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**NORTH WALES** SOCIAL CARE AND WELL-BEING  
SERVICES IMPROVEMENT COLLABORATIVE

# Dementia strategy service mapping

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# Introduction

This information was collected for the North Wales Dementia Strategy. It provides a snapshot of dementia support services available during December 2019.

The latest information about support for people affected by dementia is available on the following websites.

- [Dewis Cymru](#)
- [Wales Dementia Helpline](#)
- [Alzheimer's Society Dementia Directory](#)

Support is also available from the Alzheimer's Society [Dementia Connect](#) service which provides a new personalised dementia support service for anyone affected by dementia. It is available across North Wales and connects people with a whole range of support, by phone, on-line and face to face.

## Research methods

We began by searching Dewis Cymru and the Integrated Care Fund (ICF) projects list for dementia support services. We used this information to partially complete a service mapping template, which was shared widely for comments through the steering group and to organisations who had expressed an interest in the strategy. It was also checked against the Wales Dementia Helpline and Alzheimer's Society Dementia Directory.

The Dementia Strategy event held in November included information stands, where people shared good practice and information on what was available. The workshop sessions also included an opportunity for people to check the information collected so far and add information about any other services available. These services were added to the service mapping.

We then cross-checked the service mapping against the regional carers services mapping and the dementia action plan progress report.

## What the service mapping can and can't tell us

It provides an overview of the services available but it can't tell us how well services are meeting people's needs. For example, it doesn't highlight if there's a long waiting list or how highly valued the service is by the people who use it. Neither can it tell us

whether having more than one similar service in an area is an inefficient use of resources, as these services may be meeting the needs of different groups of people. However, it can highlight areas that need more investigation.

The service mapping findings and recommendations will be cross-referenced with the research, data and consultation findings also carried out as part of the strategy.

## Recommendations

1. Look at opportunities to make links between Dewis Cymru, the Wales Dementia Helpline and the Alzheimer's Society Dementia Directory.
2. Encourage organisations providing support to people affected by dementia to add their information to Dewis Cymru and keep it up to date. Flintshire and Wrexham Councils have developed their own service directory. Joint working with Dewis Cymru is encouraged.
3. Consider options for extending the BCUHB funded dementia support service for people who were diagnosed with dementia before October 2016.
4. Share this service mapping with partner agencies to raise awareness about the different projects taking place in North Wales.
5. Promote co-production of support services to share power and responsibility and help make sure that projects are meeting the needs of individuals living with dementia and their carers.
6. Consider options for extending services for people with a mild cognitive impairment as some support services are only available to people with a diagnosis of dementia. Raise awareness of the support services that are currently available.
7. Consider expanding early detection screening for dementia with individuals with learning disabilities and Down's syndrome across the region.
8. Review the pilot shared lives schemes for carer breaks and consider rolling them out across the region.
9. Consider ways to improve access to services in rural areas.

10. Look at carers support contracts across the region for dementia and options for joint commissioning between local authorities and the health board and increasing flexibility to meet local needs.
11. Look to provide carer support services and events outside of standard office hours so that they are also accessible to carers who work outside of the home.

## **NICE Dementia quality standard**

[Quality standard 184](#) was published in June 2019 and can help identify gaps and areas for improvement in dementia care services. The quality statements for dementia are:

1. People accessing behaviour change interventions and programmes in mid-life are advised that the risk of developing dementia can be reduced by making lifestyle changes.
2. People with suspected dementia are referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated.
3. People with dementia are given the opportunity to discuss advance care planning at diagnosis and at each health and social care review.
4. People with dementia have a single named practitioner to coordinate their care.
5. People with dementia are supported to choose from a range of activities to promote wellbeing that are tailored to their preferences.
6. People with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress.
7. Carers of people with dementia are offered education and skills training.

## **NICE guideline Dementia: assessment, management and support for people living with dementia and their carers**

Paragraph 1.3.6 of these guidelines is relevant when providing a service for people living with dementia and/or their carers:

“Service providers should design services to be accessible to as many people living with dementia as possible, including:

- people who do not have a carer or whose carer cannot support them on their own

- people who do not have access to affordable transport, or find transport difficult to use
- people who have other responsibilities (such as work, children or being a carer themselves)
- people with learning disabilities, sensory impairment (such as sight or hearing loss) or physical disabilities people who may be less likely to access health and social care services, such as people from black, Asian and minority ethnic groups.

## Overview of services

The mapping identified around 375 different services. Only 33 included information about their costs, which came to a total of £2.6 million 2019/20. Around £2 million of this was from Intermediate Care Fund (ICF) funding. Another 155 projects gave details of their funders, which included local authorities and the health board plus the Lloyds Bank Foundation, Arts Council, Comic Relief, The Big Lottery and donations. In addition, some services are funded directly by private sector or community organisations such as dementia friendly film screenings and dementia cafés.

Similar numbers of services were available in each county with differences in the types of service available. These are described in the section below, broken down by theme and summarised in [appendix 2](#).

ICF is a key funder for specific dementia services, although it's a small part of the £186 million spent each year on older people's social care and mental health in the region. ICF is short term grant funding which has been used to try new projects. It comes to an end in March 2021 and at this time it is unclear whether there will be further funding. There is therefore a risk that these projects won't be able to find further funding.

## Risk reduction and delaying onset

Welsh Government recommend [six steps](#) that people can take to reduce their risk of dementia. These are:

- Step 1: Be physically active
- Step 2: Maintain a healthy weight
- Step 3: Be socially and mentally active
- Step 4: Avoid drinking too much alcohol

- Step 5: Stop smoking
- Step 6: Commit to review your health

Many organisations, initiatives and activities are working across North Wales to support people to take the six steps. This includes many public health initiatives aimed at improving public health in general, which also help reduce the risk of developing dementia. The support available includes:

- [Help me quit](#): support to stop smoking
- NHS Wales [healthy eating advice](#)
- [Local leisure centres](#)
- [National Exercise Referral Scheme](#)
- [Health Disability Sport Pathway](#)
- [Drink Wise Wales](#)
- [Alcohol Concern Cymru](#)
- [Wales Drug and Alcohol Helpline](#)
- [British Heart Foundation](#)
- [Add to your life](#): Free NHS Wales health check
- [Five ways to wellbeing](#)

## **Dementia research**

The [Dementia Services Development Centre](#) based at Bangor University is part of the Centre for Ageing and Dementia Research in the Health and Care Research Wales research structure.

