BWRDD PARTNERIAETH RHANBARTHOL
GOGLEDD CYMRU
NORTH WALES
REGIONAL PARTNERSHIP BOARD

Gwynedd dementia listening campaign

February 2024

Mae'r ddogfen hon ar gael yn Gymraeg. This document is available in Welsh.

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

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Summary

231 people who live in Gwynedd shared their thoughts with us about good dementia care, community, and the support and help that people living with dementia need. This is what they told us.

What good dementia care looks like.

- Care is person-centred and based around what matters to the individual.
- Unpaid carers, families, and friends are supported too and have opportunities for breaks from caring.
- People live as independently as possible.
- People can make their own choices and decisions about their care.
- People are treated with dignity, understanding, and patience.
- People have the best quality of life they can and are loved.
- Care workers should be experienced.
- Care and support in the right place and as close to home as possible.
- Access to information and advice.
- Clear communication, in the language of their choice.
- Plenty of groups and activities for people to choose from.
- Communities are dementia friendly, inclusive, and accessible.
- Care and support at the right time.
- People have access to good healthcare.
- Funding care and support.
- People have the practical support they need.
- Services work together to provide integrated care that meets people’s needs.

What should be available for people living with dementia.

The kind of care described above including access to a wide range of activities based on what matters to them; access to care and support; financial support and help with legal issues; dementia awareness and training for the wider community; access to health services; support for unpaid carers; access to information and advice; and transport.

What community means to you.

What are the things that will help people living with dementia?

- Having the care and support they need.
- Recognising the importance of Welsh language and culture.
- Support for unpaid carers.
- Local groups and community support.
- Transport.
- Creating a dementia friendly community.
- Accessible services and environments.
- Making help easier to access.
- Financial help and funding.
- Access to good healthcare.

Research methods

The Community Engagement National Steering Group in conjunction with Citizen's UK produced a 'listening record sheet' including a set of questions to prompt discussion about dementia care. This work is part of the All Wales Dementia Care Pathway of Standards and contributes to standard 1, which is to carry out community engagement to identify what dementia care means to a community.

We held a Listening Campaign Event at Tywyn in South Gwynedd on 19th January and other listening sessions throughout the community including with:

- Third sector organisations that support people living with dementia and their unpaid carers, for example, Alzheimer's Society and Carers Trust.
- People with lived experience and their unpaid carers to seek their views on dementia care locally and to better understand the local service provision.
- Dementia care workers from local residential home settings and domiciliary home care.
- Local Dementia Actif Gywnedd activity groups.

The questions on the listening record sheet were also converted into an online and paper-based survey, so it could reach more people. This made the discussion more accessible to people who wanted to be involved and/or share their views on local dementia care but were unable to take part in the listening sessions.

The focus of the listening campaign was the town of Tywyn and surrounding areas. Links to the online survey were shared on the Dementia Actif Gwynedd Twitter and Facebook page. Paper surveys were shared in Dementia Actif Gwynedd classes in Tywyn, Dolgellau and Fairbourne, and local care homes in Tywyn – keeping it to the South Gwynedd area.

The listening campaign paper surveys with links to the online survey were shared during six virtual Dementia Bus training sessions which targeted unpaid carers, family members, and professionals. The Dementia Bus is a worldwide, scientifically, and medically proven method of giving a person with a healthy brain an experience of what dementia might be like, allowing them to enter the world of the person and understand which simple changes need to be made to their practice and environment to really improve lives of people with dementia.

Map showing the area of Gwynedd where the paper surveys were distributed

Map data ©2023 Google

Information about the listening campaign event at Tywyn was shared with:

- Alzheimer's Society (Memory Support Pathway)
- Carers Trust (Memory Support Pathway)
- Carers Outreach
- Age Cymru Gwynedd & Môn
- Cyngor Gwynedd Community Resources Team
- Cyngor Gwynedd Provision Services
- Cyngor Gwynedd Dementia Support Workers & Community Connectors
- Byw'n Iach Gwynedd (Leisure Services)
- BCUHB Memory Clinic Team
- BCUHB Meirionnydd Cluster Group
- Tywyn Health Centre
- Caerffynnon Surgery, Dolgellau

