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NORTH WALES SOCIAL CARE AND WELL-BEING
SERVICES IMPROVEMENT COLLABORATIVE

North Wales Dementia Strategy Event

21 November 2019 at Theatr Clwyd

Summary

Around 150 people attended the dementia strategy event at Theatr Clwyd on 21 November. The event began with a presentation by Lesley Singleton which summed up the work on the strategy so far. This included findings from background research and data, consultation and service mapping.

The participants then split into groups of around 10 people on a table based on the three themes of the strategy that they were most interested in.

- Risk reduction and delaying onset
- Raising awareness and understanding
- Recognition and identification
- Assessment and diagnosis
- Living as well as possible for as long as possible with dementia
- The need for increased support
- Support for carers

Most groups had a mix of local authority and health staff, independent and third sector providers, researchers and people affected by dementia. The groups took part in three workshops, each looking at one of the themes. They discussed whether anything was missing from the findings so far, the services available and whether they were good enough. They also considered what actions and recommendations should be included in the strategy.

Some of the key findings were that as part of the strategy we need to:

- Work together to provide more consistent and flexible support for people affected by dementia across North Wales and to share good practice.

- Improve joint working between services in local areas, including better information sharing so people don't have to repeat their story. Consider 'dementia hubs' where people can access all the support they need.
- Focus on 'what matters' to individuals and provide person-centred care.
- Help improve the quality of information and promote information about the services available at the right time and in a format that's useful to people. There's a role for community navigators to help with this.
- Continue to raise awareness about dementia including risk reduction, identifying signs and symptoms and how to support people affected by dementia.
- Raise awareness of identification schemes (such as the hidden disabilities lanyards) and look at possibilities to streamline schemes or promote the differences.
- Make sure information, assessments and support is accessible to all groups, including in Welsh and English, to people with sensory impairments and people with learning disabilities.
- Improve support for carers. Support needs to be flexible and based around 'what matters' to the carer and the person that they support. It should include training for carers.

During the breaks there were stands to showcase some of the good work taking place in North Wales, which provided a great opportunity for participants to network and share ideas.

The findings from the event will be included in the final version of the North Wales Dementia Strategy.

About the event

The event was part of the consultation on the dementia strategy which also included:

- An online survey open from May to August 2018 along with paper and EasyRead versions.
- Group and individual interviews with people living with dementia and carers carried out by the Citizen's Panel.
- Reviewing consultation findings from the North Wales Population Assessment and other local consultations.

The purpose of the day was to share the highlights from the strategy work so far and to check whether anything was missing as well as to work together to develop actions and recommendations for the strategy to take forward.

The invitation was circulated by the dementia strategy steering group, shared with the dementia strategy mailing list and everyone who had taken part in the consultation to date as well as being shared on the regional collaboration website. Attendance was managed to make sure there was a mix of local authority and health staff, independent and third sector providers and people affected by dementia.

There were around 150 people who attended on the day. The event was filmed and the video shared on the website along with a transcript of the presentation and handouts. This was then shared with people who weren't able to attend so that they also had an opportunity to comment.

Introduction

Lesley Singleton, Director of Partnerships in the Mental Health and Learning Disabilities Division of Betsi Cadwaladr University Health Board (BCUHB) introduced the event and a summary of the findings so far from the work on the strategy including background research and data, consultation and service mapping. The presentation can be viewed along with a transcript on the regional collaboration website.

The participants then split into groups of around 10 people on a table based on the three themes of the strategy that they were most interested in.

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- Raising awareness and understanding
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- Living as well as possible for as long as possible with dementia
- The need for increased support
- Support for carers

Most groups had a mix of local authority and health staff, independent and third sector providers, researchers and people affected by dementia. Three of the groups worked through the medium of Welsh. The groups took part in three workshops, each looking at one of the themes. They discussed whether anything was missing from the findings so far, the services available and whether they were good enough and what actions and recommendations should be included in the strategy.

During the breaks there were stands to showcase some of the good work taking place in North Wales, which provided a great opportunity for participants to network and share ideas.

Event findings

The event provided a lot of support for the main themes in the strategy and additional information and ideas to include. This is summarised below along with pictures of the handouts used to introduce each theme. An accessible version of the handouts can be downloaded from the regional collaboration website.

The handouts provided a summary of the information gathered so far. These are based on the following full reports which will be shared as appendices to the final strategy. The reports will be updated based on the findings from the event. Draft versions are available on request.

- Background data and information: includes more detail and references for all the statistics used in the handouts.
- Consultation report: includes a detailed analysis of the findings from the online survey and workshops held so far.
- Service mapping: a detailed spreadsheet of all the services people have submitted information about to date and a draft report analysing this data and making recommendations about where there may be gaps in services or opportunities for services to work better together.