Their work includes evaluating the effectiveness of projects and services for people living with dementia and their carers. This includes looking at the social return on investment in arts projects. They found that an input of £189,498 to deliver the groups created a social value of £980,717.

They have hosted conferences on intergenerational work, which included a speaker from the Ffrind I Mi project. The last one was in April 2019 which had over 100 attendees. Work has also taken place to increase awareness of dementia in schools.

## **Allied Health Team**

The Allied Health Team, established in February 2019, works with people newly diagnosed with dementia. The team comprises of a dietician, occupational therapist, physiotherapist, speech and language therapist and two therapy technical

instructors. They have developed a group education and exercise intervention programme designed to empower people living with dementia and their family/friends.

The session content has benefitted from the combined skills of the team and is in keeping with the '6 steps' approach, promoting social and physical activity and lifestyle changes. The team are creating strong community links to be able to signpost people to local initiatives such as the NERS (National Exercise Referral Scheme) and community activities to enable people to stay active after completing the group programme.

## **Dementia Connect**

The Alzheimer's Society are commissioned by local authorities across North Wales to provide Dementia Connect. Funding is mainly from ICF. However, each local authority differs. One-to-one support is available from specialist Dementia Advisors who support anyone affected by dementia, this includes people with a dementia diagnosis, those awaiting diagnosis, people with a mild cognitive impairment, carers, family and friends. The service is free, easy to access and was designed by people living with dementia. The specialist Dementia Advisors will connect the person to the support needed. Once a person accesses the service, they will receive on-going support throughout their journey.

A few examples of the support that can be provided:

- Help with legal and financial documents
- Emotional support when things get tough
- Connecting to local groups
- Help to understand and live with dementia.
- Coping techniques
- Support with welfare benefits

The Dementia Advisors also provide support sessions for individuals on the following subjects:

- Living well with dementia
- Carer's Information Programme (CrISP)

An element of Dementia Connect is Side by Side. Side by Side is a service designed to help people living with dementia keep doing the things they love or to try

something new. It is a volunteer-led service which helps people with an early diagnosis to live well with dementia and to continue to play active roles in their communities. Dementia Connect is available bilingually.

## Raising awareness and understanding

### Finding information and advice

There are at least three different dementia support online databases covering North Wales:

- Dewis Cymru. English and Welsh search although some of the service descriptions are in English only.
- Wales Dementia Helpline. English with Welsh homepage although the search and service descriptions are in English only.
- Alzheimer's Society Dementia Directory. English only.

There were some differences between the information available on each database. Dewis Cymru works by relying on services adding their information to the database so we need to make sure the services identified in this mapping exercise are aware of Dewis Cymru and how to add their information.

Flintshire County Council has also put together a [directory of support services](#) for people living with dementia and their carers in Flintshire. This includes a link to Dewis Cymru as well as providing useful information for Flintshire residents, such as a list of dementia friendly locations and details about how to arrange community transport or an assisted bin collection. Wrexham County Borough Council is also developing a directory of support services for people living with dementia and their carers.

Feedback from the Dementia Engagement Workshop organised by Social Care Wales in North Wales found that not all support groups will engage with these directories to have their details included as they are at capacity and so cannot provide support to any additional people living with dementia or their carers.

Following feedback received during a Caban DEEP session, Bangor University are currently leading on preparing a "what you need to know" booklet for people living with dementia. It will include details of ways to make life easier or less expensive.



In Anglesey there are dementia advisors who link with GPs and the Alzheimer's Society.

The Alzheimer's Society's Dementia Connect service provides holistic information, practical guidance and support to anyone affected by dementia.

Dementia Talking Points is the Alzheimer's Society's online community where anyone affected by dementia can ask questions and share information. People can connect with someone who is going through a similar experience and receive valuable support to help ensure that no one feels alone when they are affected by dementia. The community is free to use, available 24 hours a day and can be accessed via a smartphone, tablet, or computer. People can remain anonymous when they are using Dementia Talking Point, to discuss sensitive issues about dementia and seek support more privately.

The Alzheimer's Society also provides information programmes for carers and those living with dementia which brings groups of people together to talk about their situations and connect with others in a similar situation. For people living with dementia or carers who have served in the Armed Forces, the Royal British Legion provides an Admiral Nurse Service which provides social welfare advice and information specialising in dementia.

There are sources of support online, such as the North Wales Dementia Network Facebook group. Details of groups and events are posted here.

There are phone lines, such as the [friendly faces peer support](#).

The Royal National Institute of Blind People provide support for making services accessible. Additionally the North Wales Society for the Blind can provide written documents in an alternative format for any organisation for a fee.

## **Dementia friendly communities**

There are many dementia friendly initiatives taking place across North Wales, including partner organisations working towards dementia friendly status. Some of this work is funded through the ICF to deliver the Dementia Action Plan. The Ageing Well in Wales Programme also includes a priority for dementia friendly communities.

Alzheimer's Society has a Dementia Friendly Communities Co-ordinator whose role is to facilitate the creation of dementia friendly communities and to encourage communities and individual organisations to produce an action plan and sign up to

the society's recognition process. The latest list of communities is available on [their website](#).

Alzheimer's Society has a number of reference groups in North Wales who work with private and public organisations to create dementia friendly communities. They have worked with a number local authorities and the health board in North Wales

Local businesses and community groups have set up initiatives such as a weekly chatty hour at a café, relaxed cinema performances and quiet hours at dementia friendly supermarkets.

The North Wales public libraries all provide **Reading Well Books on Prescription** for dementia, which provides a range of books aimed at fostering a better understanding of the disease.