- Tywyn Health Centre Care Co-ordinators
- Tywyn Baptist Church
- Local Shops and businesses in Tywyn, Dolgellau & Fairbourne
- Digital Communities Wales
- Tan-y-Maen Wellbeing Centre and ICAN Support Hub
- Ysgol Penybryn School, Tywyn
- Town & Cyngor Gwynedd Councillors
- Liz Saville-Roberts MP
- Mabon ap Gwynfor- member of the Senedd
- North Wales Police
- North Wales Fire & Rescue

Prior to the event the Dementia Actif team delivered a Dementia Friends information session for year 5 & 6 pupils at Ysgol Penybryn. Some of the pupils attended the event and took part in the Q&A session with people living with dementia, where they asked questions about what it's like to live with dementia. Examples of the questions asked included "What made you think that you might have dementia?", "Were you scared when you found out you had dementia?" and, "What are your hobbies?" The Dementia Actif team felt it was an informative, honest, heart-warming, and humorous item, which stole the day.

Information stands at the event helped raise awareness of dementia, gave advice about where to seek help and promoted the listening campaign. The stands were hosted by:

- Memory Support Pathway
- Dementia Actif Gwynedd
- Age Friendly Communities
- Digital Wales
- Tan y Maen
- Tywyn Health Centre

Feedback from the listening session event

“Thank you for such an informative two days. I’m really struggling with my partner and don’t know where to turn, I am so anxious. I’ve been able to share my concerns with people and I feel that I’ve been really listened to –

I haven’t been able to show anyone my notes about all the symptoms and my concerns before and no-one ever asked until today. I have had lots of information and advice today and feel relieved so much more confident in moving forwards.”

“What a great event – it was action packed and very informative. We appreciate the opportunity of being able to share our views of how we can support people living with dementia in our community. We will be sending some items and ideas from the event to my niece in Canada, who’s supporting her husband who has Alzheimer’s!”

“Thank you for everything. They (school pupil) really enjoyed it and has told us all about the day, and how important it is to know that people with dementia may not remember what happened but that they remember the emotions!”

“As a parent I am truly grateful that my child has had this opportunity to learn more about dementia – hasn’t stop talking about the day and how funny the people with dementia were!”

Results

231 people provided responses to the listening campaign. Most of the responses came from health and care professionals or family members and friends (including unpaid carers). Most of the responses were given in English, with under 17% completed in Welsh.

Figure 1: roles of participants

Role	Number of participants	Percentage of participants
Someone who works as a health or social care professional	80	35%
A family member or friend of someone living with dementia (including unpaid carers)	74	32%
A member of the local community	55	24%
Someone providing paid care and support services	43	19%
In a different role	13	6%
Someone living with dementia	11	5%
Total	231	100%

This question allowed people to choose more than one option so the sum of responses will add to more than the total respondents / 100%.

Those who mentioned a different role included:

- Relative of person living with dementia in the past.
- Dementia advisers.
- People in roles providing support for those living with dementia.
- A retired professional.
- Professionals working in education, leisure, local government, and a local business.

We had participants from a range of age groups. Around 8% of respondents were under 25 including some under the age of 18, and 13% were aged 75 or over.

Figure 2: ages of participants

Age	Number of participants	Percentage of participants
11 to 25	18	8%
26 to 34	25	11%
35 to 44	40	17%
45 to 54	40	17%
55 to 64	47	20%
65 to 74	26	11%
75 and over	29	13%
Total	231	100%

We asked people:

What does good dementia care look like?
What should be available to people living with dementia?
What does community mean to you?
What are the things that will help people living with dementia?

We organised the answers into different themes and summarised them below.

What does good dementia care look like?

Care is person-centred and based around what matters to the individual.

Person-centred care includes the importance of treating people as individuals, with respect and dignity, allowing them to keep their individuality. Everyone is different, so good care and support for people living with dementia needs to be flexible and bespoke to the individual. It involves getting to know people, seeing the person, and taking a holistic approach. Support should be based on what is important to the individual so taking account of their likes and dislikes, using the ‘this is me’ document.

Care needs to be at the level that the person requires, appropriate, and must meet their needs. Support should respond, evolve, and adapt to the persons need, which can change daily, focusing on the persons strengths. It should be delivered in the person’s language of choice.

Understanding the needs of a person with dementia and how they perceive situations and other people. (Health and care professional, age 55 to 64)

Listening to the patient more about their needs instead of the patient working to the needs of the care package. (Unpaid carer, age 45 to 54)

Unpaid carers, family, and friends are supported too and have opportunities for breaks from caring.

