



CYDWEITHREDFA GWELLA GWASANAETHAU
GOFAL A LLESIANT **GOGLEDD CYMRU**

NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

North Wales

Dementia Strategy

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Bwrdd Iechyd Prifysgol
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Introduction

Support for people living with dementia is a priority in the North Wales Regional Plan (Area Plan) based on what people told us was important to them as part of the population assessment.

There is also a legal duty in the Social Services and Well-being Act 2014 for Regional Partnership Boards to prioritise the integration of services in relation to older people with complex needs and long term conditions, including dementia.

The strategy sets out how we will work towards integrated dementia services in North Wales. It has been developed jointly by the six North Wales councils and Betsi Cadwaladr University Health Board (BCUHB) supported by Public Health Wales, Bangor University and other partners.

About the strategy

The strategy focusses on the needs of people living with dementia in North Wales, including people with young onset dementia and people with mild cognitive impairments. It sits alongside other strategies and programmes including:

- [The North Wales Carers Strategy](#)
- [The North Wales Together for Mental Health Strategy](#)
- [The North Wales Learning Disability Strategy](#)
- [BCUHB Dementia Strategy 2018 to 2020](#)
- Ageing Well plans
- [National Institute for Health and Care Excellence \(NICE\) guideline \(NG97\) Dementia: assessment, management and support for people living with dementia and their carers](#)
- [Dementia Action Plan for Wales 2018-2022](#)
- Welsh Language (Wales) Measure 2011

A full list of strategies and legislation that influenced the strategy is in [appendix 1](#).

The welfare benefits system and the way that social care is funded are responsibilities of the UK Government and Welsh Government so are outside the

scope of this strategy, although they do have a significant impact on the well-being of people affected by dementia.

What is dementia?

The term dementia describes symptoms that may include memory loss and difficulties with thinking, problem solving or language. There are many different types of dementia. The most common is Alzheimer's disease but there are other causes such as vascular dementia or dementia with Lewy bodies.

Young onset dementia is where someone is under the age of 65 at the point of diagnosis and affects about 5% of people who have dementia.

Mild cognitive impairment is a decline in mental abilities greater than normal aging but not severe enough to interfere significantly with daily life, so it is not defined as dementia. It affects an estimated 5% to 20% of people aged over 65. Having a mild cognitive impairment increases a person's risk of developing dementia but not everyone with a mild cognitive impairment will develop dementia.

How we wrote the strategy

Background data and information

We used information from the North Wales Population Assessment and updated it for the strategy. We produced a background paper which includes the numbers of people living with dementia in North Wales now and expected in the future as well as data about equality and human rights. It also includes all the references for the statistics and research findings used in this strategy.

Consultation and engagement

We carried out a 15 week consultation (from 1 May to 19 August 2019) to find out what people thought about dementia services in North Wales, what works well, what could be improved and the themes of the strategy. The findings have been written up in a detailed consultation report. We also held an event in November 2019 to share and receive feedback on our findings so far. We have shared a [video of the event presentations and handouts](#) on the regional collaboration website, along with a detailed [event report](#).

Service mapping

We carried out a mapping exercise of the different services in North Wales. This is a snapshot of current services that was combined with other feedback to inform the strategy. The service mapping report includes more details of services summarised in the strategy. Copies of the list of individual services are available on request.

Well-being and equality impact assessment

We carried out a well-being and equality impact assessment on the strategy and updated it at key points in its development. This was to help identify any potential inequalities arising from the development and delivery of the strategy.

The assessment found that if the strategy's aims are achieved, it should have a positive impact on people's health, reduce inequalities and support the development of cohesive communities in North Wales.

It should be noted that any changes to services or new services developed in response to the strategy will need to conduct a separate equality impact assessment.

Governance

The work was overseen by a Dementia Strategy Steering Group that included representatives from the six local councils in North Wales, BCUHB, people with lived experience of dementia and other partner organisations. The steering group reported to the Regional Partnership Board through the North Wales Leadership Group.

The priorities

The strategy is based around the themes of the Welsh Government Dementia Action Plan with the addition of a specific priority for carers. These themes are based on the findings from the consultation.

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 (follow the [5 ways to wellbeing](#)).
- Step 4: Avoid drinking too much alcohol
- Step 5: Stop smoking
- Step 6: Commit to review your health

What we know about the population

Around 52% of adults in North Wales do the recommended 150 minutes of exercise each week, 22% eat five fruit or vegetables each day and around 40% are a healthy weight. Around 18% drink more alcohol than the recommended guidelines and 19% of adults smoke.