Overall

- One of the main themes was the need for joint working and providing consistent and flexible services across North Wales. This included better co-ordination between services, joint commissioning, and developing a shared language for services. One advantage highlighted of cross-border services is that friends who live in different counties can do the same activity together. The idea of a dementia hub came up in many of the different conversations as a way to bring together the different services.
- Involve the person with dementia and carer whenever a decision is being made. Take a person-centred, individualised and ‘what matters’ approach.
- Make stronger links to emerging research and innovation and share good practice across North Wales. Consider making more money available for innovation and trying different approaches to service delivery. Also need funding to continue pilot projects that have been evaluated as effective and a way to make sure we capture learning from these.
- Need commitment to change how we work and learn from each other.
- The Dementia Strategy will need to link with other areas and improve joint working across services such as the mental health strategy, Ageing Well and learning disability services. This can include learning from other services such as mental health and learning disabilities around social prescribing.

Risk reduction and delaying onset

What stories did people share?

- More people need to know about the link between health inequalities and dementia. Risk reduction in dementia also links to other risk reductions in other conditions. Don't look at 'risk factors' in isolation. Need more focus on the environment and the impact this can have.
- Need consistent messaging across North Wales around reducing risk, clear and simple. Need to reflect culture in the advice we provide, for example farming culture and work with National Farmers Union and Young Farmers. Work with young people around education and preventative solutions, such as giving up smoking or drinking. Include third sector partners and volunteers in promoting positive health messaging. Information to be shared with friends, family and support systems around the individual. Link with the work of '1000 lives' and other mainstream campaigns.
- Platforms need to be available for information to 'come to you' rather than something that needs to be actively sought – who would actually do this based on a 'small' concern?
- People should have informed choices.

- Need more research into links with autism and other conditions and also to consider how we support multiple conditions and assess priority of need.
- These changes are also important to make after diagnosis and post-diagnosis is a vital time to promote positive health.
- Recognise cognitive reserve and early diagnosis as points to reduce risk. Cognitive reserve about is people's ability to cope with changes in their brain due to ageing, disease or brain injury and lifetime experiences may help to build this cognitive reserve such education, having an engaging occupation and stimulating leisure activities, learning and social interactions.
- Need to explain what 'commit to review your health' means in the 6 steps [the more detailed 6 steps leaflet includes steps to reduce your risk of high blood pressure, heart disease and diabetes and using the 'Add to your Life' online health check].
- Need to be careful not to give the impression that avoiding these risks factors will avoid the risk of developing dementia completely or to develop a culture where people think they are to blame for not following the 'six steps' if they do develop dementia.

What other support is available?

- Genetic testing and counselling
- Well-being services
- Cognitive rehabilitation
- Cognitive stimulation
- GP screening and referral and signposting to other services.
- Dementia Friendly Steering Group

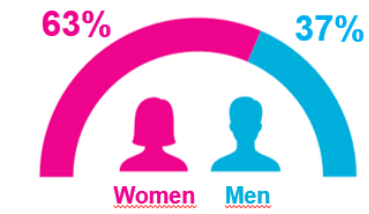
Actions and recommendations

- Consider forums, regional or sub regional to share how people are working across North Wales.

Raising awareness and understanding

What we found out

10,000 people live with dementia in North Wales



Raising awareness, understanding and acceptance is vital

Consultation participant

What people have told us

- Awareness is improving, largely thanks to dementia friendly communities.
- Need to share ideas for improving awareness and understanding.
- 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.
- 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.

Support available

- Online advice and information: Dewis Cymru, Wales Dementia Helpline, Alzheimer's Society Dementia Directory.
- Dementia friendly communities.
- Reading Well Books on Prescription.
- DEEP (Dementia Engagement and Empowerment Project).
- Safeguarding in the community: The Herbert Protocol; Keep Safe Cymru Card; Safe Places; John's Campaign (in hospitals).
- Training and workforce development: Good Work Framework; Dementia Resource for Care Professionals; Social Care Wales Review; BCUHB 'skilled' training is jointly delivered with people with dementia and carers.

What stories did people share?

- There's a real need for information about the services available at the right time and support for an online database to do this. Some feedback around DEWIS said that it's complicated to use, goes quickly out of date and tends to only be used by practitioners. There's also a need for information at a crisis point, such as out of hours services and response locally. Information also needs to be accessible to people with sensory impairments and in different languages. Suggest a dementia app. Paper copies and other ways of accessing information are needed for people who don't have access to the internet or information stands in hospitals like Macmillan do for cancer information. Need a way of quality assuring the services that are available. Improve understanding on how to access translation. Avoid jargon and abbreviations.
- Participants said the awareness of GPs around dementia varies. Some said the first response is often 'it's just age' and people have to go repeatedly to be heard. Too many GPs in Wrexham are locums. An Occupational Therapist commented that a GP was shocked at how impaired their patient is, once they meet with the Occupational Therapist, when the carer had been trying to get an assessment for a year. Participants also said GPs knowledge of the services available also varied, and suggested having someone in the GP practice that could support or

signpost people and/or a dementia hub. Some GPs have information up on the wall but often not a dementia friendly environment and it's easy for them to focus on physical needs. Lots of people are diagnosed with depression and hearing impairments. They need support. Is dementia training built into ongoing Continuing Professional Development of GPs? Not waiting for crisis point to introduce measures such as a new check or routine.