More support is needed for family and friends who provide unpaid care for individuals living with dementia, as caring is hard work, and it can be ‘tough’ watching the person decline. Unpaid carers should have people they can talk to and have opportunities to meet with people who share their experiences. Counselling or support groups should be available to families to help them cope with the diagnosis.

Unpaid carers need breaks from caring, so they can continue to provide care for the person. They should have a good support package including help with tasks they cannot manage, and time off from caring. Help and support available for carers should be promoted, and it should be timely, local, and easy to access.

Suggestions of ways to support unpaid carers:

- Respite care / day centres.
- Training, education, and advice.
- Help with care in the home.
- Someone to talk to, counselling, or a support group.
- Knowing where to go for help, including in a crisis.

Having somewhere for them to be looked after so the husband/wife/carers has some time to themselves. (Community member, age 75 and over)

People live as independently as possible.

Being supported to stay in their own home so people can live as independently as possible. Care workers supporting people in their own homes and putting things in place so they can live safely. People living with dementia want to lead a normal life, maintain ordinary day to day activities and feel confident and able to do these tasks. Providing people with the opportunity to live life to the full and giving them the same opportunities as those without dementia. People want to be treated the same as before their diagnosis, continuing to do as much as they can, maintaining their independence for as long as possible.

If monitoring or observing the person is required, this should be done discreetly, treating the person with dignity, and respecting their privacy. When residential care is needed or preferred, it should be close to their family, in a homely environment, with familiar objects around them.

Personally, I feel it is when the care is more empathetic, letting them maintain their independence and freedom ensuring their safety. Treating individuals living with dementia with respect and dignity. (Paid carer and health and social care professional, age 26 to 34)

Happy residents. Involved in all aspects of their care. Treated as individuals, people, not just the disease. Trying to ensure that the person has as much independence in their day to day living as possible. (Health and care professional, age 55 to 64)

People can make their own choices and decisions about their care.

People living with dementia should have choices, and their wants, wishes and needs should be respected. They should be supported to live the life they want, be involved in all aspects of their care, and have control. Time should be taken to listen to the person and their family.

> Listening to what the service they want and needs. Also talking to the family to set information about the service user. (Health and care professional, age 45 to 54)

People are treated with dignity, understanding and patience.

Good dementia care is kind, caring, understanding, supportive and patient. People are shown empathy, sympathy, and compassion and treated with respect and dignity. The person should feel safe. Care workers are friendly, calm, encouraging, reassuring, helpful, and creative. They should be motivated to provide good care, with a positive approach, be engaging and be there for the person in their vulnerable moments.

Staff have the skills, training, knowledge, experience, and dedication to provide high quality care and support. There should be continuity of care to ensure care is consistent and familiar, care workers need to have enough time to listen to the person and not rush them, to meet both physical and emotional needs.

> It shows patience, good communication and practice in understanding the way dementia may present itself, thus establishing a relationship with the person who has dementia – it shows a sense of "walking in the other person's shoes". (Community member, age 75 and over)

People have the best quality of life they can and are loved.

A fulfilling life where people have the best quality of life they can and have the opportunity for fun, laughter, and happiness. Living in a loving and comfortable environment is a key part of this as well as making adjustments so people can live a good, contented life, and can still feel needed and useful.

> *Dangos caredigrwydd, trio helpu y rhai sydd hefo dementia i geisio byw bywyd mor 'normal' â phosib. Rhoi cyfleoedd iddynt fel pawb arall i gael profi bywyd- hapus a*

diddorol a chael bod yn rhan bwysig o'r gymuned yn e hardal hwy. [Show kindness, try to help those with dementia try to live as 'normal' a life as possible. Giving them opportunities like everyone else to experience life- happy and interesting and to be an important part of the community in e longer area]. (Community member and role providing support for someone with dementia, age 65 to 74)

Care workers should be experienced.

Staff working with people living with dementia should be well trained in dementia care, understanding how dementia can present, and aware of all the different forms of dementia. They should be skilled and experienced, and they should be the right person for the job. All healthcare professionals, home carers and care home staff should receive dementia training, including recognising signs of dementia.

Care and support in the right place and as close to home as possible.

It’s important to receive care close to home, including home care or home visits to enable people to stay in their own home for as long as possible. Support from family, friends, the local authority, health, third sector organisations and the community, can help people stay safe at home and out in the community. People should not have to search for help, they should be advised regarding what help is available, and it should be easy to access.