More people in North Wales (53%) feel a sense of community than the Wales average (50%) and 16% of adults say they feel lonely. All these risk factors are closely linked with deprivation and other social causes of poor health.

Welsh is spoken across the region with the 2011 census showing, 27% of people aged 65 and over in North Wales speak Welsh. This ranges from 9% in Flintshire and Wrexham to 62% in Gwynedd. This has important implications for planning and delivering equal language provision across the region without Welsh speakers having to request this provision.

There is also a link between hearing loss and increased risk of dementia in adults over 55 years old and research suggests that people who wear a hearing aid for age-related hearing problems maintain better brain function over time than those who have hearing problems but do not seek help for this.

What people have told us

In the consultation people spoke about the following.

- Raise awareness about the risks of dementia and how to reduce them including links between hearing loss and dementia.
- The roles different agencies have in reducing risk including public health.
- More research into the causes and treatment of dementia.

During the Dementia Strategy Event, people also discussed the following:

- Raise awareness over risk factors and improving public health as a whole, including health inequalities, links with other conditions and the environment.
- Clear and consistent messaging across North Wales, linking with wider community, the third sector, volunteers and people affected by dementia.
- More research into links with autism and other conditions and consider how we support multiple conditions.

What we know about services

The six steps outlined above are encouraged to improve health and well-being across the whole population. There is therefore, a wide range of organisations, initiatives and activities across North Wales, which aim to improve public health. These include healthy eating advice, help to stop smoking, drug and alcohol support and exercise schemes. There is also specific support for those living with dementia through the Allied Health Team, who support those newly diagnosed. Their approach is based around the six steps approach.

People with a dementia diagnosis, people with mild cognitive impairment and their carers can access advice via Dementia Connect.

The [Dementia Services Development](#) Centre (DSDC Wales Research Centre) at Bangor University was established in 1999 and has an international reputation for ageing and dementia research, focusing on treatment and care. The DSDC team work closely with older people, people living with dementia and their carers, together with health and social care professionals to ensure our research will make a difference, improve the quality of care and inform policy and practice development.

They undertake a range of activities to support people affected by a dementia including the [North Wales Dementia Network](#).

What we do well

Access to services in the community, including support for carers.
Dementia GO classes in Gwynedd.

What we will do

Action 1: Continue to work with partners to promote and support initiatives to reduce the risk and delay onset of dementia, including links between hearing loss and dementia.

Action 2: Work with partners to support research into the causes and treatment of dementia and encourage participation.

Action 3: Facilitate a sharing practice workshop for health and social care practitioners providing care and support to adults with learning disabilities to scope the need for a regional and preventative approach to dementia early detection, assessment and support for adults with learning disabilities. This will include making links to the 1,000 lives: improving dementia care national programme and exploring links to mainstream services for dementia.

Action 4: Extend support services from just those who are newly diagnosed, so that all with dementia and mild cognitive impairment have access to support, tailored to them, to incorporate the six steps into their daily life.

Raising awareness and understanding

What we know about the population

There are between 10,000 and 11,000 people living with dementia in North Wales and the number is likely to increase as the number of older people in the population increases. Women are more likely to have dementia than men, possibly because they live longer. In North Wales an estimated 6,300 women have dementia and 3,700 men. It is also estimated that 2,700 people living with dementia in North Wales will be Welsh speakers.

What people have told us

Raising awareness, understanding and acceptance is vital.

Consultation participant

In the consultation people said that this was an area where a lot of progress had been made, especially due to the work of dementia friendly communities. They also raised the following.

- Suggestions about how people prefer to be treated and ideas for improving awareness and understanding in specific areas.
- The need to reduce stigma around the condition and to share positive messages about how to live well with dementia.
- Avoid labelling people, treat people as individuals and be considerate about the terms used to describe people.
- Raise awareness of the support available and help people find the information they need at the right time.
- Make sure that the support provided includes the active offer for those that have Welsh as their first or preferred language. The active offer means support is available for people in Welsh, without them having to ask.
- Improve staff training and awareness of dementia and the needs of carers in hospital, care homes, home care services as well as wider public services.

The following was also shared by people who attended the Dementia Strategy event:

- Raise awareness of the services available, and ensure information is shared at the right time, such as an out-of-hours service for crisis points. Information should be available in a variety of formats.
- GP awareness can vary, which delays diagnosis in some instances. Their knowledge of support services also varies.
- More in-depth training for frontline staff, students and care homes who don't specialise in dementia care and staff working with alcohol or drug related dementia.
- Awareness at banks around dementia and Power of Attorney is sometimes lacking.
- Short term funding for projects and support can result in a high turnover of staff.
- Support needs to be available in other languages for some communities.
- Need more of a focus on person centred support and knowing what the person used to do in day-to-day life.
- Support dementia friendly communities.

