr Oliver James** - the SPECAL method (Specialized Early Care for Alzheimer's) outlined in this book works by creating links between memories and the routine activities of daily life in the present. Drawing on real-life examples and user-friendly tried-and-tested methods, the book provides essential information and guidance for carers, relatives, and professionals.

**Angel in Gumboots by FCN** - a booklet that has recently been developed to help farming carers and people in rural communities that support those with memory loss; developed by Dorset farmer Jennifer Evans in association with the national charity The Farming Community Network (FCN). It is designed for families who are caring for people with memory loss and has been written for those in rural communities and those living on farms.

**Compassion with Dementia: An essential guide to living well with dementia by Hilary Cragg** - an informative handbook deemed to be essential for carers, families and every who needs honest, helpful guidance and information. The author is cited as being someone who not only knows and understand the medical, social care and legal systems, but also cares deeply that people with dementia and their families are treat with kindness, compassion, and respect.

**If only I'd known that by Susan Hartnell** - a booklet that offers helpful and practical insights for those caring for loved ones in Somerset. It has proven so popular with Carers that the League of Friends of South Petherton Hospital funded the re-printing of the booklet when the first edition ran out. The booklet is given to patients and their

families when leaving hospital; content is written in an extremely kind and informative way, by an author who, unexpectedly, became a carer for her beloved husband.

**Dementia Friends UK** – an on-line 45-minute training programme by the Alzheimer’s Society that aims to change people’s perceptions of dementia. Completion of the programme leads to attainment of becoming a Dementia Friend, with further training available to progress to Dementia Friends Ambassador or Champion.

## 6. Dementia Support within Ceredigion

This section of the review seeks to identify the provision of services to PLWD and their carers in Ceredigion. It commences with a focus on identification of formal service provision for PLWD and their carers, e.g. local authority / statutory services, then considers third sector and independent organisational support, before culminating in a review of informal services and activities that are available to care and support for individuals within their own communities.

### 6.1 Organisational Support within Ceredigion

Organisational support was identified by reviewing services provided by the following organisations: Ceredigion County Council, Ceredigion Association of Voluntary Organisations, Age Cymru, Alzheimer’s society Wales and others. Findings have been split into three categories – support provided for PLWD, support provided to the carers of PLWD and sites available for use by PLWD and their carers.

#### a) Support for PLWD

In total eighteen organisations were found to offer support for PLWD in Ceredigion. These are shown below in alphabetical order.

**Age Cymru Dyfed:** offers a range of advice, support, and ad hoc organised activities for both PLWD and their carers. The Aberystwyth Office opening hours are Monday-Wednesday: 10am-1pm and 2pm-4pm and Thursday: 10am to 2pm. Address : 27 Pier Street, Aberystwyth, SY23 2LN. Telephone: 03333 447 874; Email: [reception@agecymrudfyfed.org.uk](mailto:reception@agecymrudfyfed.org.uk)

**Alzheimer’s Society Wales:** offers a range of advice and support through information factsheets, guides, and videos to both PLWD and their carers. Opening hours for the Central helpline: 0333 150 3456; Welsh-speaking support line, Monday to Friday from 9:15am – 4pm only; English-speaking support line, Monday to Wednesday 9am – 8pm, Thursday/Friday 9am – 5pm, Saturday/Sunday 10am – 4pm.

**Arts4Wellbeing:** offers a creative resource lending library for carers and PLWD in Carmarthenshire and Ceredigion. Based at The Old Mill Soar, Pentrellwyn, Llandysul, Ceredigion, SA44 4LH, Wales. Mobile contact: 07496 879 820. Email: Sara@Arts4Wellbeing.co.uk; Mike@Arts4Wellbeing.co.uk.

**Cardigan Community Car:** offers subsidised travel to and from the Integrated Care Centre and other health appointments and shopping for the elderly and infirm. Bws Bro Bach is operated by Dolen Teifi and funded by The Friends of Cardigan Community Health Care (the former Friends of Cardigan Hospital). Telephone: 01559 362 403.

**CAVO:** provides a signposting service for events and activities in Ceredigion. As at 29.11.2024 only one dementia activity was listed (Borth Community Hub - details included in this report under informal service provision). Also offers inclusive volunteering opportunities across the County. Ceredigion Association of Voluntary Organisations (CAVO), 67 Bridge Street, Lampeter, SA48 7AB. Website: [www.cavo.org.uk](http://www.cavo.org.uk) Telephone: 01570 423 232. Email: gen@cavo.org.uk.

**Ceredigion County Council:** hosts of a number of services providing support, signposting and advice for PLWD and their carers:

- *Ceredigion Learning* - [Living with Dementia Toolkit](#) work on updating this is underway via the Age Friendly Forum.
- *Porth Gofal* (Social Services) - offers information and guidance on carer financial support, carers rights etc including young carers. Telephone: 01545 574 000. Email: socservs@ceredigion.gov.uk.
- *Porth y Gymuned* (Community Connectors) - based in Aberystwyth, provide information and signposting to local support including that available for PLWD and their carers. Ceredigion County Council, Canolfan Rheidol, Rhodfa Padarn, Llanbadarn Fawr, Aberystwyth, SY23 3UE. Telephone: 01545 574 200. Email: communitygateway@ceredigion.gov.uk / porthygyuned@ceredigion.gov.uk.
- *Centres for Independent Living in Ceredigion:* Penmorfa and Felinfach – these centres assist individuals in finding solutions and access information to help themselves with opportunities to view and test out a range of care technologies, Mobility and Independent Living aids. The Penmorfa site operates an “open-door policy” Monday to Friday from 10:30 AM to 3:30 PM and is closed weekends and public holidays. The Felinfach Centre is not open to the public. Base: Neuadd Cyngor Ceredigion, Penmorfa, Aberaeron, Ceredigion, SA46 0PA. Telephone: 01545 570 881.
- *Age Friendly Ceredigion Forum* - a community led forum convened to discuss and promote community solutions to issues relevant to the 8 Age Friendly domains (WHO, 2006) for which some commonality of themes with dementia

friendly is shared, as has been discussed in the review of literature in this report (Outdoor Spaces and Buildings; Transport; Housing; Social Participation; Respect and Social Inclusion; Civic Participation and Employment; Communication and Information; Community Support and Health Services). Telephone: 01545 574 200. Email: clic@ceredigion.gov.uk

**Dewis Cymru** - an information resource that lists dementia helplines and dementia support initiatives, such as an all-Wales Dementia Helpline for PLWD and their carers. Telephone: 0808 808 2235. Opening times: 24 hours a day, 365 days a year. Website: dementia@helpline.wales.

**Department of Works and Pensions (DWP)** - provides an “Access to Work Scheme” to help people with dementia continue to work. This national scheme provides funded support of up to £69k per person per year to ensure those with any form of disability or condition that requires adjustments to be made can be supported into the workplace. These adjustments could include provision of a mentor, carer support, training for other staff on the affected persons condition i.e. Tourette’s, transport issues i.e. compensating for inaccessible public transport bus stop sites, frequency of buses by the provision of a taxi.

**Dolen Teifi Community Transport** - provides transport solutions to and from health appointments and social activities around Cardigan, Lampeter, Aberystwyth and Borth. Dolen Teifi Community Transport, Llandysul and Pont-Tyweli Ymlaen Cyf The Old Post Office, New Road, Llandysul, Ceredigion, SA44 4QJ. Telephone: 01559 362 403. Email: info@dolenteifi.org.uk.

**Green Dragon Community Transport** - provides transport solutions to and from health appointments and social activities around Cardigan. Also provides support for other providers as and when possible, for cross county support around North Pembrokeshire. The Old School, Llanfyrnach SA35 0DP. Telephone: 01239 698 506. Website: greendragonbus.co.uk.

**HAVHAV Wellbeing Centre** – originally set up in 2015 to provide practical help, social care and companionship for people in Ceredigion with chronic, life limiting illness, with support also available for family, carers and loved ones. Services offered are devised to complement the work of the Hywel Dda Palliative Care Team. HAVHAV also hosts a weekly Afternoon Tea Experience for PLWD and their carers. HAHAV Wellbeing Centre, Plas Antaron, Southgate, Aberystwyth, Ceredigion, SY23 1SF. Tel: 01970 611 550. Email: admin@hahav.org.uk.