It can help to have care provided in a familiar place, seeing family, friends, and pets. Support should be available in the local community and when residential care is needed this should be close to home with familiar objects around the person. Hafod Hedd day centre was mentioned as an example of a provider of good care.

Being able to stay in your own house with help from the community and local services. (Person living with dementia, age 75 and over)

Access to information and advice.

The best quality information and guidance needs to be easy to access, all in one place, and help to negotiate the support available will often be needed. Advice and support should be available 24 hours a day. Families and those around people living with dementia need help to understand what dementia is, what to expect and how to provide the best care. People living with dementia and their families need to know

what support is available, how to access it and who to contact. There should be someone available to answer questions, for example a helpline. Participants mentioned how valuable Dementia Actif had been for them, providing advice and information sessions.

> Good communication. Knowing who to contact for advice as the condition progresses. Access to information about extra support as and where needed etc. Meeting and speaking with others in same situations as carers and sharing experiences. (Unpaid carer, age 75 and over)

Clear communication, in the language of their choice.

Care and support should be provided through the Welsh language or the language of their choice, for those who need it. There should be regular communication with the person and their family, it should be good and clear information. When comminating with someone with dementia it can be helpful to speak slowly and in short sentences.

Plenty of groups and activities for people to choose from.

Support groups for both carers and people living with dementia along with services and activities which help the person stay active and engaged, promote well-being, and in the language of their choice. There needs to be a choice of activities so that everyone can find something they enjoy and experience happiness and laughter. It's important that these groups are local, in the community, at a suitable time, and are adapted so people living with dementia can be involved. Suggestions include:

- Inclusive community groups, for everyone not just those with dementia.
- Sensory activities, like a sensory garden.
- Social groups.
- Music.
- Exercise.
- Support groups or counselling.
- Tea and coffee.
- Reminiscence sessions, looking at photos, talking about memories.
- Dancing.
- Going for walks.
- Pamper days.
- Enjoying the arts (drawing, poems, theatre).

Everybody is different, so it is important to offer a choice, including one-to-one activities, or home visits, for those who do not like groups.

They should have opportunities to join in community activities, and given time to talk about any memories they have. (Community member, age 75 and over)

Communities are dementia friendly, inclusive, and accessible.

There's an important role for communities in understanding and supporting people affected by dementia. This means creating an inclusive environment, where people living with dementia are integrated and valued members of the community and are treated like everyone else. Community spaces and services should be dementia friendly, accessible, and have understanding staff.

Participants suggested ways to make communities more inclusive including providing education for whole communities about dementia awareness, to reduce stigma, fear, and judgement. Education should include what dementia is, types of dementia, what people living with dementia may experience, what to expect, and how they can help.

The dementia friendly community can help support those with dementia, allowing them to be active in the community, making them feel they are not alone, and making them feel comfortable enough to share their diagnosis.

Lots of people trying to do the best they can but awareness of the dementia is still quite poor. I think the biggest problem of dementia care is loneliness, people struggle with other ignorance and lack of knowledge about what dementia is really. (Health and care professional, age 35 to 44)

Good dementia care makes someone with dementia integrate in the community as anyone else would. (Person living with dementia, age 75 and over)

Care and support at the right time.

People should have quick and easy access to dementia assessment and diagnosis, and appropriate follow up care. Support should be provided throughout the persons dementia journey, pre and post diagnosis. Care plans should be put in place which are individualised, and needs led. Ensuring support is provided at the level the person needs and a time that is convenient to the person and their family.

Care, support, and advice needs to be available 24 hours a day, seven days a week if this is needed. Care should be responsive and flexible, as circumstances can change rapidly. Resources should be readily available and not limited, provided in a timely manner, and available when you need it.

> Help for both carer and sufferer. This help needs to be available to everyone at the drop of a hat. People and situations with dementia can change quickly. The service needs to be flexible at all times. Everyone involved can feel very isolated with this condition. Sometimes it might just be a helpline that is needed. (Unpaid carer, age 35 to 44)

People have access to good healthcare.

People should have easy access to a quick and early diagnosis. The person living with dementia should have access to good support from a range of healthcare professionals including GPs, memory clinic, and community mental health nurses. All health and social care professionals should be aware of dementia and how it impacts people. Access to the most up to date medications and treatments must be available.