What we know about services

Information and advice can be found via online databases, such as [Dewis Cymru](#), [Wales Dementia Helpline](#) and the [Alzheimer's Society Dementia Directory](#). Dementia Connect provides many services, including information and advice. Information and support is also available through phone lines, social media and web forums, such as [Friendly Faces](#).

There are many dementia friendly initiatives across North Wales. Communities, organisations and the public sector are working towards becoming dementia friendly.

[Dementia Engagement and Empowerment Project \(DEEP\)](#) groups are part of a national network for people living with dementia who wish to see positive changes. These groups are led by the members and four currently exist in North Wales. Local businesses and community groups have regular dementia friendly sessions across all areas, although some of the smaller groups may not advertise too widely as they are already full.

The Royal Town Planning Institute has produced practice advice on [Dementia and Town Planning](#) to help inform how planning can create better environments for people living with dementia, which will help improve quality of life.

There are initiatives in place to safeguard people living with dementia in the local community. For example the Herbert Protocol, Keep Safe Cymru Card and Safe Places.

Social Care Wales have produced a [dementia resource for care professionals](#) to provide access to essential information, case studies, data and research. Their review of dementia learning and development in 2019 found many different resources, which were largely considered good quality. Improving collaboration and coordination between health and local authorities was recommended, via the Regional Partnership Board. The main sources of funding tend to be short term, which can cause problems with mainstreaming trials. The review identified that there was no effective approach to collect evidence about dementia learning and development and the impact it has. Specific gaps in the material covered by the training were identified. Dementia has been set as a priority area by North Wales training officers group, and these areas should be addressed.

All BCUHB clinical staff who provide direct care on a regular basis to people living with dementia must complete dementia training. All new employees undertake dementia awareness as part of their induction. Dementia friends sessions have been delivered to emergency staff and the Executive Board. Improvements to training courses are on-going and include involvement of a Dementia Strategy Ambassador, a person living with dementia. There is also a specific course covering dementia and end of life care.

Carers of people living with dementia have the right to stay with the person on all adult wards at BCUHB sites (John's Campaign). BCUHB uses Dementia Care Mapping to measure the experience of people living with dementia in care settings.

What we do well

An increased awareness about dementia, particularly because of 'dementia friendly community' schemes.

Dementia learning and training resources have been found to be good quality, North Wales training officers group have dementia as a priority area.

BCUHB leads on development of Dementia Care Mapping across Wales.

What we will do

Action 5: Continue to work towards dementia friendly status for our organisations and our communities.

Action 6: Integrate training between health and social care across North Wales.

Action 7: Continue to deliver dementia training for staff who work with people with dementia on a regular basis so that they meet the standards recommended in the Good Work Framework. Encourage dementia awareness training for all public sector staff.

Action 8: Establish regional learning and development networks to carry out joint commissioning, share information and good practice and establish an approach for assessing how learning and development informs practice. To include training for staff and carers.

Action 9: Develop DEWIS database so that it is easier to use and encourage more services to list what is available and keep it up-to-date. Include support at times of crisis.

Action 10: Have dementia champions based in the GP practice to support and signpost people.

Recognition and identification

What we know about the population

Age is the biggest known risk factor for dementia, rising from 7% of people age 65 to 17% over the age of 80.

People with learning disabilities are more at risk of developing dementia as they get older and people with Down's syndrome are particularly at risk.

Hearing assessment is recommended for all those with suspected dementia as it can mask or exacerbate the symptoms of dementia. An estimated 80% to 90% of those accessing memory assessment services have hearing impairment.

Between 5% to 20% of people aged over 65 have a mild cognitive impairment, which is a decline in mental abilities greater than normal aging but not severe enough to interfere significantly with daily life. Not everyone with a mild cognitive impairment will develop dementia but around 5% to 15% of people each year will.

There is some evidence that people that speak Welsh and English were on average three years older and with greater cognitive impairments when they were assessed in comparison with English speakers accessing services.

International research also suggests that different ethnic groups can have lower rates of diagnosis. Dementia diagnosis should be conducted in a timely way so that the persons needs are understood irrespective of their culture or language requirements.

What people have told us

My friend had a family history of dementia and had been trying to hide symptoms for years without knowing where to go for help.

Consultation participant

Participants in the consultation said that we should:

- Raise awareness of the symptoms of dementia and when to seek help.
- Support people living with dementia to understand and accept their condition.
- Reduce waiting lists for a diagnosis.
- Rule out hearing impairment prior to referral for a dementia diagnosis.