**Creu Cymru** - established to enable access to theatres and arts centres across Wales for people with impairments and their carers. Launched the PIPA Wales initiative on 26<sup>th</sup> November 2024 which aims to raise awareness of the challenges faced by parents and carers, develop strategies to support caregivers in the Welsh performing arts, build a network that will shape a family-friendly future for the sector.

Creu Cymru, PO Box 242, Aberystwyth, Ceredigion, SY23 9AX. Telephone: 01970 822 222 Email: [post@creucymru.com](mailto:post@creucymru.com) or [info@hynt.co.uk](mailto:info@hynt.co.uk).

**Hywel Dda University Health Board**- provides a range of support and signposting for PLWD and their carers including:

- *Memory Assessment Services* - Enlli, Bronglais Hospital, Aberystwyth, Ceredigion. Telephone: 01970 635 839.
- *Admiral Nurses START Programme Dementia support* via the Carers Trust Crossroads West Wales ([ctcww.org.uk](http://ctcww.org.uk))
- *Dementia Connect* ([Hywel-Dda-Dementia-Support-service-factsheet-professionals.pdf](#)). Telephone: on 03300 947 400 (Cymraeg), 0333 150 3456 (English). Email: Services Manager [donna.jenkins@alzheimers.org.uk](mailto:donna.jenkins@alzheimers.org.uk)

**National Association of Young Farmers Clubs** - provide a series of training modules developed by the Farming Community Network (FCN) and The DPJ Foundation and delivered to and via the Young Farmers' Club in England and Wales, focussing on mental health support for 10 – 16 year old YFC members and 16 – 25 years Agriculture Students, including support and advice on supporting others with a range of mental wellbeing issues including dementia. For more information about the Rural+ training, contact [help@fcn.org.uk](mailto:help@fcn.org.uk). Website: <http://www.nfyfc.org.uk/ruralpluscurve>.

**Marie Curie (Ceredigion Support)** - the largest independent provider of end-of-life care including end-of-life care for people with dementia (as main cause of death or co-morbidity) and is the largest charitable provider of hospice care beds in Wales. There are around 150 Marie Curie Nurses working in Wales, caring for around 2,400 terminally ill people and their families in their homes each year, working in conjunction with all Health Boards including Hywel Dda UHB. The Marie Curie Wales Day Service is available to any adult affected by a terminal illness. Telephone 02920 426 046 or email [WalesDayServices@mariecurie.org.uk](mailto:WalesDayServices@mariecurie.org.uk).

The Wales Bereavement Information and Support Service (BISS) is a collaborative support network between Marie Curie and Diverse Cymru to provide bereavement support for anyone in Wales who is experiencing grief following the death of someone because of a terminal illness. The Support Line is open 8am-6pm Monday to Friday and 10am-4pm Saturday to Sunday. Call free on 08000 902 309.

The only Marie Curie Hospice in Wales is based in Penarth, Cardiff.

**RAY Ceredigion** - the RAY Forget Me Knot dementia support group for PLWD and their carers meets every week on Fridays from 10.30-1pm and activities are arranged to meet the needs and interests of those that attend and include cooking, arts and crafts, singing and occasional outings to places of local interest using the RAY minibus. An additional Dementia Carer Support Group was introduced in 2024

and is held on Thursday every week 11am – 14:30pm and supports carers and those who were carers and are now bereaved. Address: Pengloyn, Tabernacle Street Aberaeron Ceredigion Wales. Telephone: 01545 570 686. Email: enquiries@rayceredigion.org.uk / rayforgetmeknot@rayceredigion.org.uk.

**Welsh Ambulance Service Trust (WAST), Ceredigion** - a WAST dementia ambulance trial was launched in 2024, focussing on ensuring the inside of the ambulance is suited to PLWD, through changing colour schemes, including selected images of the Ceredigion landscape, specific music and activity booklets. This was the first such dementia friendly ambulance scheme to look at the ambulance as an “environment” that has been developed by and with PLWD.

#### b) Support for carers of PLWD

Six further organisations were found to provide care and support for carers of PLWD in Ceredigion, listed in alphabetical order below:

**Carer’s Wales** - provide information and advice on caring; help carers connect with each other, campaign with carers for lasting change, and use innovations to improve services for carers. Email: info@carerswales.org Telephone: 02920 811 370.

**Carers Support West Wales (CSWW)** - provides advice and support on a range of issues affecting Carers, including Carers of PLWD i.e. carers allowances, respite support and discharge for hospital guidance. Email: info@carerssupportwestwales.org. Telephone: 01437 723 660. They also facilitate a number of Memory cafes in the community (more details follow under the Informal Support available section of this report). See also: [Memory Cafe - Carers Support West Wales](#).

**Ceredigion County Council** – the Carers Information Service is available via the Carers and Community Support Team based at Canolfan Rheidol, Rhodfa Padarn, Llanbadarn Fawr, SY23 3UE, Aberystwyth. Contact: Neuadd Cyngor Ceredigion Penmorfa, Aberaeron, Ceredigion, SA46 0PA. Call centre phone number: 01545 570 881 Email: [cllc@ceredigion.gov.uk](mailto:cllc@ceredigion.gov.uk). Website: [Carers Information Service - Ceredigion County Council](#).

**Ceredigion Carers** - Gofalwyr Ceredigion Carers support unpaid and family carers of all ages in Ceredigion providing support in numerous ways including:

- Providing someone to talk to who will listen and help work out a way forward
- Enabling access to the right information
- Connecting with groups, activities, trips, other services & organisations
- Providing respite support through replacement care (adult carers), activities and trips (young carers) or other ways of having a break

- Supporting a life alongside caring - with education, work, social opportunities, health, and wellbeing
- Skills and training - for your caring role, for your own wellbeing and aspirations
- Voice and influence - supporting carers to have their voices heard and to influence the organisations and services they use.
- Counselling - free service for over 18s provided by volunteers
- Funding - help to access grants, funding, and benefits
- Supporting with Hospital discharge, preparing for someone to come home from hospital and a new or changed caring role

Telephone: 03330 143 377. Email: [ceredigion@credu.cymru](mailto:ceredigion@credu.cymru).

**Hywel Dda University Health Board** - Carers Peer Support Group provides monthly online meetings for HDdUHB staff to discuss issues and compare experiences. The sessions include presentations and links to advice and support beyond the group. Email: [CarersTeam.HDD@wales.nhs.uk](mailto:CarersTeam.HDD@wales.nhs.uk)  
Carers Information page: <https://hduhb.nhs.wales/healthcare/services-and-teams/carers-information/>

**Public Health Wales (PHW)** - provides information and support for people who are carers and those they look after when it comes to attending screening either for themselves or those they look after. See: <https://phw.nhs.wales/services-and-teams/screening/carers/>

#### c) Sites offering venues for led activities for PLWD and their carers

Sites supporting led activities for PLWD and their carers identified as part of this review are listed below, however this is not an exhaustive list:

- ***Tir Coed*** – unpaid carers wellbeing days in Tyllwyd Woods, Llanfarian
- ***Gorwel Farm, Newcastle Emlyn*** – one day respite support for carers and PLWD
- ***National Trust, Llanerchaeron, Aberaeron*** – unpaid carers, volunteer days and other activities

There are also a range of support services focussed on mental health, abuse and homelessness which may, or may not, include specific support for PLWD and their carers such as:

- ***Mind Aberystwyth*** - 8 Great Darkgate Street, 1st Floor, Aberystwyth, Ceredigion, SY23 1DE. Opening hours: Monday-Friday 9am-5pm. Telephone: 01970 626 225. Email: [info@mindaberystwyth.org](mailto:info@mindaberystwyth.org).

There are also National organisations such as Dementia Adventure, Cherish your Holiday and Limitless Travel offering support and financial assistance for holidays and extended respite for PLWD and their carers.