Funding care and support.

Dementia should be adequately funded to ensure high quality care is provided. Funds should be given to contribute towards or pay for care, for those who need it.

People have the practical support they need.

In addition to good emotional support and relationships, good care includes providing the practical support needed which can include eating, staying hydrated, personal care, medications, and reminders. Some people will need support with preparing for the future. Helping to keep people healthy, such as making sure they eat and drink regularly, can help to manage their dementia symptoms and prevent delirium.

Services work together to provide integrated care that meets people’s needs.

Families and services should work collaboratively to ensure the best care is given to those living with dementia. Care, support, and advice should be provided through one seamless service, to make access quicker and easier for the person and their family.

Ar gael i bawb. Un gwasanaeth di dor, 'seamless'. Cynhwysol i bawb o ran pobl sydd yn 'byw gyda' neu yn nghwmni rywun â dementia (gofalwyr, teulu). Gofal a chefnogaeth i ofalwyr. [Available to all. One service, 'seamless'. Inclusive for all in terms of people 'living with' or accompanying someone with dementia (carers, family). Care and support for carers.] (Local government worker, age 65 to 74)

Examples of where dementia care has not been good, and some people don’t know what good dementia care looks like.

Some participants shared examples of times where dementia care is not good, and some said that they didn’t know what good dementia care looks like. Below are some examples, which highlight how difficult it can be when the good dementia care described above is not available.

I would like to be able to answer this question given that my late mother had dementia, but sadly I can't. Aside from brief glimpses of what good care looks like during sessions with Dementia Actif, and the day centre Hafod Hedd in Pwllheli, Mum's support and care was limited to the best I could manage. There may well be good support networks out there to provide good dementia care but HOW to access it? (Unpaid carer, age 45 to 54)

No idea sorry! What is dementia care "good dementia care" Still getting used to being a carer and have no idea really what care is available. (Unpaid carer, age 55 to 64)

What should be available to people living with dementia?

The good dementia support described above should be available to people living with dementia, and similar themes were strongly reflected in the answers to this question.

A range of activities based on what matters to the individual.

There was more detail given in answer to this question about activities that should be available that may appeal to different people and what these should look like. Activities should be inclusive and dementia friendly, giving the person living with dementia the opportunity to be part of the community. Activities should be adapted accordingly, dependant on the persons capabilities and the stage of dementia they are at. There should be access to groups with people of a similar age, to try new things, and meet people with similar interests. Groups and activities should be available to access in Welsh or the person's language of choice.

Those living with dementia need local safe spaces to visit, for example a hub, it should be accessible for all. Leisure facilities should be accessible and available locally. Volunteers could help to run activities and groups.

Activities mentioned included: yoga, exercise, socialising, singing, get outdoors, reminiscence activities, dementia groups, days out, coffee mornings, events, arts and crafts, support groups, dancing, sports, an allotment, religious / cultural activities, book club, bingo, quizzes, walks, memory boxes and memory choirs.

It is important to recognise everyone is different, so some people may not want to access activities, some may prefer one-to-one sessions, and some people may find accessing groups online is easier for them.

Gweithgareddau amrywiol ar adeg call o'r dydd. Llawer o bethau ar gyfer henoed yn ein hardal ni yn y bore. [Various activities at a smart time of day. Lots of things for elderly in our area in the morning.] (Unpaid carer, age 45 to 54)

Groups for people of similar ages and interests so they can keep mentally active by conversing about subjects that may stimulate memories. (Unpaid carer, age 45 to 54)

Access to care and support.

Participants talked about the need for a range of support including home visits, homecare, day centres, residential facilities, and dementia villages. It was suggested that accommodation should specifically designed to meet the needs of those living with dementia. A care plan should be in place which is adapted to meet the persons changing circumstances, to ensure the person remains safe, that they are comfortable, and their needs are met. The person should be involved in discussions regarding their care, empowering them to take an active role in their care and give them a voice. They should be listened to, and their thoughts and opinions taken seriously. Care should be provided in the persons language of choice.

Help should be easy to access, consistent, affordable, available 24 hours a day, and emergency care should be provided when it is needed. There should be someone to contact when they need to, access to professional help, a social worker or support worker. People may need support with daily tasks, shopping, help to go out, and their mental health. Some people may need access to equipment to allow them to remain safe in their home and maintain their independence. Care should allow a person to have a connection with others who understand them and to have everything everyone else has.