People who attended the Dementia Strategy Event also shared the following:

- Raise awareness to improve early identification, including support for those who have early symptoms to seek help and awareness of different types of dementia.
- Work to erase the stigma around a dementia diagnosis and the care system, for example, by sharing positive stories from a diverse range of cultures.
- Ensure access to support budget or carers support applications.
- Include dementia symptoms into standard health checks at certain ages or life stages and include as a general triage question at emergency departments.

What we know about services

The GP is the first point of contact for many people who think that they be developing dementia. No other specific service to recognise and identify dementia was found in the service mapping.

Some services are only available to people with a formal diagnosis of dementia. Awareness that other services are for people with a mild cognitive impairment or people who are undergoing assessment and diagnosis may be lacking. Early detection for people with learning disabilities and/or Down's syndrome is being developed.

What we do well

Joint working between specific teams and with different organisations.
Beginning to develop early detection screening for dementia with individuals with learning disabilities and Down's syndrome.

What we will do

Action 13: Raise awareness to encourage people who suspect they have early signs of dementia to approach their GP about their symptoms

Action 14: Raise awareness and share positive stories to help with early diagnosis and support, including from English and Welsh speakers and a wide range of communities.

Action 15: Include dementia symptoms into standard health checks at certain ages or life stages and include as a general triage question at emergency departments.

Assessment and diagnosis

What we know about the population

Around 51% of the people estimated to have dementia in North Wales are registered as having a diagnosis of dementia, called the dementia diagnosis rate. That leaves a significant number without a diagnosis. There is also a known problem with collecting the data so not everyone with a diagnosis is counted in the statistics.

Diagnosis rates can vary between different groups due to a lack of appropriate language provision and cultural factors. It's important that people have the opportunity to receive diagnostic tests in the Welsh language.

What people have told us

After diagnosis, sitting down with someone who could explain some of the likely outcomes and what support was available, would have been a great help.

Consultation participant

Some people said that they thought the process of assessment and diagnosis had improved and there was some very positive feedback about people's experiences of memory clinics. Other feedback included the following suggestions.

- Simplify the process of receiving a diagnosis.
- Involve carers in conversations about assessment and diagnosis as well as the individual.
- Provide more support immediately following diagnosis for the person living with dementia and for carers.
- Agencies and teams should work together improve systems and communication so that people don't have to tell their story over and over again.
- Send text reminders for appointments and include photos in letters of the people who will be at the appointment.
- Check in regularly with people who have received a diagnosis so that the right support is in place before there is a crisis.

- Improve the diagnosis of dementia in people with a learning disability.
- The support available should be seamless irrespective of the person's age at diagnosis.

People who attended the Dementia Strategy Event also raised the following:

- Support is needed for those who don't get a diagnosis, for example, a follow up for a review of symptoms.
- Assessment and diagnosis can take a long time. Need to ensure it is person-centred and in the appropriate language for example Welsh or British Sign Language.
- Staffing levels, the approach taken and eligibility criteria is not consistent across the memory clinics. Criteria for referral can be too restrictive.
- Difficult for some carers to get time off to accompany the person for appointments as clinics tend to run 9 to 5. Travel and parking can also be a problem.
- People with a learning disability may need a different setting to a memory clinic for assessment. The standard checks aren't always appropriate and reasonable adjustments may need to be made.
- Information sharing would help with having to repeat the same thing and assist if moving house. A dementia passport may help (similar to Children's Personal Health Record).
- Support is needed to help with accepting the diagnosis.
- Need a LGBT support group and research into how dementia affects this.

What we know about services

Research is currently underway to map challenges and enablers for adults with learning disabilities and their carers, when accessing dementia assessments.

There are seven memory clinics across North Wales. People in rural parts of Northwest Wales are only served by one clinic and may face challenges with travelling there. They may also face challenges accessing Welsh language support.

There is a new project to identify hearing impairment in people with suspected dementia before they are referred to a memory clinic. The project aims to improve accuracy of diagnosis, delay the onset of dementia and improve wellbeing.

What we do well

The assessment and diagnosis process, including memory clinics is now working well.

What we will do

Action 16: Continue to explore options for a new memory clinic or a mobile memory clinic with bilingual staff, which is more accessible to people in rural areas.

Action 17: Implement recommendations from research on mapping the challenges and enablers for adults with learning disabilities and their carers.

Action 18: Continue to develop and roll out projects to identify hearing impairment for people with dementia.

Action 19: Incorporate a better Make Every Contact Count approach to all interactions and interventions, including third sector and non-statutory services.

Action 20: Introduce a user friendly service map/pathway that's co-produced and local and resources to support others following diagnosis.

Action 21: Develop a co-produced set of standards for services.