There's also **DEEP** (Dementia Engagement and Empowerment Project) which engages and empowers people living with dementia to influence attitudes, services and policies that affect their lives. The Dwyfor and Meirionydd DEEP group meets every two months in Barmouth. The Deeside DEEP meet the first Thursday of every month. There is also a Caban DEEP run by Bangor University.

Evidence has shown that good quality housing and well-planned, enabling local environments can have a substantial impact on the quality of life of someone living with dementia, helping them to live well for longer and of course, town planning has a key role to play if health and social care policies are to succeed. The Royal Town Planning Institute has produced practice advice on [Dementia and Town Planning](#). It gives advice on how good planning can create better environments for people living with dementia. It summarises expert advice, outlines key planning and health policy and highlights good practice case studies.

Other initiatives which aim to support people living with dementia within their community's include:

- The Herbert Protocol: A form kept at home or in a safe place, with important information about a vulnerable person. Should they go missing, information is easily on hand about routines, medical requirements and favourite places to visit and can be handed over to the police.
- Keep Safe Cymru Card. The card holds basic information about an individual such as how they communicate, any health issues and any emergency contacts. It can be used when the card holder needs assistance, whether they

are lost, a victim of crime or any situation that means they need some extra support. It gives them access to the Police Disability Line, which is a dedicated non-emergency phone number that can be used to contact the police.

- **Safe Places.** A safe place helps vulnerable people if they feel scared or at risk while they are out and about in the community and need support right away. So far Wrexham and Denbighshire have signed up to the national network.
- [Orange Wallet](#): a communication tool, which can be used by people who sometimes find difficulty communicating their needs to staff when using public transport.
- [Hidden disability lanyards](#) (a green lanyard with a pattern of sunflowers). These are available for use in supermarkets, airports, trains and buses. Also recognised in the US.
- [Forget-me-nots](#) (blue flower badges): these pins are worn to raise awareness and support for people affected by dementia.
- [Hynt Card](#): national access scheme to theatres and arts centres in Wales.
- [This is me](#) is a leaflet that people living with dementia can use to share details about themselves. Families and care homes are encouraged to keep a copy on hand to use if needed.

### **Giving people affected by dementia a voice**

- Tide (together in dementia everyday) run an involvement network for carers of people living with dementia.
- The [3 Nations Dementia Working Group](#) is made up of people with a diagnosis of dementia. They aim to become the 'go to' group in England, Scotland and Wales for anyone seeking input from people living with dementia. They also provide support for people living with dementia.

### **Training and workforce development**

Social Care Wales have produced a [dementia resource for care professionals](#) to provide access to essential information, case studies, data and research.

Social Care Wales also commissioned a review to map dementia learning and development across Wales in 2019. This identified many different resources and found they are largely of good quality. They recommended a role for the Regional Partnership Board when overseeing regional workforce development plans to improve coordination and collaboration between health and local authorities. They

highlighted that funding tends to be short term, largely through the ICF, which provides good opportunities to try new initiatives but these can be difficult to then mainstream. Also, although participants in the research were happy with the quality of the resources, there wasn't an effective approach to collecting evidence about how learning and development informs practice and the difference it then makes to people's lives.

The review identified the following gaps in training from the interviews carried out.

- Moderate and late-stage dementia
- Pain recognition
- Managing distress, particularly in hospital settings
- Engaging with carers
- More detailed specialist training
- Understanding triggers for behaviours
- De-escalation techniques
- Managing risk

The North Wales training officers group have dementia as a priority area, which should help address some of the challenges identified in the Social Care Wales review. The list of courses available is in [appendix 1](#).

In addition, Flintshire County Council are arranging student placements with Bangor University to place an Applied Behaviour Student to support people living with dementia and families that are facing difficulties with behaviour as a result of the dementia.

Alzheimer's Society provide specialist training and consultancy services to external organisations across all sectors. They train health and social care staff directly responsible for delivering dementia care and support, as well as staff who may come into contact with people living with dementia. Their high-quality, affordable training programmes and consultancy services are based on best practice in dementia care and delivered by experts in the field. They aim to equip staff with the knowledge, understanding and practical skills to provide person-centred care and support people affected by dementia to live well.

### **Good Work: A Dementia Learning and Development Framework for Wales**

The framework was produced by the Care Council for Wales (now part of Social Care Wales) in 2016. It sets out underpinning values and key learning and

development topics for three broad groups of people; those who are **Informed**, those who are **Skilled** and those who are **Influencers**.

The model uses a complementary model of expertise, where everyone has something to contribute as shown in the model below.



## **Betsi Cadwaladr University Health Board (BCUHB) dementia training and initiatives**

Through the BCUHB Dementia Strategy 2018-20 completion of 'skilled' level dementia training is mandatory for clinical staff who provide direct care on a regular basis to people living with dementia. That training is in place and there has been an acceptable increase in the number of staff trained.

All new starters coming into post with the health board undertake dementia awareness as part of their induction period. There is an expectation that every member of staff has the opportunity to become a Dementia Friend and opportunities are increasingly available and attended.

The health board has reviewed its offer of dementia training to staff at both the 'informed' and 'skilled' levels that are set out by the 'Good Work' framework. That review has been aimed at strengthening the involvement of people living with dementia and their carers/families. Working closely with our Dementia Strategy Ambassador (a person with dementia) we have jointly delivered dementia friends sessions including to the Executive Board and Emergency Department teams and, developed a new training module focussed on understanding and responding to behaviour change. Working with TIDE, an involvement network for carers of people living with dementia, hosted by the Life Story Network CIC, we are supporting carers to share their experiences by training them to acquire appropriate skills and competencies in delivering training. The project is overseen by a Consultant Nurse for dementia.

### **John's Campaign**

BCUHB was the first health board in Wales to commit to John's Campaign (the right for carers to stay with people living with dementia in hospital), which is in place in all adult wards.

### **Dementia Care Mapping**

BCUHB was the first health board to use Dementia Care Mapping and has led the development across Wales in partnership with Public Health Wales 1000 Lives team (now called 'Improvement Cymru'). In agreement with Bradford University BCUHB has innovated the use of Dementia Care Mapping as a measure of cultural change and published this work in an international peer reviewed social research journal. Dementia Care Mapping is a method of staff observation in care settings and is a way to measure the experience of people living with dementia.