Some additional suggestions about what care should be available were that ‘everything’ should be available, benches with information if someone is lost, meals on wheels service and befriending. These services should be well marketed, so people are aware they are available.

A good, strong support network with readily available resources and help for both. Anything a person with dementia (Community member, age 18 to 25)

Cael gofal yn iaith eu hunain yn y cartref, ysbyty neu lle bynnag maent yn gorfod bod. [Get care in their own language in the home, hospital or wherever they have to be.] (Unpaid Carer)

Financial support and help with legal issues.

Groups and activities should be available for people living with dementia to access free of charge. Financial support for care and support should also be provided to those who need it. People may need help to understand their legal rights and advocacy support.

Dementia awareness and training for the wider community.

Education facilities should be available to unpaid carers and the wider community to learn more about dementia. Education for the whole community should include awareness, understanding dementia and the different varieties, and how they can help. Carers should be able to access information on how to care for someone living with dementia. Staff who have contact with people with dementia should have training about dementia care, and to better understand what it is like for the person and their family.

Training should be provided regularly so people stay up to date with the latest information and the courses should be widely promoted. It should give people the opportunity to share their experience to help educate others.

Places should be made more dementia friendly, for example making buildings and public locations accessible and signage should be clear, using words and pictures.

> Training- professionals who 'don't get it' and appreciate how hard it is. Training community to be able to assist supporting families/individuals. (Paid carer, age 55 to 64)

Access to health services.

The GP surgery should be aware that certain patients have dementia and should be easy to access, local, home visits if needed, and with timely access to appointments. An early and prompt diagnosis for dementia is important, it should be available in Welsh, with regular reviews to monitor progress, and an annual health review.

People should receive a high standard of medical care including from admiral nurses, speech therapists, community mental health nurses and memory clinics. Services should be easy to access, without long delays, and local. Families should have access to the person’s medical information when needed.

> Access to early diagnosis. Support and information following diagnosis. Access to mental health support to deal with feelings of depression, anxiety and self esteem. (Unpaid carer, health and care professional and community member, age 55 to 64)
>
> Regular (one to three monthly) visits by the CPNs or similar. We have been visited by them 2 to 3 times at best since diagnosis 18 months ago...

patients needs can change rapidly so regular reviews of individual requirements for BOTH patient and carer I feel is essential!!!!!!!!!!- thanks. (Unpaid carer, age 45 to 54)

Support for unpaid carers.

Support for carers was reiterated in the responses for this question. Support needs to be available for carers to allow them to have a break from caring, get advice, attend support groups, get peer support, reassurance, and support in the home. Caring was described as ‘mentally and physically strenuous’, with carers ‘overloaded’ and experiencing ‘carer’s fatigue’.

The carer also needs support and reassurance that they are doing the best that they can. Caring for someone 24/7 is very mentally and physically strenuous. (Unpaid carer, age 65 to 74)

Access to information and advice.

Information and advice must be easy to access, accessible, and provided before diagnosis or promptly after. Suggestions included have a point of contact, leaflets, information sessions, and a phone line. It should provide information on help that is available, who to contact in emergencies, and where and how to access support.

Just someone to talk to that can give me guidance. (Unpaid carer, age 75 and over)

Information – everything is vague e.e. 'this is running, i think'. someone doing things but don't know where or when. (Person living with dementia, age 55 to 64)

Transport.

Transport was highlighted as something that should be available locally. Dementia friendly transport should be available to activities, for trips, and to shopping or church for those who need it. Any facilities used for activities should be accessible using public transport and have easy parking for those who drive.

What does community mean to you?

Participants described how communities can be based around shared or common purpose, goals, cause, interests, circumstances, characteristics, rules, and values, places (such as the local area), cultural heritage, language, or be any kind of close-knit group of people. A community includes people who have a shared expectation for the place they live. People also talked about how community is lots of different people coming together from different backgrounds, with different skills or knowledge. A community does not always have to be a physical place, they can exist online too.

Some participants said that communities meant a lot, everything, or the world to them and their community is central to their life. Some mentioned how important community is to those living with dementia and their families for support, advice, and someone to listen.

Someone pointed out how sometimes many communities can exist within one community, as the people have different needs.