Action 22: Evaluate the provision of the active offer of Welsh language during assessments and the use of Welsh language assessment for Welsh speakers that require assessment

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

What we know about the population

Although the most people living with dementia are older people, around 5% of people who have dementia are aged under 65, an estimated 520 people in North Wales. The majority, around 410 people, are aged 60 to 65.

One in five people aged 75 and over are living with sight loss and the prevalence is slightly higher among people living with dementia, especially those living in care homes.

Hearing impairment affects the daily lives of 42 per cent of people over 50 years and 71 per cent of over 70 year olds. Using hearing aids can improve communication and wider engagement for people living with dementia.

Lesbian, gay, bisexual and transgender (LGBT) people can face additional challenges when living with dementia. They may be less likely to have family and children to support them and have experienced discrimination that makes them feel unsafe when accessing health and social care.

What people have told us

The 'living as well as possible' is key as socialising and enjoying a range of activities is key to helping keep the disease at bay for longer and helping battle the likelihood of associated depression.

Consultation participant

- Make sure there are a wide variety of activities for people to be involved with so that people can find those that suit them and in the language that they are able to communicate in. This should include different activities for people with early

stage, late stage and young onset dementia as well as support for people with different types of dementia.

- Support people to continue to be involved in their normal activities.
- Make sure communities are inclusive and dementia friendly to reduce loneliness and isolation, including people with learning disabilities and LGBT people.
- Make sure the funding and resources are in place to deliver high quality dementia care services including for the voluntary and community sector and particularly for people with young onset dementia. This also includes the need for good pay and conditions for care staff, challenges around short-term project funding and concerns about the way dementia care is paid for by individuals.
- Make sure people living with dementia and carers are listened to and involved in making decision about their care. Advocacy should be available to help with this.
- Improve access to services particularly in rural areas and for people who don't have access to transport.
- Improve coordination between different teams and agencies so that individuals receive a seamless service.
- Improve consistency of services available across North Wales.
- Improve staff continuity.
- Provide support for people with a mild cognitive impairment who don't have a diagnosis of dementia.
- Improve support for the physical health needs of people living with dementia.
- Adapt the built environment to make places accessible to people living with dementia and to support people to live longer at home. This includes better adapted existing homes, purpose built new homes and developing intergenerational spaces and connected communities.
- Promote the role of assistive technology and telecare.
- Look at support that meet the linguistic needs of the person.

People who attended the Dementia Strategy event also raised the following:

- The 'living well' approach was supported, including the work to reduce stigma and normalise dementia. The focus on supporting what the individual person wants and likes to do is seen as a positive.
- Providing opportunities for volunteering and supporting people affected by dementia with employment.

- Suggestions for ways to improve support for hearing loss and dementia included hearing loss champions, sign language courses and Makaton could be introduced.
- Improve consistency around access to medication, therapeutic interventions and resources such as hug toys and gym for health.
- Short term projects, with no follow on or continuation can have a detrimental impact.
- Social isolation a problem across all communities, not just rural areas, because of transport, forgetting dates and the group not being inclusive of dementia.
- Support services for cancer are seen as a good example.

What we know about services

The Alzheimer's Society provides advocacy across all of North Wales for people who are undergoing a diagnosis, or are already diagnosed with dementia. Further advocacy services are provided by Age Cymru, North Wales Advice and Advocacy Service, Advocacy Services North East Wales and Dewis Centre for Independent Living. Mental Health Matters Wales and BCUHB provide specialist advocacy services for people who lack mental capacity.

There is a wide range of services available for people in their local community. These include hobby based activities, befriending services, support groups, exercise classes and local businesses with dementia friendly initiatives. The offer varies across communities in response to local needs, and so it is difficult to assess if there are gaps in coverage. The strategy will therefore focus on creating the right conditions for these groups and services to develop in local areas.

Carers Trust North Wales Cross Roads provide a dementia support service across North Wales for those with a diagnosis of dementia after October 2016, funded by BCUHB. Alzheimer's Society Cymru and local charity based initiatives provide support for those with a diagnosis prior to this, however, the service provided may not be consistent across North Wales.

Support for people with younger onset dementia is available across North Wales, but the type of support is different in each county as services have developed to meet

local needs. There may be opportunities to standardise, share good practice and different ways of working between these services.

Day care, day opportunities and carer breaks are provided in various settings provided by local authorities, care homes and BCUHB. There are also opportunities for carer breaks, which vary by local authority area.

There are various resources available to support people living with dementia. These include Reminiscence Pods, the HUG sensory device, interactive games, sensory boxes, robotic pets and dementia friendly equipment.