## 6.2 Findings of the Organisation support search

This review provides a good insight into the depth of organisational support available for PLWD and their carers in Ceredigion, ranging from the provision of information, financial and practical advice to respite support, direct payments support to UK wide dementia holiday providers.

The search also highlighted that much of the support is focused in the more populated regions of the county which gives rise to issues of accessibility and equity of service provision.

Of the 18 Organisations providing care and support for PLWD and their carers in Ceredigion all are based in the south of the County:

- Aberystwyth (n=6) of which 1 is jointly located in Aberaeron and 1 is jointly located in Carmarthenshire
- Central base outside of Ceredigion (n=4)
- Aberaeron (n = 2)
- Llandysul (n=2)
- Cardigan (n=2)
- Carmarthenshire (n=1)
- Lampeter (n=1)

Two of the above support a service in the same region of north Ceredigion; Borth, these being CAVO who advertise the Borth Dementia Café and Dolen Teifi who support a Dial-a-ride bus from the Borth Community Hub. Additionally, all the carers support networks listed are based in either Aberystwyth or Aberaeron or are jointly located in both Towns and of the four listed “others” 2 are based in Aberystwyth, 1 in Aberaeron and 1 in Newcastle Emlyn.

### 6.2.1 No support in Ceredigion found

As part of this search, RHCW noted that Ceredigion is not included on the following National dementia support databases:

- a) UK: Wales - Memory Cafe Directory: No café's listed for Wales (accessed 11.09.2024)
- b) DEEP - Find a DEEP Group in your Region: DEEP (dementivoices.org.uk) No group in Ceredigion (accessed 11.09.2024)

- c) Methodist Homes Association: Find a Community Group | Activities & Social Groups for Older People | MHA No group in Ceredigion, linked to transfer of ownership of Hafan y Waun, Waunfawr, Aberystwyth, Ceredigion (accessed 11.09.2024)

### 6.3 Community Level Support within Ceredigion

A desktop search was undertaken between 1<sup>st</sup> September 2024 and 31<sup>st</sup> October 2024 of all advertised community-based dementia and / or dementia carers support activities across Ceredigion. This search covered 118 Towns (n=7) villages and hamlets (n=111), encompassing 68 community venues covering the north of Aberystwyth (n=13) and south and west of Aberystwyth (n=55). This equates to approximately 25% of the named locations within Ceredigion.

Where villages and hamlets share a community venue due to community / Village / Church / leisure centre closures this, is noted in the search summary (Appendix 2). From this search dedicated dementia support activities were identified in four locations and are shown below in day / time order:

- *Borth*: Community Hub, Clarach Road, Dementia Café, Monday 10am – 12pm
- *Llandysul*: Tysul Church Hall, Church Street, Llandysul, Memory café 4<sup>th</sup> Wednesday of the month 10am – 12pm
- *Aberystwyth*: Caffi Cofion and Afternoon Tea Experience, HAVHAV Wellbeing Centre, Wednesday 2pm – 4pm
- *Newquay*: Memorial Hall, Friendship Group, Thursday 12pm – 2pm

Carers support was identified at 3 locations and are below in day / time order:

- *Borth*: Community Hub, Clarach Road, Carers Arts4Wellebing group Monday 10am -12pm
- *Aberaeron*: RAY Ceredigion, Pengloyn, Tabernacle Street, Aberaeron, SA46 0BN, Dementia Carers Group, Thursday 11am - 2:30pm
- *Aberystwyth*: 312, Canolfan Rheidol, Llanbadarn Fawr, Aberystwyth (Ceredigion County Council staff only), Last Thursday of the month 12pm - 1:30pm

Age-related activities in which PLWD and their carers could participate, were identified and are shown below in day / time order:

- *Ffostrasol*, Ffostrasol Arms, Board Games and Social Group for the over 50's Monday 11am
- *Aberystwyth*, Morlan Centre, Wednesday 10:30am – 11:30am Seated Exercise for the over 50's with Age Cymru
- *Felinfach*, Theatr Felinfach, Hwyl a Hamdden / Social group for the over 50's, Wednesday 1:30pm – 3pm
- *Aberaeron*, Llanerchaeron Estate, 50+ years Woodland Walks Thursday 10am
- *Aberystwyth*, Penparcau Hub, Seniors Friendship Group, Thursday 1pm – 3pm

No specific community led activities for carers were identified.

The map below illustrates Organisational and Community led support available for PLWD and their carers in Ceredigion.

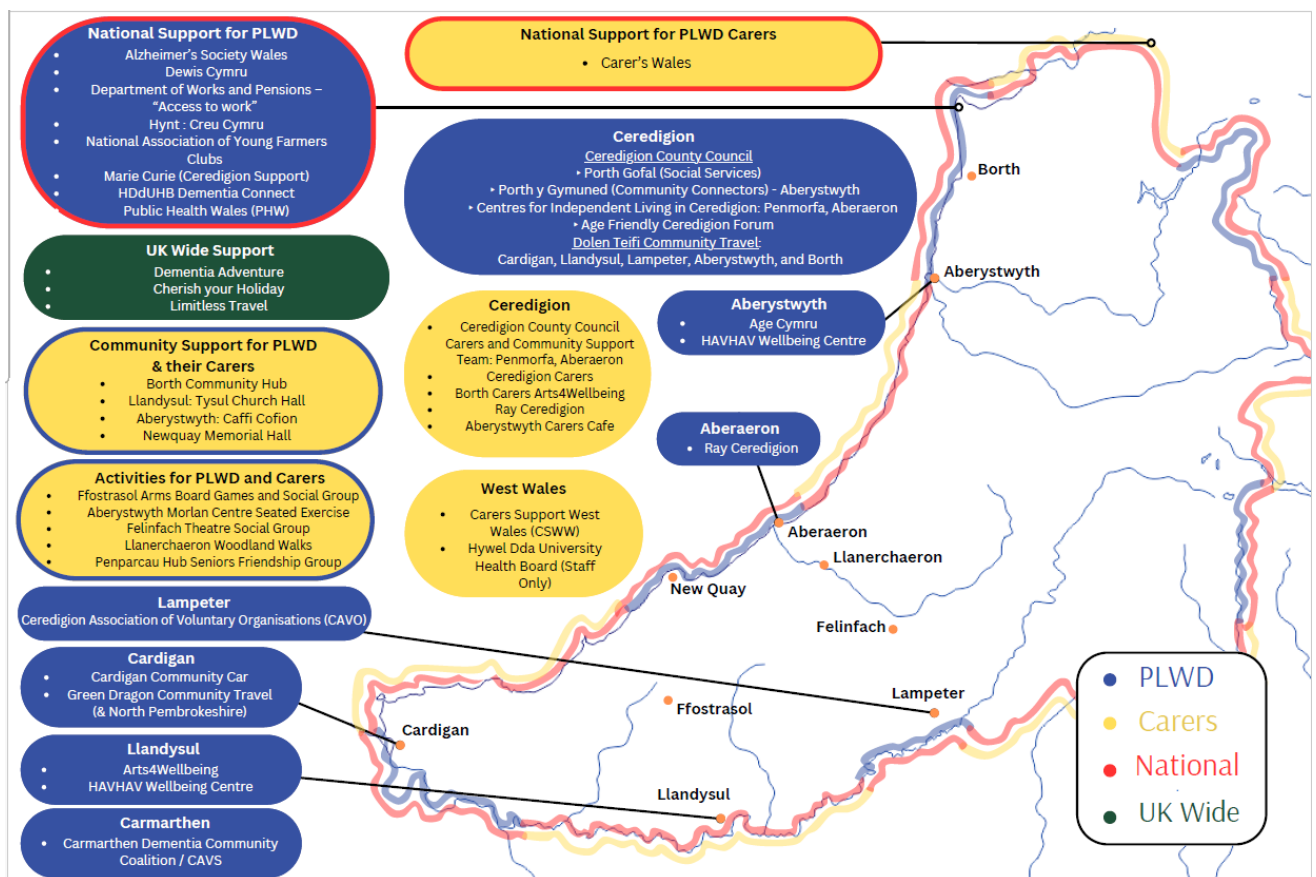


Fig. 9: Pictural of Dementia Friendly and Age Specified organisational support and community–led activities within Ceredigion