### **Palliative Care**

Specialist dementia care and specialist palliative care services have jointly developed a training programme which includes introducing advance care planning and the subsequent identification of people living with dementia approaching end of life.

### **Engagement**

BCUHB established a reference group of carers who road-tested the 'skilled' level dementia top-up module. The training team delivering the 'skilled' level of dementia training, which includes two people living with dementia and a carer. An alliance of BCUHB and third sector organisations has been formed to develop further the concept of direct involvement in dementia education and training.

## Recognition and identification

There were no services identified in the service mapping that were specifically aimed at recognising and identifying dementia, although GPs would be the first point of contact for many people. The aim of this section in the Welsh Government Dementia Action Plan is that people are aware of the early signs of dementia; the importance of a timely diagnosis; and know where to go to get help.

Some services to support people with memory loss and other related problems are only available to people with a diagnosis of dementia. This means there is not always support available for people who have a mild cognitive impairment and/or those who are going through the process of assessment and diagnosis.

There are some areas in North Wales that are beginning to develop early detection screening for dementia with individuals with learning disabilities and Down's syndrome.

Alzheimer's Society are currently engaging with all GPs across North Wales to provide them with information about the Dementia Connect Service. They are encouraging GPs to give out the Dementia Connect telephone number so that individuals can receive timely advice and support as well as guidance around the diagnosis process.

## Assessment and diagnosis

There are seven memory clinics across North Wales, which provide assessment, diagnosis, treatment and post diagnostic support. These are shown in the map below. This highlights that the Gwynedd and Ynys Môn Memory Clinic covers a wide geographical area and people in rural areas may face challenges with travelling to and accessing the clinic.



There is a research project taking place to look at mapping the challenges and enablers for adults with learning disabilities and their carers, when accessing dementia assessments. The findings are due in July 2020 and could be used as a basis for improving services in this area. Carers Trust North Wales Crossroads advice service is available for people with a learning disability who would like to access a memory assessment.

There's also a new ICF funded project to identify hearing impairment in those people with suspected dementia and refer for hearing aid provision prior to memory service referral; thereby reducing inappropriate dementia diagnosis, delaying onset of dementia, improving wellbeing and reducing need for health and social care services.

## **Living as well as possible for as long as possible with dementia**

### **Advocacy services**

Advocacy is available in all areas from the Alzheimer's Society for people who are undergoing a diagnosis or already have a diagnosis of dementia. Mental Health Matters Wales provide Independent Mental Capacity Advocates (IMCA) for people



who lack capacity and have no-one other than paid staff to support them. There's also advocacy available for people aged over 50 in Gwynedd and the Isle of Anglesey from Age Cymru. Anglesey also has a service with North Wales Advice and Advocacy Service. In Flintshire and Denbighshire advocacy can also be accessed from Advocacy Services North East Wales (ASNEW). They also offer a community based advocate service for Wrexham. North Wales Advice and Advocacy Service provide a service in Wrexham. Dewis Centre for Independent Living provide advocacy services for people aged 18+ who are in need of an advocate in Conwy and Denbighshire.

Specialist independent advocate provision for older people detained under the Mental Health Act, subject to Deprivation of Liberty, in need of social care and, for those who lack capacity and have no appropriate family is provided for by BCUHB.

## **Community services**

There are many different services available for people in their communities. These included:

- Assistive technology
- Befriending services
- Bowls
- Community arts and music projects, including Art in the Arm Chair and Art Memory Café at Theatr Clwyd, art classes in Wrexham, cARTrefu arts in care homes programme, Mind Music sessions in Prestatyn, Lost in Art visual project in Denbighshire, Carry on Singing group in Rhyl, Cerdd ni singing groups in Denbighshire and Wrexham and music and movement classes across North Wales.
- Companion pets (robotic pets used for therapy purposes) and pet therapy with live animals.
- Dementia cafes and luncheon clubs
- Dementia friendly towns across North Wales
- Drop in sessions
- Exercise classes and therapy including Dementia GO and National Exercise Referral Scheme
- Friendly faces peer support scheme
- Gardening projects and sensory gardens
- Heritage projects

- Intergenerational projects
- Men's shed (some have specific dementia friendly sessions)
- Peer support groups
- Reading groups and reading well books on prescription from local libraries
- Reminiscence therapy
- Supermarkets with dementia friendly times and links with taxi companies
- Swimming
- Tea dances
- Walking groups

These services have often evolved based on a combination of people's interests and the skills and resources that communities have access to (sometimes called co-production), so they do vary across North Wales. It's difficult to say whether there are any gaps, either geographically or for different groups of people, although there are activities happening within each of the six counties.

Instead of trying to standardise the community support available, the dementia strategy may be able to play a role in creating environments where these ideas can thrive, for example by promoting dementia friendly communities initiatives. It can also help with sharing information about what's available to help facilitate the spread of good ideas across the region. Services are encouraged to register on the DEWIS website so that they are more easily found.

### **Dementia support service**

Carers Trust North Wales Cross Roads are funded by BCUHB to provide a dementia support service. The service provides dementia coordinators based in memory clinics and Taith Ni, which are monthly local support groups for people living with dementia and their family and friends. These services are available to people who have been diagnosed with a type of dementia after October 2016 and their carers and families. The service cannot accept referrals from another source and cannot support anyone who was diagnosed prior to this date. This was raised as an issue in the consultation.

Alzheimer's Society Cymru and local charity based initiatives help provide support for those diagnosed at any time, therefore anyone affected by dementia can receive support from these services regardless of the date of diagnosis.

## **Support for younger people living with dementia**

Dementia Connect is available across all of the local authorities in North Wales and supports younger people living with dementia. The support is person centred and the Dementia Advisor will provide appropriate advice and support.

In Flintshire there is a dedicated social worker for people with younger onset dementia as well as the Old Brewery in Shotton, which offers support and respite to people with early onset dementia in a specialist Early Onset Resource Centre on a Monday, Tuesday, Thursday and Friday. They also fund a 'Team around the individual' model for young people living with dementia.