Living in rural areas can mean that services are difficult to access, as they tend to be found in larger towns. The Wales Audit Office has found that councils are not yet finding sustainable ways to help rural communities overcome these challenges, which should build on the strengths within those communities.

Access to transport can affect whether a person can access a service or not. The Alzheimer's Society states that one in every three people with a dementia diagnosis is still able to drive. The Driver and Vehicle Licensing Agency and insurance providers should be notified. Community transport is available in many areas, but there are gaps in the service provided.

What we do well

Specialist nurses to support people with young onset dementia and people with learning disabilities who have onset of dementia.

The focus on 'living well' and supporting people to do what they enjoy as an individual.

Linking hearing loss and dementia.

BCUHB have developed [Supporting me to be the person I want to be](#), a guide to understanding, reflecting and responding to transgender issues in dementia care.

The growth in intergenerational work is also positive with some counties employing officers to facilitate links across the generations

What we will do

Action 23: Promote dementia friendly communities and initiatives

Action 24: Look at options for extending the BCUHB funded dementia support service for people who were diagnosed with dementia before October 2016. and raise awareness of the other services that are available to support people living with dementia.

Action 25: Improve consistency of services for younger onset dementia, including support for people with learning disabilities, across North Wales and share good practice.

Action 26: Consider options for improving access to services in the rural area, including promote existing community transport schemes and working with transport planners, providers and people affected by dementia to make sure services are more inclusive of people living with dementia.

The need for increased support

What we know about the population

People living with dementia may have other conditions which need equivalent access to diagnosis, treatment and care as people who do not have dementia. This can include pain, falls, diabetes and incontinence. People living with dementia who are admitted to hospital have an increased risk of delirium and will need an assessment that balances their current medical needs with the additional harms they may face in hospital.

What people told us

- The importance of home care to help people remain at home. Care should be flexible, person-centred with consistency and continuity of highly-trained staff. Need support to recognise when home care is no longer appropriate and consider other options.
- Care homes should have sufficient staffing and person-centred care, including care for people in distress and in an emergency.
- Improve support in an emergency and in hospital emergency departments.
- Improve support for hospital in-patients and dementia friendly wards.
- Improve support for people when leaving hospital, including finding appropriate residential or nursing accommodation.
- Make sure Welsh language support is available throughout the journey with dementia.
- Improve safeguarding of people living with dementia including around postal scams and using recommended tradespeople.
- Care for people in the later stages of dementia and improve planning for individuals and carers around this. This includes access to good quality residential care, emergency hospital care, palliative care, end of life care and bereavement support.

The following areas were also raised by those who attended the Dementia Strategy Event:

- People with younger onset dementia couldn't always access an age appropriate placement in a care home.
- Need rural provision as problems in accessing services in rural areas are wider than just transport.
- Inconsistent policies across GP practices for anti-dementia medication.
- Support needed to make sure Lifetime Power of Attorney is planned for and support for carers through the whole journey and with bereavement.
- Improve process around inappropriate assessments for care home placements, including a phased introduction by beginning with day services.
- Need longer home care visits.
- Issues around care staff retention and re-training.
- Day services won't always accept referrals if personal care is needed, which can be required in late stage dementia.
- Support needs to be collaborative, working with the person's views and understanding that language of support is not a choice but a clinical need.

Liberty Protection Safeguards and advanced care planning

The issue of Power of Attorney and Deprivation of Liberty Safeguards (DoLS) (will become Liberty Protection Safeguards from October 2020) is a subject area that was raised by various people in different contexts during the preparation of this strategy.

The NICE guidelines for dementia recommend early and ongoing opportunities for people living with dementia and their carers are given regarding lasting power of attorney and preparing an advance statement about their wishes, preferences, beliefs and future care.

People with advanced dementia are likely to require the protection of the DoLS. Every person who is deprived of their liberty is entitled to a relevant person's representative, who is consulted and informed about matters relating to their care or treatment, including making decisions on their behalf. The Department for Health has produced a guide on this, although it should be noted that this will be replaced with new guidance in October 2020.

What we know about services

There are dementia support workers across all of North Wales. The Care Inspectorate Wales website provides details of care homes and home care in North Wales. Some of these provide specialised dementia care. BCUHB provide training for care homes.

Step up step down beds, where patients are admitted from home as an alternative to acute hospital admissions, or are admitted following a hospital stay when they are not yet ready to return home, are available across North Wales. Some areas provide dedicated extra care beds for people living with dementia.

The fire, police and ambulance services have committed to working towards being dementia friendly employers and ensure staff have awareness, skills and understanding to support people living with dementia. Emergency departments are working towards becoming dementia friendly.