### 6.3.1 Other Community Activities

In addition to the activities already shown in this section, many more were identified with no age or health condition indicator, giving the potential for more community-led activities being made available to support PLWD and their carers than may at first be recognised. These are shown below in alphabetical order by location:

Aberaeron / Penmorfa - Caffi Cwtsch y Gwenyn: Coffi a Chlonc, Tuesday 10:30am – 12pm

Aber-Arad / Adpar / Cwmcou / Newcastle Emllyn / Pont Ceri - Our Lady of the Peace Roman Catholic Church Hall: Community Wellbeing drop in, Second Wednesday of the month at 1pm

Aberporth - Village Hall: Community Coffee Morning, Friday 10am – 1pm; Canolfan y Dyffryn: Te a Sgwrs, Monday 3pm; Tafarn y Llong: Coffi a chlonc, 2<sup>nd</sup> and 4<sup>th</sup> Wednesday of the month, 1pm; Village Hall: Community Lunch Monday 11am  
Village Hall: Lunch Club, Thursday 11am - 12pm

Aberystwyth - Tesco Community Room, MIND: Coffee, Information and Advice Mornings, Wednesday 10am – 12pm; Morlan Centre: Visually impaired Club, 1<sup>st</sup> and 3<sup>rd</sup> Monday of the month, 6-week course (bookable) Arthritis Care Group. Courses run concurrently.

Bethania / Cross Inn / Llannon / Nebo / Penuwch - Rhos yr Hafod: Monthly Community Coffee Morning. Wednesday 10:30am – 12pm.

Blaencelyn - Pontgarreg Memorial Hall: Coffee Morning, 1<sup>st</sup> Saturday of the month 10am – 12pm.

Borth - Community Hub: Men's Shed, Monday 10am – 12pm; Community Hub: Wellbeing Walks, Friday 10:30am – 11:30am; Community Hub: Community Café, Friday 11:30am – 1pm.

Bow Street / Rhydypennau / Llandre - Rhydypennau Hall, Penygarn: Coffee Morning, Friday 10am – 12pm; Rhydypennau Hall, Penygarn: Fit for life – exercise class, Wednesday 5:30pm – 6:30pm.

Brynhoffnant / Plwmp / Rhydlewis - Rhydlewis Village Hall: many regular session held but no confirmed day and time: Parent and Toddler Group, Dance Exercise, Short Mat Bowls, Gardening Club, Walking Group, Art Group, Local History Group, U3A, Table Tennis, Short Mat Bowls, Yoga, Toning, Community Café, St Michael's Church Services, Ladies Boxercise, Snooker Club.

Capel Seion - Neuadd y Paith, Capel Seion Village Hall (and playing fields): Children's play facilities.

Cardigan - Community Room, Bro Teifi Sheltered Housing: Cake a Chlonc, no day / time advertised externally; Hafan y Pwsgotwyr: CYD Aberteifi, Friday 11am – 12:30pm.

Cwmystwyth / Devil's Bridge / Llwynog / Ponterwyd / Pontrhydygroes / Swyddfynnon / Trisant / Ysbyty Ystwyth / Ystrad Meuring / Ystumtuen - Mynach Community Centre: Bore Coffi, Friday am; Mynach Community Centre: Coffee morning and book exchange, Thursday 10:30am – 12pm.

Eglwysfach/ Furnace / Derwenlas/ Glandyfi - The Iron Room: Regular exercise classes, book group, WI, ad hoc coffee mornings and soup kitchens. Warm space.

Lampeter / Silian - Caffi Hedyn Mwstard and Café Conti alternately: Siop Siarad, 2<sup>nd</sup> Thursday of the month; Llys Pedr Sheltered Housing Complex: Cake a chlonc, 2<sup>nd</sup> Thursday of the month 10:30am – 12:30pm; St Thomas's methodist Church: Coffee Morning, Tuesday 10am – 12pm.

Llandysul - Y Porth: CYD Llandysul, once a month.

Llanfarian / Glan yr Afon / Moriah / Trawsgoed - Llanfarian Village Hall: Coffee Morning ad hoc Wednesdays 10am – 12pm.

Llanfihangel y Creuddyn / Llanfyllin -Llanfihangel y Creuddyn Community Centre: Regular sound bath classes.

Llangrannog / Penbryn / Pentregât / Pontgarreg / Tresaith - Pentre Arms Pub: Sesiwn Sgorsio, 1<sup>st</sup> and 3<sup>rd</sup> Friday of the month, 7:30pm; Pontgarreg Memorial Hall: Coffee Morning, 1<sup>st</sup> Saturday of the month 10am – 12pm.

Llanilar - Community Centre: Craft club, 2<sup>nd</sup> Friday of the month 10:30am – 12:30pm.

Llannon -Cymuned Pennant Community: Coffee morning, Thursday 10am.

Llechryd - Coracle Hall: Bore da! Village Coffee Morning, 1<sup>st</sup> Saturday of the month, 10am – 12pm.

Penryhncoch - Penryhncoch Village Hall: Fit for life exercise classes Wednesday 4:15pm – 5:15pm; Penryhncoch Village Hall: Fun size fit exercise classes Tuesday 1:30pm – 2:30pm.

Taliesin - Llanfach Hall: Coffi a chlonc, Wednesday 10:30am – 12pm; Llanfach Hall: Chair yoga, Monday 1pm – 2pm; Llanfach Hall: Garden Group, Saturday 9am – 12pm.

Tre'r Ddol - Cletwr: Knit and natter, Tuesday 2pm – 4pm.

Waunfawr - Waunfawr Community Hall: Residents' coffee morning, Saturday (once a month); Waunfawr Community Hall: Social club afternoons, Frida. y

### 6.3.2 Informal community support findings

For individuals in areas north of Borth, outside the more populated regions of the mid and south of Ceredigion, access to community activities could represent an issue, dependant on the availability of transportation to and from locations, cost implications and suitability of activity for PLWD and their carers.

Issues may also arise from the closure of village and church hall, community centres which limits the ability to host local social events, with many villages and hamlets having to combine resources. Whilst a healthy step, this gives rise to the additional issue of accessibility due to poor transportation networks.

A range of other activities with no age or condition denomination were identified and a full list of all 25 locations, the venues and the activities is attached as Appendix B.

### 6.4 Overall findings of the Organisational and Community led support for PLWD and their carers review

Key findings of this review have two main themes:

- 1) Mapping, co-ordination, and promotion of activities available
- 2) Accessibility

In the main there is very little co-ordination of service provision at an organisational or community level. There are several areas of cross over and potential for duplication, specifically in the provision of information relating to financial support (Ceredigion County Council, Carers Support West Wales and Marie Curie as examples, but there are many others). The potential for confusion, availability of out-dated information and carer frustration is therefore increased.

Central co-ordination of service support is essential to ensure all initiatives, organisational or community led, are actively engaged with, promoted and supported. In this respect, Ceredigion should take note of the progress made in Gwynedd, Swansea and Powys in uniting services and signposting into a single point of contact / hub.

Planning and policy decisions regarding transportation and refurbishment, or relocation, of services should consider the impact on community-led activities and the support they provide to those unable to readily access central, town-based support services.

Wherever possible, resources should be made available to protect and maintain existing community hubs and other such venues from closure, to ensure equitable access is available to localised social activities across Ceredigion

A focus on support needs in the north of Ceredigion specifically should be considered, as the area north of Aberystwyth accounts for a quarter of the landmass in Ceredigion, with a significant number of population needs in this area being unmet.

## 7. Conclusion

It is clear from the work undertaken in this review that the population of Ceredigion has access to a wide range of support and care services, both at a county level and within local communities. As is evidenced in the literature, as well as in the practicalities of delivering these services, the lack of a central point of contact, a “one stop shop” for access to information, support, and engagement, potentially impedes further accessibility to these services. The use of assistive technologies to enable a more consistent delivery of such services and activities is also hampered by poor technological infrastructure.