- More training and qualifications should be available to frontline staff and this should be more than a 30 minute online course and include information about how to help and to identify the main symptoms and warning signs. Training to students about how to ask questions on wards to avoid people just answering 'no' and make sure they have experience on dementia wards. Continuing professional development such as call taking competencies, advanced competence, social care workforce registration. Community of scholars.
- Sometimes families have concerns that care is not being delivered, when it is, but the patient can't remember it.
- Banks can lack awareness around dementia as they don't let families assist before they get a Power of Attorney.
- Library drop-ins are often accessed by people that they are not necessarily aimed at, for example, there are a lot of housing and drug and alcohol problems.
- Much of the funding for projects is short-term which can lead to high rates of staff turnover.
- Need to make sure there is enough support available in Welsh including encouraging Welsh speaking volunteers and recognising the informal community-based support available. Take a person-centred approach.
- There's a need for support in languages other than English and Welsh, for example, for the Polish and Portuguese communities in Wrexham. Also to raise awareness among different ethnic minority groups where awareness is known to be low.
- The importance of knowing what people used to do, for example, people who used to be farmers waking up at 3am every day wanting to bring the animals in or people who used to be cleaners being calmed by being given some cleaning to help with.
- Not everyone wants to use a lanyard / wristband system.
- Dementia connect – advertising on radio Heart/Smooth, independent pharmaceutical bags.

- Need more focus on person centred support and early engagement with those who know, such as the hospital.
- Lack of knowledge about supporting people with alcohol or drug related dementia, which means staff supporting client groups at high risk may not be accessing dementia specific training.
- Support local communities to be dementia friendly communities. Opportunities for raising awareness included with the workforce, mental health awareness campaigns, school campaigns, challenging assumptions, helping identify dementia and recognising it as a long-term conditions, retail sector. Challenges around capacity and pressures on workforce. The challenges of self-service machines in shops. Suggestions include 'take your time' line in shops like Tesco. Using free press and hospital radio to raise awareness.
- May be a role for Dementia Friendly Steering Groups to do more although they need more people to meet demand and resource for people to raise awareness and recognition. It's not all about funding, it's about getting it right.
- Dementia Friendly Singapore initiative
- Raise awareness with care homes that don't specialise in dementia around understanding the condition and how to live well with it.
- Encourage people to write down questions before appointments.

What other support is available?

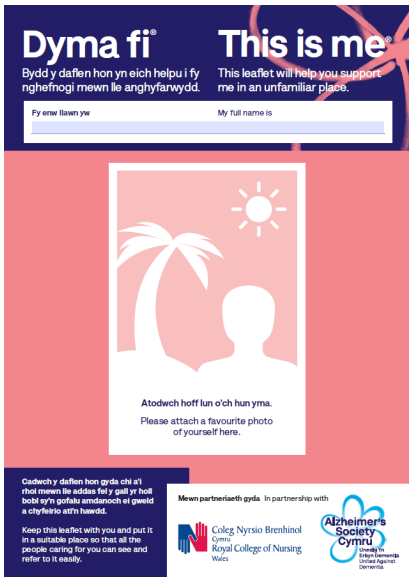
- Hidden disability lanyards (a green lanyard with a pattern of sunflowers). These are available free from M&S/Sainsbury's for use around store (Tesco's from December 2019) or can order in bulk online. They are used in airports, trains and buses. Also recognised in the US.

- Butterfly scheme: At-a-glance discreet identification via the Butterfly symbol 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.

- Forget-me-nots (blue flower badges): these pins are worn to raise awareness and support for people affected by dementia, rather than as a symbol that the person wearing it has dementia (unlike the hidden disability lanyard and butterfly scheme).

- There is a dementia lead in Emergency Departments and training for emergency staff (two-day course and reflective piece).
- Peer support, training and advice such as Friendly Faces and work by Chris, Jane and Theresa.
- Hynt Card: national access scheme to theatres and arts centres in Wales.
- This is me is a leaflet that people with dementia can use to share details about themselves. This is becoming used more widely, for example, the Red Cross completing it with people in the Emergency Department, some people arrive at hospital with one already completed and people are encouraging families/care homes to keep a copy on hand to use if needed.



- Examples of good practice by supermarkets: Sainsbury's work with local taxi company's so people can shop and then have a taxi ordered. Tesco's in Denbighshire have a dementia friendly aisle and graphics of currency.
- Community navigators can help people find out about and access the services available in communities. Examples include Age Connect, Social Services, Talking Points in Denbighshire, Community Well-being Team (soon to be the Staying Well Team) in Conwy, Red Cross and library drop-ins with Dementia Social Care Practitioners. Local Voluntary Councils across North Wales (Medrwn Môn, Mantell Gwynedd, CVSC, DVSC, FLVC and AVOW can all help signpost people to community services. One group commented on how this role was often called different things in each county and suggested it would be better to have the same named group or team across North Wales.
- Community Resource Teams and other co-located teams can bring together staff including nurses, occupational therapists and physiotherapists in one place, which can help provide a better understanding of each other's' roles and a really good service.
- The laith 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.

- Theatr Clwyd show a film in the cinema once a month especially for people living with dementia and their carers. Colwyn Bay Theatre also runs dementia friendly screenings.
- RNIB: support with making information accessible
- Patsy Pope 'All about dementia' training and consultancy.