BCUHB has three acute admissions wards for people with dementia covering all of North Wales. These are for patients with a high level need, which cannot be met in other settings. The three district General Hospitals and thirteen community hospitals all provide care to people living with dementia. Dementia support workers practice across all hospitals. In addition, two consultant nurses support the dementia care agenda across BCUHB. Dementia discharge coordinators work in Gwynedd and Anglesey.

There are three hospices in North Wales: Nightingale House in Wrexham, St Kentigern in St Asaph and St David's in Llandudno. St Kentigern employs an Admiral Nurse to help with end of life care for people with dementia.

Feedback from various sources during the production of this strategy emphasised how important it was to provide a service in Welsh. One example of a project which could be rolled out across North Wales, 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.

The Older People's Commissioner for Wales has published a report *Dementia: more than just memory loss*, which details the experiences of people living with dementia and those who care for them. The report concluded that improvements could be made and a [checklist of recommendations](#) has been published. The Welsh Language Commissioner and the Alzheimer's Society have also published a report on [Welsh Speakers Dementia Care](#) including 15 recommendations.

BCUHB employs Dementia Social Care Practitioners who link in with people living with dementia and their carers to look at alternatives to admission to nursing homes. There are various case studies, where additional support and trialling new things has meant that the person with dementia has not needed to move into a new setting.

What we do well

Dementia Social Care Practitioner work across North Wales

What we will do

Action 27: Work with emergency services to support people affected by dementia

Action 28: Encourage community and health services work together so people with dementia are less likely to need to go to hospital. For example, by providing some treatments at home.

Action 29: Support care homes to improve awareness to meet specific individual needs of people with dementia and improve commissioning of appropriate placements.

Action 30: Commit to support people with dementia attending Emergency Departments. For example, providing a quiet room or 'bus stop' and try to make them feel as comfortable as possible.

Supporting carers

What we know about the population

It is estimated that of the cost of health and social care overall for people with dementia, 16% is for healthcare, 39% for social care and 44% for unpaid care. For the two-thirds people with dementia who live in the community, the percentage cost of unpaid care is 75%.

The population assessment identified that around 73,000 people provide unpaid care in North Wales, about 11% of the population and the number of carers is increasing. People aged 50 to 64 are the most likely to provide unpaid care. Around half of all carers are in employment and 30% of carers are retired.

Between 60% and 70% of all unpaid dementia carers are women and there are 2.5 times more women than men who provide intensive on-duty care for someone 24-hours a day. They are also 2.3 times more likely than men to have been providing care to someone with dementia for more than five years and therefore make up a large portion of the carers who are supporting someone with advanced dementia.

NICE (2018) recommend informal carers of people living with dementia should be offered training and psychoeducation to help them develop care skills and manage their own physical and mental health.

Action area 5 of the World Health Organisation's public health response to dementia recommends access to affordable, evidence-based online technologies for education, skills training and support.

What people have told us

There is an increasing need for those who care and support individuals affected by dementia, especially for daily advice and comfort.

Consultation participant

- More carer breaks, especially for carers of people in the later stages of dementia.

- Need a variety of different types of breaks and flexibility to meet the individual needs of the care and the person they care for. For example, some people want support in the home, support to spend time together or time apart.
- Provide emergency or crisis care, for example if the carer goes into hospital and support with planning for this.
- Carer training and advice, including someone to talk to and ask questions of particularly out of hours such as a helpline. Peer support from other carers can be very helpful.
- Improved awareness around Lasting Power of Attorney as well as concerns about the cost and the lack of a system to check everything is in place.
- Employer support for staff with caring responsibilities.
- Support for carers with feelings of loss after diagnosis and following bereavement.

Participants who attended the Dementia Strategy Event also raised:

- Need to consider individual circumstances of each carer before providing support to ensure it is appropriate. This should be throughout the whole experience with dementia, including pre and post bereavement. Need to make sure that they don't feel abandoned with the assumed role of caring.
- Need services to be well advertised and ensure carers, agencies and staff are aware of services available.
- Financial concerns and problems with carers allowance and thresholds not increasing with wages and inflation.
- Many people don't see themselves as carers but as husband, wife, son, daughter, friends, family or supporters. They also need to know the importance of a carers assessment to support them as a family.
- More support for young carers.
- Dementia friendly employers and offering flexible hours to carers.
- Include carers in patients' medical care, including appointment details and prescriptions, taking into account issues around consent.
- More access to care at short notice.
- Carer break (respite) provision needs to take account of the challenges in rural locations as travel to and back home to the bank alone may now take 2 hours with no time for other activities such as shopping or 'respite'.