There is also a lack of clarity throughout this review regarding the extent to which services in Ceredigion seek to engage with and involve PLWD in decision making and the arrangement of services. From the literature reviewed, it has been abundantly clear that the arrangement, provision and delivery of services and activities for PLWD should be (in part if not in whole) designed by PLWD and their carers, to ensure real life needs are being met and that any initiative provided is appropriate and sustainable.

It is noted that this is not the case for the Age Friendly Ceredigion forum, which hosts its meeting remotely across a range of residential locations where residents (some of whom may or may not have dementia) gather in the lounge or dining areas to contribute to developments and requests for information. A similar system be, if not already existent, be put in place for a Dementia Friendly Ceredigion.

Wales does have pockets of good practice in terms of inclusion of PLWD and their carers' in the development of dementia support services, such as inclusion of the CABAN group when developing research at Bangor University; the Swansea Dementia Hwb and more recently opened Carers Centre; the North Wales Dementia Recognition and Accreditation Scheme; Dementia Friendly Gwent e-resources; the use of DEEP training resources to inform and enlighten thinking around the participation of PLWD in research, activities and “normal” engagement with the public. Ceredigion would be able to learn from these examples and easily and effectively adopt elements of this identified best practice into its relevant processes.

The adoption, maintenance and monitoring of the Good Work Framework principles should be mandatory across all healthcare pathways in Wales, including healthcare education and recruitment processes, thus ensuring that all healthcare professionals are suitably skilled and trained in dealing with PLWD.

Ceredigion's educational institutions (Aberystwyth University and Coleg Ceredigion) are very active in their support and development of dementia education, training and awareness raising, which would readily support steps towards a dementia friendly Ceredigion. Incorporation of such learning could be considered across other educational institutions, e.g. UWTSO, secondary and primary schools, given that most people will have familial experience of dementia, some from a very young age. For "sandwich carers" this may also prove beneficial as they try to balance the needs of their young families with the care needs of older relatives with a dementia diagnosis.

The makeup of the Ceredigion landscape means that additional care needs to be focussed on the potential inequity of access to services and activities due to location. The literature evidences quite strongly that the general perception of dementia support is geared towards urban communities, who face relative ease in accessing transportation, be that public bus or train services or community transport hubs. Inhabitants of more rural communities are at a disadvantage in this respect, therefore more needs to be done to support them in order to ensure fair and equitable service provision across the county.

Changes at a UK Government level to building control regulations have the potential to have an amplified impact on less populated and rural communities linked to the removal of landmarks and "familiar places", leading to wayfinding issues and increased confusion for PLWD, as well as a reduction in access to green and open spaces and the potential impact on agricultural economies.

Whilst financial considerations are not a core component of this review, it is clear that additional financial investment into dementia support services would be advantageous in order to provide support for both the increasing, number of PLWD and the proportionately decreasing number of unpaid or familial carers (due to the nature of the ageing population) within Ceredigion.

The literature evidences the increased reliance in rural and remote areas on unpaid or familial caregiving, due to the inaccessibility of service provision. Of equal importance is the potential inability of health care professionals to access remote and rural communities, due to both the inaccessibility of track roads and resource costs (both time and financial). Alarming, anecdotal reports of ambulances having to cancel scheduled pick-ups from remote locations and refer patients to community transport alternatives have been heard as part of this review (PACTO, 2024).

The successful development of a Dementia Friendly Ceredigion must include extensive and mandatory education and training for all organisations, businesses and education providers, with easy accessibility to such resources provided for the public. Such awareness raising would have the potential to enable a more

empowered and supported county development, enabling organic growth and therefore sustainability.

The centralisation of information and advice for PLWD and their carers should be a priority, to limit confusion and the potential for duplication and inaccuracies. Likewise, the provision of tools to enable access to the numerous technological advances would support equity across the urban / rural communities of the county, such as iSupport Carer Services (Bangor University), mobile health apps, care and support services from the local authority, CAVO and others.

In summary, whilst Ceredigion is making good progress, including working towards a combined Age and Dementia Friendly Strategy (CCC, August 2025) to support its population living with dementia and their families/carers, lessons from counterparts in Wales could provide valuable advice and guidance for further progress, supported by active engagement of PLWD in decision making, management and evaluation of all relevant initiatives, in order to move towards a truly Dementia Friendly Ceredigion.

## 8. Recommendations and action plan

1. The creation of a county-wide “one stop shop” or **central dementia hub** for all information and support for PLWD and their cares, akin to that already in existence in Swansea and Wrexham
2. Consideration of a **dementia-friendly badge of recognition** for businesses and public places that welcome and are familiar with serving PLWD (e.g Wrexham’s Purple Angels campaign)
3. Creation of a **dementia checklist for carers** (e.g. Knowledge is Power – carers DSDC Bangor University and the Bangor University iSupport resources)
4. A specific focus is required on the care and support needs of those in the **north of Ceredigion**, beyond Aberystwyth, to address county level inequity
5. Increased provision of **dementia education and training** across the county, not only for PLWD and their families / carers, but also to health and care professionals, students and the public who will, no doubt, be impacted directly or indirectly by dementia at some point in their lives
6. Potential for **community led activity leads** to meet up on a quarterly basis to discuss developments, challenges and issues relating to dementia, generating linked activities within communities i.e. Solva Care (2019), Sustainable Communities (2024)

7. Planning and policy decisions regarding **transportation, and refurbishment, or relocation of services** should consider the serious impact this can have on community-led activities and the support they provide to those unable to readily access central, town-based dementia care and support services
  
8. The protection and maintenance of existing **community meeting places** (e.g. village halls / schools / chapels) to prevent closure should be prioritised in order to enable socialisation and community engagement which are critical for mental health and wellbeing
  
9. Active **involvement and consultation with PLWD and their families / cares** in all aspects of decision making and planning that has public impact

**This report contains a factual record of service and support findings which are accurate at the time of publication and their inclusion is not an endorsement from RHCW**

## APPENDIX 1 : About Rural Health and Care Wales

In January 2014, the Welsh Government commissioned the Welsh Institute for Health and Social Care to explore options for the provision of a high quality, sustainable healthcare service in Mid Wales, which resulted in the publication of a Mid Wales Healthcare study (Prof. Marcus Longley et al., Oct. 2014) that contained twelve key recommendations.

The twelfth recommendation of the study was that the three Health Boards covering the mid Wales area, working with local universities and other partners, should develop and support a “*centre for excellence in rural healthcare.*” The recommendation for this centre was that it should focus on “*research, development and dissemination of evidence in health service research that addresses the particular challenges of Mid Wales.*” It was noted that such a centre would have great potential to conduct work of relevance internationally.

A Centre for Excellence in Rural Health and Social Care (CfERH) was thus set up by the three health boards working across Mid Wales (Powys Teaching Health Board (PTHB), Betsi Cadwaladr University Health Board (BCUHB), and Hywel Dda University Health Board (HDdUHB)) and was formally launched by Professor Mark Drakeford AM, Minister for Health and Social Services at that time, on 24<sup>th</sup> March 2016.

A two-year Memorandum of Understanding was drawn up that confirmed the intent of the signatories, who were also members of the CfERH Management Board, to co-operate in the establishment of the CfERH and to work together for the benefit of the rural population of Wales. The Memorandum of Understanding took effect as from 1<sup>st</sup> June 2016 and was signed by the three Health Boards (PTHB, BCUHB, HDdUHB), the Welsh Ambulance Service NHS Trust, three Local authorities (Powys, Gwynedd and Ceredigion), Y Coleg Cymraeg Cenedlaethol and five Higher Education Institutions (Aberystwyth University, Bangor University, Cardiff University, Swansea University and the University of Wales Trinity Saint David).

In February 2017, staff were employed by CfERH to deliver Work programmes outlined by the CfERH Management Board and the Mid Wales Health Collaborative (now the Mid Wales Joint Committee for Health and Care). In March 2017, the name of the CfERH was amended to “**Rural Health and Care Wales**”. Guided by the Welsh Government, ambitious Vision, Aims and Objectives were adopted for Rural Health and Care Wales (RHCW) in 2017 that recognised its significant role and potential to be an exemplar in rural health and care within Wales, the UK and World-wide.