Actions and recommendations

- Promote the use of identification schemes, such as the hidden disability lanyards and 'This is me' leaflets. Consider taking part in a national campaign and using hidden disability lanyards in hospitals and emergency departments.

- Look at streamlining the number of identification schemes and/or promoting the differences between the schemes more clearly.
- Improve the information available on online databases about support available for people with dementia, including at times of crisis. Suggestions included working with third sector organisations, such as Age Connect, and funding a permanent post to collate and keep information up to date and who is known to the community, practitioners and third sector.
- Raise awareness for everyone about the need to consider their end of life wishes in case they develop dementia during their life.

Recognition and identification

What we found out

One in 15 people **age 65** and over have dementia

One in 6 people **age 80** and over have dementia

- Age is the biggest known risk factor for dementia.
- People with learning disabilities (particularly Down's Syndrome) are more at risk.
- Between 5% to 20% of people aged over 65 have a mild cognitive impairment.
- Diagnosis rates vary between ethnic groups.

What people have told us

- Raise awareness of the symptoms of dementia and when to seek help.
- Support people 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.

> 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

Support available

- GPs are the first point of contact for many people.
- Many services are only available to people with a diagnosis, and not to people who have a mild cognitive impairment and/or are going through the process of assessment and diagnosis.
- Some areas in North Wales carry out early detection screening for dementia with individuals with learning disabilities and Down's Syndrome.

Dementia Action Plan

Welsh Government want people to:

- be aware of the early signs of dementia;
- understand the importance of timely diagnosis; and,
- know where to get help.

What stories did people share?

- There's a need for early identification and participants were asking how to promote the signs to look out for in people and the challenges of when the symptoms are masked. The changes may be subtle and difficult for families and communities to identify. Support people to admit to symptoms as well as raising awareness.
- Need to erase the stigma to support people to discuss it and seek support. People are afraid a diagnosis means "you're useless". Empower individuals to seek early diagnosis.
- People said "I knew there was something wrong", "Tendency to disguise symptoms", "We get on with it".
- Think about different ways of getting the message across such as co-production and social media. Making every contact count and gathering information from different sectors to form a story.
- Provide information for carers, permission around grieving process and time, telling stories.
- Making sure people have access to a support budget or carers support application.

- There can be pressure on older grandchildren who are expected to take on the caring role but might not be receiving the available support for carers or welfare benefits.
- People sometimes stop providing care/support once they realise there are support services available.
- People can be terrified of the care system, care homes and diagnosis because of the media. Need positive stories in mainstream media.
- People can delay diagnosis to maintain the status quo in a relationship and because they don't want to acknowledge it or for practical reasons for example, the carer doesn't drive and depends on the cared for partner to drive. It can take time and support to overcome this.
- Need to provide a variety of support and provide carer breaks/respite so that carers can attend training without worrying about the person they care for
- Can be an obsession with current 'flavour of the month' diagnosis, such as sepsis.
- Could memory be built into health MOTs at certain ages / life stages?
- Could NHS A&E ask about dementia as a general triage question and ask everybody over age 45 if they have any concerns about their memory over past 12 months – but to follow up / onward referral. Think this is asked about in Wrexham Maelor triage areas.

What other support is available?

- Dementia friendly training / awareness raising and building dementia into ongoing training. BCU Dementia Awareness Course
- Virtual dementia bus. "You have to go on it!" Encourages patience and acceptance. Great for people who don't understand / have any comprehension of what living with dementia (as a carer) can be like and is based on real life. Need to book
- Bus Stop Sign – over 45 – have you had any concerns about memory – leaflet
- Power of Attorney information
- 'Still Alice' – film about young onset dementia.
- Teepa Snow The GEMS Brain Change Model (see YouTube)
- 'Somebody I used to know' book and blog by Dr Wendy Mitchell (on Radio 4).

Actions and recommendations

- Promote information about what signs and symptoms people need to look out for.

Assessment and diagnosis

What we found out

51% dementia diagnosis rate, partly due to data collection problems. The diagnosis rate may be lower for some groups, such as black men.

Support available

- Memory clinics
- Alzheimer's Society Dementia Advocacy Service

What people have told us

- The process of assessment and diagnosis has improved.
- Some people have a very positive experience of memory clinics.
- Need to 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 with dementia and for carers.
- Agencies and teams should work together to 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.

> 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

What stories did people share?

- There can be a big difference in the medical response to a diagnosis of dementia compared to cancer or other conditions. Need parity between mental health and physical health. One participant described it as being diagnosed and sent away "it's like the door was shut". Other participants talked about being given an overload of information and paperwork after diagnosis and then being discharged. Groups said that post-diagnostic guidance/support is critical. This could be more personalised and help provided soon after diagnosis about how to access practical help, advice and education on how to live well. Information needs to be accessible, for example, provided in audio format.
- Are memory clinics the best setting for everyone and should there be more options? What support is available for people who don't receive a diagnosis? Don't get a review unless there's a problem and it would be helpful to receive a follow-up. There are different staffing levels across memory clinics and inconsistent models and eligibility criteria, for example around learning disabilities, alcohol and substance misuse. The same services should be provided across memory clinics. Suggest a hub for healthcare professionals to complete assessments while on 'waiting list' for consultant. Also to research and

look at the evidence base around why patients are not followed up after diagnosis. There can be delays in accessing the memory clinic. Some participants said they found that memory services discharge patients quickly and are limited in what they can offer.