What we know about services

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 with dementia across North Wales. Feedback suggests that the services provided are not always available at times that are accessible to carers who work outside the home. There is also specific provision for young carers. Due to the number of different contracts there may be opportunities to joint commission services between health and local authorities.

Many services are available in Welsh and English, however, it is not clear if having the capacity and commitment to provide the services, means that service users are not having to ask for a Welsh language service. Research has found that there is good practice, but there are gaps in care, and on the whole, the needs of Welsh speaking service users are not fully met. This needs to be addressed in order to achieve the rights of Welsh speakers to receive services in the language of their choice and to improve individual's well-being and outcomes.

The More than just words strategic framework is being implemented across North Wales led by the North Wales More than Just Words Forum. This includes sharing information and good practice and working toward specific challenges and objectives.

What we do well

'Coping with caring and loss' initiative in the West region of North Wales

What we will do

Action 31: Joint commission services wherever possible

Action 32: Continue to promote the active offer of Welsh language services, implement the strategic framework across North Wales and recommendations from research.

Action 33: Promote successful new initiatives such as 'coping with caring and loss', currently led by Psychology in the West.

Putting the strategy into action

Developing the strategy has highlighted that a lot of activity is already taking place under each of these themes, some of this is organised by very local groups and a lot takes place at local authority level. Much of this activity is already collated regionally twice a year in the Dementia Action Plan report to Welsh Government.

We propose adding an additional self-assessment checklist to the Dementia Action Plan report for each local authority and BCUHB to report on their progress against the specific actions and recommendations developed in this strategy. This will be developed jointly with partners to try to simplify and reduce overall reporting demands. It will also provide an opportunity to incorporate relevant recommendations from other reports such as those from the Older People's Commissioner and Welsh Language Commissioner.

All the reports produced to inform the strategy, including the background information paper, consultation reports and the service mapping report will be made available on the regional collaboration website. This will provide evidence to support decision making by commissioners and service providers about dementia support services in North Wales. It will also provide the evidence needed if additional grant funding comes to the region, such as further Integrated Care Fund (ICF) funding.

Governance and monitoring

The North Wales Dementia Strategy Steering Group will continue to oversee the implementation of the strategy. The group will meet at least twice a year following the production of the Dementia Action Plan report so they have the opportunity to address any issues highlighted. They will also lead on any regional projects developed in response to the strategy, facilitate the sharing of good practice across the region and identify funding to support the steering group and other regional projects.

Appendix 1: Strategies and legislation

- A Healthier Wales
- Ageing Well plans
- Alzheimer’s Society and Welsh Language Commissioner: Welsh Speaker’s Dementia care (2018).
- Article 27 1966 International Covenant on Civil and Political Rights Connected Communities: A strategy for tackling loneliness and social isolation and building stronger social connections 2020
- BCUHB action plans being developed in response to the HASCAS and Ockenden reports.
- BCUHB Dementia Strategy 2018-2020
- Care Homes for Older People: North Wales Market Shaping Statement 2018
- Equality Act 2010
- Human Rights Act 1998
- Integrated Care Fund (ICF) Revenue Investment Action Plan to deliver the Dementia Action Plan for Wales 2018-2022.
- Mental capacity act 2005: deprivation of liberty safeguards
- National Assembly for Wales Research Service (18-017) (2018). [Research Briefing: Access to dementia services for bilingual \(Welsh and English\) residents.](#)
- National Institute for Health and Care Excellence (NICE) guidance quality standard 50 Mental wellbeing of older people in care homes
- National Institute for Health and Care Excellence (NICE) guidance quality standard 123 Home care for older people
- National Institute for Health and Care Excellence (NICE) guidance quality standard 184 Dementia
- National Institute for Health and Care Excellence (NICE) guidance quality standard 187 Learning disability: care and support of earning disability: care and support of people growing older people growing older
- National Institute for Health and Care Excellence (NICE) guideline (NG97) Dementia: assessment, management and support for people living with dementia and their carers

- North Wales Carers' Strategy
- North Wales Learning Disability Strategy
- North Wales Workforce Strategy
- Older people's Commissioner for Wales: Dementia more than just memory loss
- Social Services and Well-being (Wales) Act 2014
- The North Wales Regional Partnership Board plan to deliver Healthier Wales (transformation programme)
- The Social Care Wales commissioned overview of dementia learning and training across Wales
- UN Principles for Older Persons (UNPOP): there are 18 principles which can be grouped under five themes: independence, participation, care, self-fulfilment and dignity.
- Well-being of Future Generations (Wales) Act 2015
- Welsh Government Dementia action plan 2018-2020
- Welsh Language (Wales) Measure 2011