Annual Work Programmes have since been developed and delivered by RHCW, that are now approved by the Mid Wales Joint Committee for Health and Care (Previously the Mid Wales Health Collaborative), along with an annual budget. Whilst the three named Health boards continue to provide some core funding, RHCW has been increasingly successful in attracting external grants and external funding to support its work in addressing rural health and care issues and seeking to pilot and evaluate solutions to challenges that are faced by people living in rural Wales.

## Appendix 2: Community Led activities for PLWD and their carers

| Scoping reference summary - Ceredigion: coverage approximately 25% of identified Ceredigion villages and hamlets plus 7 Towns |  |   |                            |               |                   |              |   |
|---|--|---|----------------------------|---------------|-------------------|--------------|---|
| Town / Village  | Venue  | Title                                   | Day                        | Time          | Dementia Specific | Age Specific | Other   |
| Aberaeron   | RAY Ceredigion, Pengloyn, Tabernacle Street, Aberaeron, SA46 0BN | Dementia Carers Group                   | Thursday                   | 11am - 2:30pm | Yes               | No           | Carers  |
| Aberaeron   | RAY Ceredigion, Pengloyn, Tabernacle Street, Aberaeron, SA46 0BN | Forget me knot club                     | Friday                     | 10:30am - 1pm | Yes               | No           |   |
| Aberaeron   | Caffi Cwtsch y Gwenyn  | Coffi a Chlonc                          | Tuesday                    | 10:30 - 12pm  | No                | No           |   |
| Aber-Arad   | Our Lady Queen of Peace RC Church Hall, Newcastle Emlyn,         | Community Wellbeing Drop in             | 2nd Wednesday of the month | 1pm           | No                | No           | Last seen advertised Nov 2023   |
| Aberporth   | Aberporth Village Hall, Aberporth, Ceredigion, SA43 2EW          | Community Coffee Morning                | Friday                     | 10am - 1pm    | No                | No           | Community lunch Monday 11am onwards pay what you can; Lunch club – Thursday 11am – 12pm pay what you can                            |
| Aberporth   | Canolfan y Dyffryn   | Te a Sgwrs                              | Monday                     | 3pm           | No                | No           |   |
| Aberporth   | Tafarn y Llong   | Coffi a chlonc                          | 2nd and 4th Wednesday      | 1pm           | No                | No           |   |
| Aberystwyth   | HAVHAV Wellbeing Centre  | Caffi Cofion                            | Wednesday                  | 2pm - 4pm     | Yes               | No           | Afternoon Tea experience for PLWD and their carers  |
| Aberystwyth   | 312, Canolfan Rheidol  | Carer's café                            | Last Thursday of the month | 12pm - 1:30pm | No                | No           | Carers  |
| Aberystwyth   | Morian Centre, Queen's Road, Aberystwyth SY23 2HH                | Friendship Group                        | Friday                     | 12 - 2pm      | No                |              | Visually Impaired Club – twice monthly (1st and 3rd) on Monday 2pm, Arthritis Care Group - bookable 6-week course runs concurrently |
| Aberystwyth   | MIND - Tesco Community Room                                      | Coffee and Information, Advice mornings | Wednesday                  | 10 - 12pm     | No                | No           |   |

|              |  |  |                                  |              |     |  |  |
|--------------|--|--|----------------------------------|--------------|-----|--|--|
| Adpar        | Our Lady Queen of Peace<br>RC Church Hall,<br>Newcastle Emlyn,               | Community<br>Wellbeing<br>Drop in      | 2nd<br>Wednesday of<br>the month | 1pm          | No  | No                                       | Last seen advertised Nov 2023  |
| Bethania     | Rhos Yr Hafod, (Pub) Cross<br>Inn, Llannon                                   | Monthly<br>Community<br>Coffee Morning | Wednesday                        | 10:30 - 12pm | No  | No                                       |  |
| Blaencelyn   | Pontgarreg Memorial Hall   | Coffee Morning                         | 1st Saturday<br>of the month     | 10am - 12pm  | No  | No                                       |  |
| Borth        | Borth Community Hub,<br>Clarach Road, Borth                                  | Carers<br>Arts4Wellebing<br>group      | Monday                           | 10am -12pm   | No  | No                                       | Carers   |
| Borth        | Borth Community Hub,<br>Clarach Road, Borth                                  | Dementia<br>Friendly Group             | Monday                           | 10 - 12pm    | Yes | No                                       | Men's Shed - Monday 10 - 12. Wellbeing<br>walks – Friday 10:30 – 11:30, Friday<br>Community Café 11:30 – 13:00   |
| Bow Street   | Rhydypennau Hall,<br>Penygarn, Bow Street, SY24<br>5Bq, Aberystwyth SY24 5BQ | Coffee Morning                         | Friday                           | 10am - 12pm  | No  | No                                       | Wednesday "Fit for life" 5:30 – 6:30pm   |
| Brynhoffnant | Rhyd Lewis Village Hall,<br>Rhyd Lewis, SA44 5PE,<br>Ceredigion, Wales       |  |                                  |              | No  | No                                       | Regular sessions but no details available<br>on line: Parent and<br>Toddler Group, Dance Exercise, Short Mat<br>Bowls, Gardening Club, Walking Group, Art<br>Group, Local History Group, U3A, Table<br>Tennis,<br>Short Mat Bowls, Yoga, Toning, Community<br>Café, St Michael's Church Services, Ladies<br>Boxercise, Snooker Club (in dedicated<br>snooker room) |
| Capel Seion  | Neuadd y Paith, Capel Seion<br>Village Hall,                                 |  |                                  |              | No  | Yes -<br>play<br>centre<br>and<br>fields | Children's play facilities mainly  |

|                |   |                             |                            |              |    |  |   |
|----------------|---|-----------------------------|----------------------------|--------------|----|--|---|
| Cardigan       | Communal Room, Bro Teifi Sheltered Housing, SA43 1DQ, Cardigan                          | Cake a Chlonc               | ??                         | ??           | No | No                                     |   |
| Cardigan       | Hafan y Pysgotwyr   | CYD Aberteifi               | Friday                     | 11 - 12:30   | No | No                                     |   |
| Cross Inn      | Rhos Yr Hafod, (Pub) Cross Inn, Lannon  | Monthly Community Café      | Wednesday                  | 10:30 - 12pm | No | No                                     |   |
| Cwmcou         | Our Lady Queen of Peace RC Church Hall, Newcastle Emlyn,                                | Community Wellbeing Drop in | 2nd Wednesday of the month | 1pm          | No | No                                     | Last seen advertised Nov 2023   |
| Cwmystwyth     | Ponterwyd Village Hall - campaign to save but not updated - use Mynach Community Centre | Bore Coffi                  | Friday                     | ??           | No | No                                     | Coffee morning and book exchange Thursday 10:30 – 12pm  |
| Devil's Bridge | Mynach Community Centre   | Bore Coffi                  | Friday                     | ??           | No | No                                     | Friday Bore Coffi - no regular pattern of dates   |
| Dihewyd        | Mydroilyn Village Hall Penlan Fach Dihewyd Lampeter SA48 7QP                            |                             |                            |              | No | No                                     | No information found  |
| Eglwysfach     | Iron Room Eglwysfach  |                             |                            |              | No | No                                     | Regular exercise classes, warm spaces, book groups, WI. Ad hoc coffee mornings, Soup kitchens |
| Felinfach      | Theatr Felinfach, Lampeter, SA48 8AE  | Hwyl a Hamdden              | Wednesday                  | 1:30 - 3pm   | No | Yes - A social group for the over 50's |   |