- Not seeing the same GP regularly makes it difficult to develop a relationship where the GP can notice changes in a person that cause concern.
- People with learning disabilities may need a different setting for assessment. Need to be creative around communication with people who are not literate or struggle with language and not rely on age related checks. Some said they struggled with diagnosis, assessment and support for people with learning disabilities, for example, professionals recognising dementia as an extra support need. It can be difficult for carers.
- Need to make it easier for family members/carers to access support to gain a diagnosis for their family member/person they care for.
- Getting time off for appointments can be a challenge for citizens and carers, there are a lot of tests that you have to receive to get a diagnosis and services are 9 to 5. Evening and weekend sessions may be needed. Some people may drop out or not attend appointments because the process is so long winded and they can't afford the time. Travel can also be a challenging, including time, distance and problems parking.
- Shared information is needed to reduce the need for repeated storytelling, although the story can change along the way and also to link carers with the person cared for in records. The process of moving area, even within North Wales, is sometimes not smooth. There was also a suggestion that there could be better links between services such as health, social care and benefits so that the person with dementia and the carer don't have to apply many different times for the different services and benefits that they are entitled to.
- One group suggested dementia passports as a way to transfer someone's information about their dementia journey from diagnosis with them, a bit like the Childrens Personal Health Record (Red Book), which would keep all of their information as it changes in one place and can be used by all health, social care and third sector partners to understand what is happening to them.
- Find ways to speed up the process of assessment. Participants described the time it took for them to get a diagnosis, including 7 months, 12 months and 2.5 years. Another group said the assessment process had improved but that people

may wait over 5 months to see a doctor if their GP is not good. Need more specialists and people who can do the test.

- Some said that the process can feel service driven and not person-centred, and it feels like we have lost the personal approach.
- A question was raised about how you manage a bad reaction to questions of memory. For example, fear can create an aggressive response. Some people don't want to know the diagnosis.
- Need to ensure the right information is gained from patients within a short time scale.
- Need access to physical health advice, for example, around urinary tract infections, and recognise changes in physical health. Suggestion that we could do more questionnaires in waiting areas to identify possible health risks or concerns.
- There can be misdiagnosis due to language, when using the mini mental state examination (MMSE) in English when a person's first language is Welsh. Some of the tests are not available in Welsh. One group talked about someone misdiagnosed with dementia by English ward staff until a Welsh-speaking patient liaison officer spoke to her in Welsh and realised the mistake.
- Integrate palliative care needs from diagnosis through the journey of dementia.
- A lack of LGBT support groups and need more research about how dementia can affect a person's gender identity and sexuality. Need improvements in services and support for LGBT people. Think there is an LGBT group that works on issues around diagnosis and being dementia friendly and there may be an LGBT domestic support group in North Wales but awareness should be mainstreamed.
- Need less restrictive criteria to access services.
- Need to support people to an acceptance of the diagnosis.
- Communication is key to manage expectations – it's not the same as having a cold.
- Include stories of how the process of assessment and diagnosis works and should be.
- The financial implications of young onset dementia and employment.
- We all function better at different times of the day and this needs to be considered for assessment.
- British Sign Language (BSL) individuals who use BSL can struggle to access services appropriate to them and translation through a third person can impact

the assessment. Maybe staff should have training to engage with the Deaf community and BSL training.

What other support is available?

- A friendly face for anyone affected by dementia, who wants to talk to someone living with dementia. Supported by Bangor University.
- After diagnosis there's a referral to Carers Trust North Wales Cross Roads dementia support service. Provide a local information booklet.
- GP although question about whether GP training is adequate for this. Initial assessment by GP should include blood tests to avoid other conditions and a brief cognitive assessment.
- Community mental health team
- Geriatrics / Stroke
- Young onset diagnosis often through mental health services.

Actions and recommendations

- Look at opening up pilot projects to include more services where they can improve services.
- Look at incorporating a better Make Every Contact Count approach to all interactions and interventions, including third sector and non-statutory services.
- Look at developing a user friendly service map/pathway that's co-produced and local.
- Consider developing a co-produced set of standards for services.
- Improve sharing of information between services/

Living as well as possible for as long as possible

What we found out

- Most people living with dementia are aged 65 and over.
- Around 5% of people who have dementia are aged under 65 (520 people in North Wales).
- Hearing impairment affects many people living with dementia and using hearing aids can help.
- LGBT people can face additional challenges.

Support available

- Advocacy services
- Community services (art, music, sport and exercise, reading, befriending, peer support and many more)
- Dementia support services (Carers Trust North Wales Cross Roads)
- Support for younger people with dementia
- Day care, day opportunities and carer breaks

What people have told us

- Need activities to suit individuals including people with early stage, late stage and young onset and different types of dementia.
- Support people to keep up their normal activities.
- Make sure communities are inclusive and dementia friendly.
- Need funding and resources, good pay and conditions for care staff, longer-term project funding.
- Concerns about the way dementia care is paid for by individuals.
- Listen to people with dementia and involve them in decisions about their care, including advocacy.
- Improve access to services in rural areas and for people who don't have access to transport.
- Improve coordination between different teams and agencies so services are seamless.
- Improve service consistency and staff continuity.
- Support people with a mild cognitive impairment.
- Improve support for people's physical health needs.
- Adapt the built environment to make homes and public places accessible.
- Promote the role of assistive technology and telecare.
- Look at support available for people who were diagnosed before October 2016.