The Alzheimer's Society is commissioned by Denbighshire to provide specific dementia support to younger people living with dementia. In Gwynedd and Anglesey there are dementia support workers who support older people and younger adults with moderate to severe memory related issues or with a diagnosis of dementia.

In Wrexham there is a dedicated young onset services with a Community Psychiatric Nurse within BCUHB.

In Conwy, the Community Wellbeing Team have been working with those with early on-set dementia to help them facilitate a social group outside of their hospital environment.

## **Day care, day opportunities and carer breaks**

Day care services included:

- Specialist day care (Hafan) Bryn Beryl in Gwynedd
- Specialist day services (Hafan) Bryngwran in Anglesey.
- Dementia hubs established in partnership with Dementia Support Workers and Local Asset Co-ordinators.
- Shared Lives Scheme provided short breaks service on Anglesey and Gwynedd.
- In Conwy, Llys Elian is a local authority run 23-bed residential unit and day service specialising in dementia care, with 4 overnight respite beds available.
- Daffodil Day Centre in Colwyn Bay offers a weekday service throughout the year with a range of activities
- Many independent care homes in Conwy offer day opportunities.

- Integrated community based support is offered via the PSS Trio service in Conwy.
- Caffi Conwy is an informal social support group held every other week and facilitated by Crossroads Carers Trust. Hafan Deg, Rhyl day service for people living with dementia
- St Asaph Gofal Dydd. Day care two days a week and home respite services.
- Flintshire County Council provide dementia day care 6 days a week for older people.
- Hafal provide respite for mental health carers in Flintshire.
- NEWCIS and Marleyfield House offers 12 weeks of respite on a Saturday in a day care setting in Flintshire
- There are day hospitals across North Wales which provide a range of services aimed at assessment, relapse prevention and carer support.
- There is a day opportunity for people living with dementia (Hafan Ni) held every Wednesday at Llangoed. Transport can be provided.
- Carers Trust (Crossroads) can provide respite for carers to attend health appointments. This is provided for all of North Wales.
- The Independent Domiciliary Care Sector provide a sitting service in Denbighshire.
- Wrexham County Borough Council has decommissioned its traditional day centre facilities in favour of integrated community based support. The main provider is PSS through a shared days model.
- Many care homes in Wrexham County Borough Council offer day opportunities to individuals where there is no option to access community opportunities.

### **Carer breaks**

Other carer breaks (respite) opportunities that were mentioned are that NEWCIS provide access to carer breaks with Extra Care or a hotel setting for two days for people living in Denbighshire, Flintshire and Wrexham. NEWCIS also offer Bridging the Gap, which offers carers flexible access to 15 to 18 hours of respite over six months in Flintshire and Wrexham.

Flintshire County Council have a Dementia Project Community Worker who will be reviewing respite in the county.

In Anglesey there is a domiciliary care carer's fund, funded by ICF.

Gwynedd and Anglesey are running a pilot shared lives scheme to provide short term and respite services for people living with dementia. If the pilot project is successful it will extend to provide long term care as an alternative option to residential care.

PSS are running the TRIO service in Conwy. TRIO is a unique Shared Lives project to support older people living with dementia to take an active part in their communities with the support of Shared Lives Carers known as TRIO Companions.

Flintshire PSS and their Shared Lives Carers are working with Flintshire County Council to provide alternatives to traditional respite for people living with dementia, including young-onset, and their carers. This is a pilot project running until March 2020.

### **Direct payments / support budgets**

Social Services at your local council can assess, and if eligible, fund some or all of your care needs. The council can provide the service directly to you, or you can receive direct payments or a support budget for you to arrange and pay for care services yourself. More information is available [here](#).

### **Access to services in rural areas**

Many of the services we've identified are theoretically available throughout North Wales, but in practice many place-based services are found in the larger towns, which may be difficult to access for people in more rural areas.

The Wales Audit Office produced a report in 2018 about local government services to rural communities that found 'councils are not yet finding sustainable ways to help rural communities overcome the challenges they face and need to think and act differently'.

Recommendations for how this could be improved were:

- Taking a strategic place based approach based around the work of the Public Services Boards (PSBs).
- Working collaboratively and integrating service delivery, for example by providing multi-service hubs in communities.
- Addressing infrastructure gaps.
- Supporting self-help in rural communities.

## Transport

Transport is key when accessing services, attending appointments and when taking part in day-to-day tasks such as shopping or leisure activities. Anyone with a driving licence who is diagnosed with dementia is required to inform the Driver and Vehicle Licensing Agency of their diagnosis. The Alzheimer's Society states that one in every three people with a dementia diagnosis is still able to drive. The ability to drive safely is what determines if they are able to keep their driving licence. Those with a dementia diagnosis are also required to notify their vehicle insurance provider. Dr James McKillop has written a guide [Driving and Dementia – My Experiences](#).

Transport, or a lack of available public transport options, can be an additional barrier those living in rural areas face when accessing services. The following community transport is available in North Wales. There are gaps in the areas covered:

### Anglesey:

- Mon Community Transport scheme
- Benllech and District Good Turn Scheme
- A Good Turn Scheme Co-ordinator has been appointed and is currently supporting the development of good turn schemes (volunteer car driver schemes in villages) in some areas of Anglesey
- Car Link Môn – volunteer driver scheme operated through Medrwn Môn CVC

### Gwynedd:

- British Red Cross Community Transport Ysbyty Gwynedd
- RVS Volunteer Car Driver Scheme (covers Anglesey and North Gwynedd)
- Cymrod Travel (Pwllheli)
- O Drws i Ddrws (Nefyn)
- Barbara Bws, Tregarth
- Centre for Independent Living de Gwynedd (Porthmadog)
- Bethesda Electric Vehicle Community Car
- pilot community transport scheme in Penygroes (minibus trips out for isolated older people)
- Abergynolwyn Electric Vehicle Community Car
- Freewheelers

### Conwy:

- Conwy Rural Community Car Scheme (managed by CVSC)

- Cerrig Friends (Cerrigydrudion)
- Quarry Village Community Transport (Pemmaenmawr)
- Plas Menai General Practice