|              |   |                |                              |               |    |  |   |
|--------------|---|----------------|------------------------------|---------------|----|--|---|
| Ffostrasol   | Ffostrasol Arms, Ffostrasol, SA44 4SY   | Board Games    | Monday                       | 11am          | No | Yes - A social group for the over 50's |   |
| Furnace      | Iron Room Eglwysfach  |                |                              |               | No | No                                     | Regular exercise classes, warm spaces, book groups, WI. Ad hoc coffee mornings, Soup kitchens |
| Glan yr Afon | Llanfarian Village Hall<br>5 Lon Ty Llwyd,<br>Clos Elan,<br>Llanfarian<br>Aberystwyth<br>SY23 4UL | Coffee Morning | ad hoc<br>Wednesday          | 10 - 12pm     | No | No                                     | No regular events found   |
| Glandyfi     | Iron Room Eglwysfach  |                |                              |               | No | No                                     | Regular exercise classes, warm spaces, book groups, WI. Ad hoc coffee mornings, Soup kitchens |
| Lampeter     | Caffi Hedyn Mwstard and<br>Caffi Contis alternately   | Siop Siarad    | 2nd Thursday<br>of the month | ??            | No | No                                     |   |
| Lampeter     | Llys Pedr Sheltered Housing<br>Complex, SA48 7DD,<br>Lampeter                                     | Cake a Chlonc  | 2nd Thursday<br>of the month | 10:30 - 12:30 | No | No                                     |   |
| Lampeter     | St Thomas's Methodist<br>Church, St Thomas Street,<br>Lampeter, SA48 7DQ                          | Coffee Morning | Tuesday                      | 10:00 - 12pm  | No | No                                     |   |
| Llandre      | Rhydypennau Hall,<br>Penygarn, Bow Street, Sy24<br>5Bq, Aberystwyth SY24 5BQ                      | Coffee Morning | Friday                       | 10am - 12pm   | No | No                                     | Wednesday "Fit for life" 5:30 – 6:30pm  |

|                         |   |                                 |                            |             |     |  |   |
|-------------------------|---|---------------------------------|----------------------------|-------------|-----|--|---|
| Llandysul               | Tysul Church Hall, Church Street, Llandysul | Memory café                     | 4th Wednesday of the month | 10am - 12pm | Yes | No   |   |
| Llandysul               | Y Porth                                     | CYD Llandysul                   | Once a month               | ??          | No  | No   |   |
| Llanerchaeron           | Llanerchaeron Estate                        |                                 | Thursday                   | 10am        | No  | 50+ yrs befriending woodland walks Thursday 10am |   |
| Llanfihangel y Creuddyn | Llanfihangel y Creuddyn Community Centre    |                                 |                            |             | No  | No   | Regular Sound bath and Art classes at a cost. |
| Llanfyllin              | Llanfihangel y Creuddyn Community Centre    |                                 |                            |             | No  | No   | Regular Sound bath and Art classes at a cost. |
| Llangrannog             | Pente Arms Pub                              | Sesiwn Sgorsio                  | 1st and 3rd Friday         | 7:30pm      | No  | No   |   |
| Llangrannog             | Pontgarreg Memorial Hall                    | Coffee Morning                  | 1st Saturday of the month  | 10am - 12pm | No  | No   |   |
| Llanilar                | Community Centre                            |                                 |                            |             | No  | No   | Craft club every second Friday 10:30 – 12:30  |
| Llanon                  | Cymuned Pennant Community, Llannon          | Coffee Morning                  | Thursday                   | 10am        | No  | No   |   |
| Llechryd                | Coracle Hall                                | Bore da! Village Coffee morning | 1st Saturday in the month  | 10 - 12pm   | No  | No   |   |

|                 |   |                             |                            |              |     |               |  |
|-----------------|---|-----------------------------|----------------------------|--------------|-----|---------------|--|
| Llywernog       | Ponterwyd Village Hall - campaign to save but not updated - use Mynach Community Centre | Bore Coffi                  | Friday                     | ??           | No  | No            | Coffee morning and book exchange Thursday 10:30 – 12pm                             |
| Nebo            | Rhos Yr Hafod, (Pub) Cross Inn, Lannon  | Monthly Community Café      | Wednesday                  | 10:30 - 12pm | No  | No            |  |
| Newcastle Emlyn | Our Lady Queen of Peace RC Church Hall, Newcastle Emlyn,                                | Community Wellbeing Drop in | 2nd Wednesday of the month | 1pm          | No  | No            | Last seen advertised Nov 2023  |
| Newquay         | Newquay Memorial Hall   | Friendship club             | Thursday                   | 12-2pm       | Yes | No            | Bingo Friday 7pm, Art class Tuesday 1:30pm   |
| Penbryn         | Pente Arms Pub  | Sesiwn Sgorsio              | 1st and 3rd Friday         | 7:30pm       | No  | No            |  |
| Penbryn         | Pontgarreg Memorial Hall  | Coffee Morning              | 1st Saturday of the month  | 10am - 12pm  | No  | No            |  |
| Penparcau       | Community Education Hub, Penparcau  | Seniors Friendship Group    | Thursday                   | 1pm - 3pm    | No  | Yes - Seniors | Last Newsletter dated May 2024 no updates on events since                          |
| Penrhyncoch     | Penrhyncoch Village Hall, Penrhyncoch, Aberystwyth, Ceredigion SY23, UK                 |                             |                            |              | No  | Yes           | "Fit for life" sessions Wednesday 4:15 - 5:15pm "Fun size fit" Tuesday 1:30 - 2:30 |
| Pentregât       | Pontgarreg Memorial Hall  | Coffee Morning              | 1st Saturday of the month  | 10am - 12pm  | No  | No            |  |

|                |   |                             |                            |              |    |    |   |
|----------------|---|-----------------------------|----------------------------|--------------|----|----|---|
| Penuwch        | Rhos Yr Hafod, (Pub) Cross Inn, Lannon  | Monthly Community Café      | Wednesday                  | 10:30 - 12pm | No | No |   |
| Plwmp          | Rhydlewis Village Hall, Rhydlewis, SA44 5PE, Ceredigion, Wales                          |                             |                            |              | No | No | Regular sessions but no details available on line: Parent and Toddler Group, Dance Exercise, Short Mat Bowls, Gardening Club, Walking Group, Art Group, Local History Group, U3A, Table Tennis, Short Mat Bowls, Yoga, Toning, Community Café, St Michael's Church Services, Ladies Boxercise, Snooker Club (in dedicated snooker room) |
| Pont Ceri      | Our Lady Queen of Peace RC Church Hall, Newcastle Emlyn,                                | Community Wellbeing Drop in | 2nd Wednesday of the month | 1pm          | No | No | Last seen advertised Nov 2023   |
| Ponterwyd      | Ponterwyd Village Hall - campaign to save but not updated - use Mynach Community Centre | Bore Coffi                  | Friday                     | ??           | No | No | Coffee morning and book exchange Thursday 10:30 – 12pm  |
| Pontgarreg     | Pontgarreg Memorial Hall  | Coffee Morning              | 1st Saturday of the month  | 10am - 12pm  | No | No |   |
| Pontrhydygroes | Ponterwyd Village Hall - campaign to save but not updated - use Mynach Community Centre | Bore Coffi                  | Friday                     | ??           | No | No | Coffee morning and book exchange Thursday 10:30 – 12pm  |

|             |  |                |                           |               |    |    |   |
|-------------|--|----------------|---------------------------|---------------|----|----|---|
| Pontsian    | Neuadd Pontsian Community Hall   |                |                           |               | No | No | Ad hoc sessions and activities  |
| Rhydlewis   | Rhydlewis Village Hall, Rhydlewis, SA44 5PE, Ceredigion, Wales         |                |                           |               | No | No | Regular sessions but no details available on line: Parent and Toddler Group, Dance Exercise, Short Mat Bowls, Gardening Club, Walking Group, Art Group, Local History Group, U3A, Table Tennis, Short Mat Bowls, Yoga, Toning, Community Café, St Michael's Church Services, Ladies Boxercise, Snooker Club (in dedicated snooker room) |
| Rhydowen    | Neuadd Pontsian Community Hall   |                |                           |               | No | No | Ad hoc sessions and activities  |
| Rhydypennau | Rhydypennau Hall, Penygarn, Bow Street, Sy24 5Bq, Aberystwyth SY24 5BQ | Coffee Morning | Friday                    | 10am - 12pm   | No | No | Wednesday "Fit for life" 5:30 – 6:30pm  |
| Silian      | Caffi Hedyn Mwstard and Caffi Contis alternately                       | Siop Siarad    | 2nd Thursday of the month | ??            | No | No |   |
| Silian      | Llys Pedr Sheltered Housing Complex, SA48 7DD, Lampeter                | Cake a Chlonc  | 2nd Thursday of the month | 10:30 - 12:30 | No | No |   |