> 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

What stories did people share?

- There was support for the focus on 'living well' and the need to support people to do the things they enjoy as an individual. This included working to reduce stigma and 'normalise' dementia so that people can continue to live as closely as possible to the way they lived before the diagnosis. This should include rural ways of life and family. Support carers avoid being too risk averse and to build confidence in providers around positive risk taking. This needs to be balanced with the need to keep people safe. Focus on what people want to do, like to do and can do, not what they can't do.
- One participant shared that they had excellent support from their GP, memory clinic and Carers Trust.
- Making links between hearing loss and dementia, some good work taking place. Challenges include parts of hearing tests that are difficult for people with dementia, hearing aids can be uncomfortable and people can forget to put it in or how to use it. Suggest hearing loss champions, sign language courses and Makaton. One group questioned whether using hearing aids did help as they can make background noise worse and asked about the reasons that hearing

impairment is affects people living with dementia. [There is more information in the background data and information produced for the strategy about the evidence that using hearing aids can help improve communication and wider engagement in those living with dementia and reduce cognitive decline.] One group said we need to promote these links more along with issues around vision impairments and understanding the needs of people with dyslexia and autism.

- Channel 4 programme The restaurant that makes mistakes.
- Provide opportunities for people with dementia to volunteer and take part in worthwhile work.
- Avoiding using terms like ‘severe mental impairment’ and ‘severe cognitive impairment’ and use terms like hidden disability instead.
- Highlighted that everyone is different and people need to be supported to do what they want to do. For example, one organisation supported someone to go to Belgium on a beer run and another on a trip to Silverstone. Not everyone likes reminiscence work.
- Challenges around short term projects with no continuation, for example someone finds an amazing singing group championed by a celeb and it’s ‘life changing’ but after 16 weeks it’s all over and that can be more detrimental.
- Improve consistency, for example availability of resources such as hug toys and gym for health.
- Need to make sure welfare checks are available.
- NICE recommend an annual mental health check.
- Social isolation is a problem, not necessarily just in rural areas. Access to services and social events can be affected by transport, forgetting dates, group members not making an extra effort to be inclusive or people struggling to see the person, just the diagnosis. Need to support families, carers and peers to understand, overcome any fear, and develop the skills to continue to be there for the individual.
- Some people live independently with dementia, need to maintain independence with adaption.
- Mistrust of care sector and media coverage.
- Look at the support available from cancer services as an example of good practice.
- Early access to medication and other therapeutic interventions.

What other support is available

- North Wales dementia network: supported by Bangor University, the network aims to share best practice, improve collaboration and increase the impact of dementia research into practice across North Wales.
- Dementia GO: Physical activity classes for people living with dementia and their carers in Gwynedd.
- Shared lives: A Shared Lives carer shares their home and family life with someone who needs support to live an enjoyable life. Can provide short-term or long-term care.
- PSS/TRIO: PSS is a provider of Shared Lives and TRIO is a Shared Lives project to support older people with dementia to take an active part in their communities with the support of Shared Lives Carers known as TRIO Companions. Available in Conwy.
- Age Cymru
- Community Navigators
- Social lunch
- Respite care / carer breaks
- Welfare rights
- Men's Shed: community spaces for men to connect, converse and create. The activities are often similar to those of garden sheds, but for groups of men to enjoy together.
- Taith Ni / Carers Trust: Monthly local support groups, part of the Dementia Support Service
- Talking points in Denbighshire: held in local community venues where people can have a face to face conversation about what help is available to support their health and well-being in their local area.
- NEWCIS: carer services provider. Includes support with Lifetime Power of Attorney, Bridging the Gap and Marley fields Saturday Sessions.
- Communication passport: key information about people with complex communication difficulties including their most effective means of communication.
- Dementia passport – the West – why isn't it the same across North Wales
- Life story book
- Assistive technology – apps, 'book of life'
- Book of you: reminiscence therapy
- Blue badge

- Side by side: a volunteer-led service which helps people living with dementia to continue to play active roles in their communities (available in Wrexham, Flintshire and Denbighshire)
- Young Onset Dementia outdoor recreational groups
- GP referral for leisure membership
- Direct payments / support budgets
- The outdoor partnership
- The Silver Line 0800 47080 90. Free confidential helpline providing information, friendship and advice to older people, open 24 hours a day, every day of the year.
- Memory clinics

Actions and recommendations

- Consider rolling out pilot projects, such as Dementia GO and TRIO across other North Wales counties.
- Look at models to provide transport, for example, Corwen community car/driver rolling out ‘dial a ride’, maintaining or increasing bus routes, car sharing and lifts from support groups/volunteers, Welsh Border Community Transport – costs (01244 544474). Suggest mapping what’s available and how well it links up with where people with dementia live.