#### **Denbighshire:**

- Denbighshire Dial a Ride (North Denbighshire)
- South Denbighshire Community Partnership

#### **Flintshire:**

- Estuary Cars
- Welsh Border Community Transport
- Flintshire Council community bus

#### **Wrexham:**

- Chariotts Wrexham

### **Resources**

Resources available to support people living with dementia include:

- RemPods: Reminiscence Pods are pop up reminiscence rooms that work by turning a care space into a therapeutic and calming environment.
- HUG is a sensory device designed to bring pleasure and comfort to people living with dementia. HUG is designed to be cuddled and has a beating heart within its soft body. HUG can play music that can be easily changed to a favourite playlist.
- [Tovatavel](#): interactive games for people living with dementia.
- Sensory boxes of activities for care home residents with dementia.
- Robotic pets can be used for therapy purposes.
- Dementia friendly equipment, ranging from easy to use music players to assistive technology.

Wrexham County Council are keen to share their experiences of using Rempods and other resources with other providers.

ICF dementia funding is enabling research to bring together the emerging best practice regarding the use of modern technology, apps and devices such as Amazon's "Alexa" units, with a view to producing guidance for the workforce and for families themselves, in relation to what is available and how it can help.

# The need for increased support

## Dementia support workers

There are 8 Alzheimer's Society working across North Wales delivering the one to one support element of Dementia Connect.

- Wrexham – 2 advisors
- Flintshire – 1 advisor
- Denbighshire – 1 advisor
- Conwy – 1 advisor
- Gwynedd – 2 advisors
- Anglesey- 2 advisors

Commissioning for Dementia Connect covers all elements of the service including, telephone support, online support and face to face support. There is a risk that if funding ends in one local authority that the provision will not be available across North Wales as it is now. As with all funding, this is time limited and is not consistent across North Wales which potentially puts services at risk. Much of the income comes from ICF which is due to end in 2021.

## Care homes and home care

A full list of care homes and home care (domiciliary care) providers in North Wales is available on the [Care Inspectorate Wales website](#). Rather than duplicating this, we focussed on specific projects running in care homes or by a care home agency that others may be interested in. These include:

- Dementia skills training for care homes by BCUHB.
- Community mental health teams. These teams are provided by the Mental Health and Learning Disability Division in BCUHB and operate across all six counties. They offer specialist support for people with acute mental health problems as an alternative to hospital admission. They provide support to the care home sector and the scope of that support is under review.
- Llys Elian in Conwy and Garreglwyd in Anglesey have an 'Enhanced Dementia Service Model'
- Gwynedd Council is developing dementia units in residential care home including dementia nurse support and training for dementia care staff. There are currently 3 dementia units completed - Llys Cadfan (Tywyn), Plas Hedd



(Bangor), Plas Hafan (Nefyn) and another 3 in development Bryn Blodau (Llan Ffestiniog), Hafod Mawddach (Barmouth).

- Age Cymru run the [cARTrefi](#) arts in care homes programme. The third phase beginning in September 2019 involves workshops about how to run creative activities in care homes and support to develop a year-long activity plan.
- Intergenerational community development work takes place in some care homes.
- Some care homes have sensory gardens.
- Wrexham County Borough Council has a scheme providing Sensory Boxes of activities for people living with dementia in care homes.

## **Step up step down beds**

Step up step down beds are where patients may be admitted from home as an alternative to acute hospital admission (step up) or be admitted following a hospital stay where they are not yet able to return home (step down). These are available in all counties.

## **Extra care housing**

Flintshire County Council have extra care schemes with 30 dedicated dementia only apartments. Flintshire are also providing additional support for people living with dementia moving into a new extra care facility in Flint.

Denbighshire County Council has worked in partnership with Grwp Cynefin on new extra care schemes in Denbigh and Ruthin. The local DEEP were involved in the design of the facilities to make them dementia friendly.

Work on a new extra care facility, which is due to open in 2022, is currently underway in Anglesey. The facility will include dedicated dementia friendly flats. There are 12 dedicated dementia only apartments at Hafan Cefni ECH in Llangefni.

A third development of extra care housing opened in January 2019 in Gwynedd.

There are two extra care schemes in Wrexham that can accommodate people living with dementia.

Extra care schemes are available in communities in Conwy County Borough.

There is also a piece of research being conducted by colleagues in Conwy's Housing Strategy department and relates to Housing Options, looking at the housing needs of people with dementia.

## **Emergency services**

The fire, police and ambulance services have all committed to:

- Working towards being dementia friendly employers with suitable employment policies and procedures in place to allow us to support colleagues who become carers or those who themselves develop dementia.
- Ensure staff have the necessary awareness, skills and understanding to recognise and support people living with dementia before, during and after an emergency incident.
- Working together and with our local partners to maintain and improve the general safety of people living with dementia, their families and carers.
- Supporting Alzheimer's Society in their quest to develop more dementia friendly communities and Dementia Friends in line with the Prime Minister's Challenge on Dementia and the subsequent duty on all public services.

There may also be times when other services such as Search and Rescue Teams or the Coastguard are involved in an emergency response following a 999 call. **Welsh Ambulance Services NHS Trust**

The Welsh Ambulance Services NHS Trust provide:

- unscheduled care services (emergence and urgent care) to patients ranging from illnesses that are immediately life-threatening to minor injuries;
- non-emergency transport services to help patients get to hospital and medical services; and,
- NHS Direct Wales and 111 services to provide phone and online advice to patients who feel unwell.

As part of the trust's dementia action plan they have implemented a training plan to implement the Good Work Framework as well as actions in other areas of work. The organisation can help better support and identify people with or without a diagnosis of dementia when transporting them to hospital. They can also help to keep people at home and signpost families to different organisations.

## Hospitals

The health board has three specialist acute admissions wards for people living with dementia in Wrexham, Colwyn Bay and Llangefni.

The wards provide a service for those people with high level acute mental health needs alongside their dementia where those needs cannot be met in any other setting.