|                |   |                            |                           |              |    |    |   |
|----------------|---|----------------------------|---------------------------|--------------|----|----|---|
| Silian         | St Thomas's Methodist Church, St Thomas Street, Lampeter, SA48 7DQ                      | Coffee Morning             | Tuesday                   | 10:00 - 12pm | No | No |   |
| Swyddfynnon    | Ponterwyd Village Hall - campaign to save but not updated - use Mynach Community Centre | Bore Coffi                 | Friday                    | ??           | No | No | Coffee morning and book exchange Thursday 10:30 – 12pm        |
| Talgarreg      | Neuadd Pontsian Community Hall  |                            |                           |              | No | No | Ad hoc sessions and activities                                |
| Taliesin       | Llanfach Hall   | Coffi a chlonc             | Wednesday                 | 10:30 - 12pm | No | No | Chair Yoga Monday 1pm – 2pm, Garden group 9am – 12pm Saturday |
| Tre'r Ddol     | Cletwr  |                            |                           |              | No | No | Knit and natter Tuesday 2pm – 4pm                             |
| Tresaith       | Pente Arms Pub  | Sesiwn Sgorsio             | 1st and 3rd Friday        | 7:30pm       | No | No |   |
| Tresaith       | Pontgarreg Memorial Hall  | Coffee Morning             | 1st Saturday of the month | 10am - 12pm  | No | No |   |
| Trisant        | Mynach Community Centre   | Bore Coffi                 | Friday                    | ??           | No | No | Friday Bore Coffi - no regular pattern of dates               |
| Waunfawr       | Waunfawr Community Hall,  | Residents' coffee mornings | Saturday once a moth      | ??           | No | No | Social Club Friday afternoons                                 |
| Ysbyty Ystwyth | Ponterwyd Village Hall - campaign to save but not updated - use Mynach Community Centre | Bore Coffi                 | Friday                    | ??           | No | No | Coffee morning and book exchange Thursday 10:30 – 12pm        |

|                |   |            |        |    |    |    |  |
|----------------|---|------------|--------|----|----|----|--|
| Ystrad Meuring | Ponterwyd Village Hall - campaign to save but not updated - use Mynach Community Centre | Bore Coffi | Friday | ?? | No | No | Coffee morning and book exchange Thursday 10:30 – 12pm |
| Ystumtuen      | Ponterwyd Village Hall - campaign to save but not updated - use Mynach Community Centre | Bore Coffi | Friday | ?? | No | No | Coffee morning and book exchange Thursday 10:30 – 12pm |

### Appendix 3: Tabular summary of dementia awareness raising and momentum identified from the literature

| 35 years of Dementia Awareness Development Timeline (1989 - 2024) |   |                               |
|---|---|-------------------------------|
| 1989  | DSDC Stirling University is established   | Scotland                      |
| 1990  | The first Admiral Nurses are appointed  | England                       |
| 1991  |   |                               |
| 1992  |   |                               |
| 1993  |   |                               |
| 1994  | First Admiral Nurse Team is appointed in London   | England                       |
| 1995  | FOTON Bruges established as a centre of excellence through the "Inclusive city" project                                   | Belgium                       |
| 1996  |   |                               |
| 1997  | I am still the person: Kitwood, published   | England                       |
| 1998  |   |                               |
| 1999  | The first Admiral Nurse service outside London is opened in Kent<br>DSDC (Wales) at Bangor University is established      | England<br>Wales              |
| 2000  | Admiral Nursing across the UK commences<br>Alzheimer's Society adopt the Forget me not emblem                             | England<br>Worldwide          |
| 2001  |   |                               |
| 2002  | The Scottish Dementia Working Group was inaugurated - made up people with a dementia diagnosis to help and support others | Scotland                      |
| 2003  |   |                               |
| 2004  | Change of terminology to reference the condition not its symptoms   | Japan                         |
| 2005  | Early research in rural and remote dementia care: Blackstock  | Scotland                      |
| 2006  | Age Friendly Movement   | The World Health Organisation |
| 2007  | Active Ageing Framework (WHO)   | Worldwide                     |
| 2008  | I am still the person (Reissued): Kitwood<br>First Commissioner for Older People (Wales) appointed                        | UK<br>Wales                   |
| 2009  | De Hogeweyk opens   | The Netherlands               |
| 2010  |   |                               |

|      |  |   |
|------|--|---|
| 2011 | National Dementia Vision for Wales: Dementia Supportive Communities: Alzheimer's Society<br>Living well with dementia : Good Practice Compendium: A National Strategy published  | Wales<br>UK   |
| 2012 | DEEP - a group of people with a dementia diagnosis aiming to educate and improve diagnosis outcomes and develop dementia friendly societies<br>Dementia without walls project (York) launched<br>Dementia recognised as a Public Health Priority (WHO)<br>Overcoming the Stigma of Dementia - World Alzheimer's Report   | England<br>England<br>Worldwide<br>Worldwide            |
| 2013 | Dementia Friends Training launched: Alzheimer's Society  | Worldwide   |
| 2014 | DSDC (Ireland) is established<br>Centre for Ageing and Dementia Research: Aberystwyth, Bangor and Swansea Universities set up<br>Wrexham launches the Purple Angel Initiative<br>Tönbeön am See Dementia Village opens   | Ireland<br>Wales<br>Wales<br>Germany                    |
| 2015 | Living and dying with dementia in Wales : Barriers to care report published: Alzheimer's Society and Marie Curie Cancer Care   | Wales   |
| 2016 | European Foundations' Initiative on Dementia Mapping DFC's across Europe<br>Svendborg dementia village opens<br>Heathrow Airport becomes world's first dementia friendly airport   | Europe<br>Denmark<br>England                            |
| 2017 | The CABAN Group PLWD and their carers first meeting to inform dementia research at Bangor Uni.<br>"Nothing with us, without us" borrowed from the Disability Movement<br>Bellemere - First dementia Micro Town opened<br>Target of two million Dementia Friends achieved: Alzheimer's Society<br>Kia Ora Dementia Village opens<br>Carpe Diem Dementia Village opens | Wales<br>UK<br>Australia<br>UK<br>New Zealand<br>Norway |
| 2018 | First National Dementia Action Plan for Wales launched 2018 - 2022<br>Global Research on Assistive Technologies (WHO)<br>Bruff - Dementia Village opens<br>Monza Alzheimer's Village opens   | Wales<br>Worldwide<br>Ireland<br>Italy                  |

|      |   |  |
|------|---|--|
| 2019 | The person is still here (Revised & updated): Kitwood, Published<br>Harmony House, Rochester opened<br>The Harmonia, Dover opened<br>Langley Village opens<br>Villaggio Emanuele Alzheimer's Village opens  | England<br>England<br>England<br>Canada<br>Italy |
| 2020 | Korongee Village opens<br>DAX Alzheimer's Village opens   | Tasmania<br>France                               |
| 2021 | Age Friendly Wales: Our strategy for an ageing society published  | Wales  |
| 2022 | All Wales Dementia Care Pathway of Standards: PHW launched<br>Dementia Friendly Gwent Launched  | Wales<br>Wales                                   |
| 2023 |   |  |
| 2024 | North Wales Dementia Friendly Recognition and Accreditation Scheme launched<br>Jura Dorf opens<br>Knowl Park House Centre of Excellence in Care and Research opens<br>Over 450 Admiral Nurses are now in post around the UK<br>Age Friendly Ceredigion Launched | Wales<br>Switzerland<br>Scotland<br>UK<br>Wales  |

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