The need for increased support

What we found out

- People 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 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.

Support available

- Dementia support workers
- Care homes and home care
- Step up step down beds
- Extra care housing
- Emergency services
- Hospitals

What people have 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.
- Improve safeguarding of people 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.

What stories did people share?

- It can be difficult to provide appropriate support for younger people with dementia who need a placement in a care home as it's not ideal to place them in an older people's care home.
- There's a need for more rural provision as some people live far from a local hospital. Rural issues are more than just a transport issue too.
- There are different prescription policies across North Wales with GPs for anti-dementia meds.
- Need care planning at each stage of dementia including Lifetime Power of Attorney (PoA) and advanced statement at end of life stages, such as vegetarian diet. This should include clear information about the different care options available. If PoA is too late (capacity) trust can become an issue. Need support that mirrors the progression of the illness so people don't have to 'battle' for services. Need mental health support for carers through the journey and bereavement support such as 'Caring and coping with loss in dementia' training.
- Need to reflect and improve inappropriate assessments for care home placements. Engage social worker to support appropriate placement, provide time prior to respite to familiarise people with the setting, for example day

services first then overnight, so a phased induction. Some found that the care homes were claiming a person hadn't got a physical disability when the carer was saying they had.

- Suggest providing a hub for services which could provide overnight services, immediate access for blood tests, tests for urine infection and provide antibiotics if needed. Could be based on existing group.
- Home care visits are too short, not long enough to support in a caring way.
- There's an issue around care staff retention and re-training issue and a need for continuity in caring and to maintain routines. There's a high turnover of care staff.
- Care in late stage dementia includes toileting and feeding. Day services won't accept referrals at times if personal care is needed.
- Training to maintain skills both at home and in care setting.
- Suggest alternatives to traditional counselling services for hard to reach people.
- Support should be collaborative, people shouldn't feel that they're being controlled or dictated to.
- Prevention equipment is key – hydration 'droplet cups'
- Psychodynamic support
- Mistrust of care sector and media coverage.
- Concerns that families can use the NHS as a carer break/respite service, for example, bringing a relative to hospital as they go on holiday, rather than planning for a carer break.
- Providing Bus Stop signs in A&E for people to wait by.
- Dementia professionals need more support from commissioners making decisions, such as Welsh Government, and more staff at the operational level.

What other support is available?

- Red Cross post-discharge support
- Advocacy
- Falls prevention service, National Exercise Referral Scheme (NERS) Fall Risk Assessment Tool (FRAT)
- Occupational Therapy home assessment
- Admiral nurse to support end of life care – currently only at St Kentigerns St Asaph
- PSS home from hospital

- PALS (Patient Advice and Liaison Service): Provide confidential advice, support and information on health-related matters and a point of contact for patients, their families and carers. Patient rights and liaison.
- Preventative assistive technology

Actions and recommendations

- Support community and health services to work together so people living with dementia are less likely to need to go to hospital. For example, by providing IV treatment at home.
- Promote advanced care planning.
- Work to improve more appropriate care placements.
- Consider options 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.

Support for carers

What we found out

- Unpaid carers (family and friends) are the largest providers of care for people living with dementia.
- About 73,000 people in North Wales (11%) provide unpaid care and the number is increasing.
- People aged 50 to 64 are the most likely to provide unpaid care.
- Around 50% are in employment and 30% of carers are retired.
- Between 60 and 70% of all unpaid dementia carers are women.

Support available

- Tide involvement network
- Carers Trust North Wales Cross Roads dementia support service (funded by BCUHB)
- Carers Outreach
- Carers Information and Support Programme (Alzheimer's Society)
- Carers support workers and development workers
- GP and Community Hospital Facilitators to support carers
- Carer groups

What people have told us

- Need more carer breaks, especially in the later stages of dementia.
- Need different types of breaks and flexibility to meet the needs of the carer and the person they care for.
- Provide emergency or crisis care and support with planning for this.
- Carer training and advice, including someone to talk to and ask questions of, particularly out of hours. Peer support from other carers can be very helpful.
- Need improved awareness around Lasting Power of Attorney. Concerns about the cost and the lack of a system to check everything is in place.
- Need employer support for staff with caring responsibilities.
- Support carers following bereavement.

North Wales Carers' Strategy

A vision and offer for carers in North Wales so that individual carers' 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.

www.northwalescollaborative.wales/carers

What stories did people share?

- Participants said that it's very important to listen to carers, to get to know the family before providing support and to provide a range of support options. Just as a person with dementia is unique, so are the carers. They all cope and support people differently so we need to adapt care and support to suit. For example, options for carer support to be given in the home and phone calls to check in from voluntary organisations can be helpful and 'nice to have a chat'. Carer groups are not always suitable for people. It's useful to have one point of contact.
- One group suggested that carers should be entitled to a certain number of days of carer breaks / respite each year in the same way that employees are entitled to annual leave.
- Participants said that it was important for services to be well advertised so that people are aware of them when they need them. For example, through social services, social media and newspaper adverts.
- There were stories about problems with carers' allowance. One person worked two days a week but when minimum wage went up she lost carers allowance as she earned 15p more than allowed, which highlighted the need for the government to make sure minimum wage and benefits all move with inflation.