In North Wales, there are three District General Hospitals and thirteen community hospitals two of which, Llandudno and Holywell, are substantial in scope of services provided. All provide care to people living with dementia and a number of dementia support workers practice across the wards in these hospitals. All three participated in three rounds of the National Dementia Audit and implement the recommendations from that audit.

Mental health liaison services are available to all general hospitals. Emergency departments are working towards becoming increasingly dementia supportive in line with the BCUHB dementia strategy. Ysbyty Gwynedd, Glan Clwyd Hospital and Wrexham Maelor Hospital all have I CAN Centres available at Emergency Departments between the hours of 7pm and 2am. They support people in crisis (including people living with dementia and/or their carers) who present there, but don't require medical treatment or admission to a mental health facility. The service has also recently begun supporting patients and family members who are emotionally distressed on our hospital wards.

There are two Consultant nurses in post to support the dementia care agenda across the health board. Both act as autonomous clinicians delivering expert clinical practice and have academic and research positions. They are involved in developing strategy and leading on a number of clinical initiatives and improvements.

In Gwynedd and Anglesey there are dementia discharge coordinators funded by ICF who facilitate discharge from hospital for people living with dementia. In Gwynedd, there are plans for a pilot project 'enhanced observation for patients', which provides one to one support for patients within community hospitals to maintain the safety of patients and reduce the number of incidents of absconding, wandering and falls and promote activities to enhance recovery .

The [Butterfly scheme](#) is an at-a-glance discreet identification via the Butterfly symbol and is available for hospital patients who have dementia-related memory impairment

and wish staff to be aware of it. All staff who interact with patients are trained to offer a specific five-point targeted response. The Butterfly alerts all staff to the existence of an easy-to-use carer sheet.

## **End of life care**

According to Hospice UK there are three hospices across North Wales (excluding children's hospices). These are:

- Nightingale House Hospice in Wrexham which supports individuals and their families living within Wrexham, Flintshire, East Denbighshire to Barmouth and the border areas.
- St Kentigern Hospice in St Asaph which supports people across North East Wales, taking in Colwyn Bay in the west along the coast to Northop in the East and inland encompassing Mold, Ruthin, Corwen, Denbigh and Llangernyw.
- St David's Hospice in Llandudno which provides hospice care to adult patients across Conwy, Gwynedd and Anglesey.

A 4 bedded Satellite Hospice is being developed at Ysbyty Penrhos Stanley in Holyhead. This will be ready by the summer of 2020.

St Kentigern Hospice has employed an Admiral Nurse since 1 October 2019, jointly funded by the hospice, Dementia UK and BCUHB. The post's remit is to develop education within care homes to support nurses with end of life care for people living with dementia. They also run a Monday medley session for people with early-stage dementia to give access to art therapies and reablement physical therapy.

## **Supporting carers**

The [North Wales Carers' Strategy](#) sets out a vision and offer for carers in North Wales so that individual carers' needs, including language needs, are met in the best way and that carers come to mind as soon as the person cared for. This includes early identification of carers and involving carers in decision making and planning processes.

There is support available for carers of people living with dementia in all six counties as described below. Due to the number of different contracts there may be opportunities to joint commission services between health and local authorities.

Feedback received from the Dementia Engagement Workshop organised by Social Care Wales in North Wales was that it wasn't always possible to find carer support and events outside of standard working hours. For carers who work outside of the home, it meant that accessing the support available to them could be difficult.

### **Across North Wales**

- Carers Trust North Wales Cross Roads are funded by BCUHB to provide a [dementia support service](#) for carers.
- Carers Trust (Crossroads) provide respite for carers
- Hafal provide family support for carers
- Alzheimer's Society's Dementia Connect Service provides support to carers, friends and anyone affected by dementia. They can support the person independently from the person they are caring for. They can meet away from the home and can also make appointments outside working hours as and when needed.
- Alzheimer's Society provide Carer Information Programmes (CrISP) They have two programmes one around information relevant at the initial diagnosis and one for the latest stages. Some of these programmes are delivered in the evening as carers have found that it is easier to attend.
- [Carers Wales](#) gives expert advice, information and support.
- Dementia Carers Count provide free courses for people caring for someone with dementia.

### **Isle of Anglesey**

- Carers Outreach provide carer support, carer awareness and social opportunities.
- Carers emergency support, including 24 hour emergency phonenumber.
- Carer Support Officers based at Ysbyty Gwynedd and in Hergest Ward.

### **Gwynedd**

- Carers Outreach provide carer support, carer awareness and social opportunities.
- Carer support officers are based at Ysbyty Gwynedd

### **Conwy**

- Carers Outreach provide carer support, carer awareness and social opportunities.
- CVSC Support for carers (for example, a mindfulness course)

- Carers Trust (Crossroads) provide a sitting service
- The dementia outreach support team provide support to people living with dementia and their families/carers to remain independent in the community.

### **Denbighshire**

- A Carer support worker is based with the Home Treatment Team
- Health carers worker. Supports all carers to identify their own health needs, including those supporting people living with dementia.
- Working Denbighshire Team: Project to help carers of people living with dementia to move closer to the labour market.
- Carers Trust (Crossroads) provide a sitting service.
- The Independent Domiciliary Care Sector provide a sitting service.
- NEWCIS provide general carers support
- Wellbeing officers (NEWCIS)

### **Flintshire**

- GP Facilitator and Community Hospital Facilitator to support carers within these settings (NEWCIS)
- CHC Development worker that supports carers of people with multiple complex conditions including dementia
- Development workers to complete Carers Needs Assessments and What Matters Assessments
- Respite and well-being support for carers is provided for by the Neuro Therapy Centre
- NEWCIS provide general carers support

### **Wrexham**

- Dementia carer group (NEWCIS)
- Carers Information, Advice, Support & Respite Service (NEWCIS)
- Hafal provide family support for carers

### **Young carers**

There is also support for any young carers of people living with dementia from the following sources:

- Action for Children have a carer support officer based at Ysbyty Gwynedd.
- Barnardo's offer support for young carers in Flintshire.
- Credu provide support in Conwy, Denbighshire and Wrexham.

# Welsh language

Most of the services identified said that they were available in Welsh and English. However, we know that having the capacity and commitment to provide services in Welsh does not necessarily mean that people are receiving services in Welsh without having to ask for them.

The Welsh Language Commissioner and Alzheimer's Society Cymru have carried out research into the care and support services delivered to Welsh speakers with dementia<sup>1</sup>. They found that there is good practice at a local level and that awareness of the Welsh language and the active offer at a strategic level has improved, but that there are many gaps in the care and very few examples where the needs of Welsh-speaking service users are being fully met. The recommendations from the report are included in the background data and information paper [\[add link\]](#) prepared as part of the dementia strategy.

The More than just words forum is a partnership including representatives from the health board, six local authorities, Social Care Wales, the Wales Ambulance Service NHS Trust, Bangor University's School of Healthcare Sciences and Health Education and Improvement Wales (HEIW). It facilitates the implementation of the More than just word strategic framework across North Wales, including sharing information and good practice as well as working on specific challenges and objectives. This includes recruitment challenges and supporting the independent sector to achieve the requirements of the framework.

One example of a project took place at Ysbyty Alltwen, where all Welsh speaking patients were given the option to be able to display a Welsh logo on their bedside, which meant that staff would make every effort to ensure that a Welsh speaking member of the team be present to be able to translate any conversation if required to other staff members.

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<sup>1</sup> Alzheimer's Society Cymru and Welsh Language Commissioner 2018. Welsh Speakers' Dementia Care.

The [Iaith Gwaith](#) brand can be used to identify Welsh speakers when used on badges and lanyards. There are also 'Dysgwyr' lanyards and badges for Welsh learners.



# Appendix 1: Training and development

Training courses available during 2019-20

## Isle of Anglesey

- Dementia awareness and effective communication
- Dementia Champion
- Dementia - Becoming a Butterfly workshop
- Level 2/3 Award In dementia
- Dementia bus
- Working with families of individuals with dementia
- Dementia - Becoming a butterfly workshop
- Dementia Awareness
- Level 2 Health and Social Care
- Level 3 Health and Social Care

## Gwynedd

- Level 3 Award In dementia
- Dementia Friends
- Dementia Jewels
- Preventing distressed reactions to care
- De-escalation in dementia care
- Therapeutic activities in dementia care
- Implementing positive behaviour support plans

## Conwy

- Dementia L3 Award
- Level 2 Health and Social Care
- Level 3 Health and Social Care
- Dementia Friends
- Dementia Champions
- Dementia Bus
- Dementia – Putting Personhood into Professionals Toolkit
- Dementia – Relationship based dementia care and the key worker programme

## Denbighshire

- Dementia and alcohol / drugs (half day)
- De-escalation in Dementia Care

- Nutrition and Hydration in Dementia Care
- Jewels in Dementia Care

## **Flintshire**

- Dementia Awareness

## **Wrexham**

- Best practice in dementia care accredited programme
- Dementia Friends
- Person Centred Dementia Care
- Dementia Awareness
- Dementia interpreter training
- Dementia bus
- Stirling

## **Other courses**

Successful training from previous years that wasn't able to be commissioned for 2019-20 is listed below.

- Awareness of dementia (half day)
- Dementia management for care home managers
- Communication in dementia
- Meaningful activities in dementia care
- Young onset dementia
- Advanced dementia and end of life care
- Dementia and the environment
- Nutrition in dementia care
- Assessment of dementia
- Dementia observation / training days for Extra Care and Residential Care
- Moving and handling workshops for staff and carers supporting citizens with dementia

## Appendix 2: Summary of service mapping

Type of support	Services available	Summary/gaps	Anglesey	Gwynedd	Conwy	Denbighshire	Flintshire	Wrexham
Risk reduction and delaying onset	Public health and other initiatives to support people to take the 'six steps'.	No issues identified for the region.	Available	Available	Available	Available	Available	Available
Raising awareness and understanding	Dementia information databases. Dementia friendly communities. Training and workforce development.	May be some duplication in dementia information databases.	Available	Available	Available	Available	Available	Available
Recognition and identification	GPs	May be a gap as no specific services available and many services require a diagnosis to access.	Partly available	Partly available	Partly available	Partly available	Partly available	Partly available
Assessment and diagnosis	Memory clinics. Advocacy for people undergoing diagnosis.	Maybe some challenges for people in rural areas.	Available	Available	Available	Available	Available	Available
Living well for as long as possible	Advocacy	May be some duplication.	Available	Available	Available	Available	Available	Available
	Community services	A lot of variety, may be gaps but difficult to identify.	Available	Available	Available	Available	Available	Available

Type of support	Services available	Summary/gaps	Anglesey	Gwynedd	Conwy	Denbighshire	Flintshire	Wrexham
	Dementia support service.	Services only available to people diagnosed with dementia after October 2016.	Available	Available	Available	Available	Available	Available
Living well for as long as possible	Support for younger people living with dementia	Available in all counties, although the service offered does vary	Available	Available	Available	Available	Available	Available
	Day care		Available	Available	Available	Available	Available	Available
	Carer breaks	Pilot projects in some areas providing alternative breaks.	Available	Available	Available	Available	Available	Available
	Access to services in rural areas	All rural areas may be affected.	Partly available	Partly available	Partly available	Partly available	Partly available	Partly available
	Transport		Partly available	Partly available	Partly available	Partly available	Partly available	Partly available
Increased support	Dementia support workers		Available	Available	Available	Available	Available	Available
	Care homes and home care	Available in all counties plus specific projects related to dementia.	Available	Available	Available	Available	Available	Available
	Step up step down beds		Available	Available	Available	Available	Available	Available
	Extra care housing		Available	Available	Available	Available	Available	Available

Type of support	Services available	Summary/gaps	Anglesey	Gwynedd	Conwy	Denbighshire	Flintshire	Wrexham
	Hospitals	Specialist acute admissions wards in Wrexham, Colwyn Bay and Anglesey	Available	Available	Available	Available	Available	Available
Supporting carers	Carer support	Available in all counties.	Available	Available	Available	Available	Available	Available