Another person talked about finances being a major worry that affects both carers and people living with dementia.

- Labelling carer as ‘supportive person’ / ‘supporter’.
- Young carer support – schools need to understand dementia and support needs to be flexible.
- Employers to be dementia friendly and offer flexible hours for carers.
- Many carers don’t see themselves as carers – they are a husband, wife, daughter son and so on, which could be a barrier to accessing carer support and services. It’s important to help people maintain their dignity and family roles and include a definition of carer.
- Carers need space to think about wellbeing and may need a small amount of support.
- Need to involve carers, for example, sending them details of appointments and letting them know what medication is needed.
- Need contingency planning for carers.
- Carers need emotional support pre-bereavement as well as post-bereavement.
- Community Mental Health Teams don’t necessarily know about services available post-diagnosis, for example, Carers Trust.
- Sometimes carers want to go into a care home with a loved one.
- Suggest care agency on tap to support attendance at social engagement at short notice (not just appointments)
- There need to be a practical offer of coping mechanisms. Role play based? Suggest we need a crash course in caring.
- Carers can feel abandoned with the assumed role that they’re expected to step into.

What other support is available?

- Dementia Connect can be accessed by carers.
- Social Services provide dementia education sessions that are attend by lots of carers.
- U3A provide musical groups. This could be an opportunity for people with dementia who play instruments to get together and play.
- Taith ni groups – provide an opportunity to talk and share experiences
- NEWCIS
- Independent Counselling Service
- Age Cymru

- Young Carer Allowance
- DEEP
- PSS
- Tide is a UK wide involvement network. Recognising carers as experts by experience. Gathering info, such as, personalised memory boxes.
- CRISP course (Alzheimer's Society)
- Liverpool memory museum – play video clips. 4 short films. Hospital. Getting on the bus. Supermarket.
- Dementia dolls
- Support for carers up to 65: Cared for together (pub group) but after 65 can't keep going. A continuation service needs commissioning.
- Informal support mechanisms
- District nurse
- Community Resource Teams

Actions and recommendations

- Consider offering the same training to carers as care staff receive, for example, manual handling. As well as training that includes coping strategies, such as mindfulness.
- Promote new initiatives such as 'coping with caring and loss', currently led by Psychology in the West.

Event feedback

Event feedback forms were filled in by 101 of the 150 people who attended. Of these, 95% said they found the event useful and 96% said they felt able to give their views. The comments included:

> “Really useful day - learnt a great deal about different agencies and from people living with dementia. Thank you.”

> “Great opportunity to learn about what's going on in other areas. Very well organised. It was beneficial to stay on the same table throughout the day. Excellent lunch! Braf cael bwrdd Cymraeg [Good to have a Welsh table]”.

> “Well structured and very informative”

> “Really wonderful to be part of such a mixed group with such a varied background. Such a wealth of information. Let's hope we can make changes. Great having a 'leader' on the table keeping us on point”

Many of the participants commented how much they’d enjoyed getting to know people in their group and how useful it was to have a mix of staff from different organisations along with people living with dementia and carers. There were a lot of comments from people who said they’d gained greater insight into different services and people’s lived experiences as well as appreciating the opportunities for networking.

Overall there was positive feedback about being able to stay in the same group all day with participants saying they thought this helped conversations to develop and flow well, although a couple of people said they would have liked the groups to mix more. There was particularly positive feedback about the facilitators and how well they had guided the discussions. There were also comments about how good it was to have Welsh language discussion groups. Unfortunately due to the size of the event there were a couple of tables without facilitators and so the comments were more mixed from these tables - some said they still found the conversations useful while others would have preferred more structure and direction.

A couple of people commented that they would have liked to see the detail on the service mapping slide in the presentation. The slide gave an example of the way the information was being analysed rather than providing a summary of the findings, as

this work is still under-development. As this had been raised during the event, it was addressed in the closing remarks and anyone who wanted more information was advised to contact the event organisers.

Theatr Clwyd worked really well as a venue for the event with good support from the conference organising team. It was reasonably priced, there were a good mix of spaces to use, good audio visual equipment and many participants said they enjoyed the lunch. There was one comment that said more signage around the venue would help make it more dementia friendly. Unfortunately there was a problem with the heating on the day and quite a few participants commented on the cold although the venue organisers did what they could to help, including providing additional electric heaters.

The evaluation forms also included comments highlighting some of the key issues around dementia services, including the need to have consistent services as the event highlighted how different services can be across the region. There were a couple of comments about the challenges caused by short-term and inconsistent funding and the need to work in partnership between organisations and with other services areas, such as services for people with learning disabilities. One participant shared a paper they'd put together about their experiences and recommendations which has been incorporated into the event feedback report. A couple of people felt that they were having to defend the organisation they worked for in the discussions and there was one comment expressing frustration with the lack of change resulting from previous consultations.

There were comments about the need to make sure that participants get feedback from the day along with feedback about any outcomes and changes made as a result of the event. As well as responses stressing how important it is that the feedback is used to improve services and make a difference in practice.