Characteristics of communities included:

- People and relationships, including family, friends, neighbours, church, services, local authority, health and care professionals, businesses, and acquaintances.
- Being part of a group or involved in groups. A sense of belonging, inclusion, familiarity, and acceptance. Feeling part of something, not alone or isolated. A

friendly environment where you feel safe, valued and not alone or isolated. Groups can include social groups, language hubs, support groups, or special interest clubs.

- Working together to support and help each other in times of need and for the good of the community. A support network, where people look out for the vulnerable and those in need. People work as a team, everyone has something to offer, cooperating, sharing skills and strengths.
- Practical help, such as with shopping, tasks, homecare, fundraising, and transport. Helping those who are disadvantaged or vulnerable when they need it, enabling people to live full, rewarding, and safe lives.
- Knowing you can ask for help or advice when you need it, where nothing is too much to ask, not feeling like a ‘nuisance’, and someone to check on you.
- Respectful, non-judgemental, and accepting of diversity. Inclusive, making everything accessible, everyone is included, all ages together, including people with dementia and anyone who is vulnerable. Everyone is valued and understood.
- Bringing people together, doing things together, cooperating, united, and creating a network. Everyone can get involved, sharing ideas, and celebrating successes together.
- Opportunities for socialising, getting together, keeping in touch, connecting, and getting to know people so that people aren’t isolated. Developing friendships, meeting regularly, eating together, listening, and sharing worries. Being friendly, welcoming, likeminded, and connected. Knowing and caring about your neighbours. Including those with dementia and their families.
- Fun, happiness, laughter, and enjoyment.
- The public services that serve the community. The local shops, health services, social care, facilities, and transport. Access to national services. Services are linked, available locally, and people know their local councillor.
- Community events and activities and places to meet or drop in. Local people organising events, activities, and days out, to get people together, and letting everyone know about them. These are accessible for all, and everyone feels included.
- People want a good place to live. It is a friendly and happy environment that feels safe and secure, with a neighbourhood watch. People help make things happen that benefit everybody, improve lives, and promote a healthy lifestyle.

- Communicating with others in your first language, including access to groups and services in that language.
- Peoples have choices and their views are listened and responded to. People can choose whether to join in or not, whether to be on their own or with people, they decide how much they want to be involved.

Below are some examples of the way participants described what community means to them.

Being able to be a part of the social population, cultural and social group. Being part of a group of people, contributing and having influence, supporting the group and having means to help others and having my views responded to and valued. Community is central to the life of most people and families. Without a sense of belonging and social contact, people suffer isolation, rejection and many other negative effects. (Unpaid carer, paid carer, health and social care professional, community member and other role, age 65 to 74)

A place where I feel safe and included, where i can join in or not, where I can be alone or "together" with neighbours, friends and visitors, indoor or outside. (Unpaid carer and community member, age 75 and over)

Community means kindness to me, being able to look out for each other in a way that promotes wellness and not being a nuisance. Being able to have a helping hand when needed. (Health and social care professional, age 55 to 64)

Community is important to us all and encourages people to help each other. (Person living with dementia, age 75 and over)

Gallu I gyfathrebu yn yr iaith gyntaf. Cefnogaeth gan naill ar llall Digwysdiadau i bobol leol. [Ability To communicate in the first language. Support from one another. Events for local people.] (Unpaid carer, age 45 to 54)

Lle mae pobl yn edrych ar ol ei gilydd, yn gofalu am eu cymdogion yn enwedig unigolion bregus. Lle mae yna canolfannau ac cymunedau lleol i unigolion bregus yn y gymuned. [Where people look after each other, caring for their neighbours especially vulnerable individuals. Where there are local centres and communities for vulnerable individuals in the community.] (Health and social care professional, age 35 to 44)

What are the things that will help people living with dementia?

Having the care and support they need.

This includes sufficient paid care and support available for people in their homes, to allow them to remain living in their own home, as long as possible. It includes care to support both their physical and emotional needs. This should be from trained staff based on the values described in the section ‘what does good dementia care look like?’.

There should be support to take people out for exercise and activities, and support to complete day to day tasks outside the home such as reminders, shopping, food deliveries, and medication. Support should be in place to allow those living with dementia to carry on with daily activities and lead as normal a life as possible. People should visit or befriend those who can’t get out to visit groups. People should have access to local day centres or places such as community centres, dementia cafes, dementia centres, or community hubs, to provide safe spaces to meet with others.

People should be asked what they need, giving them choices, including what help they need and what time of day would suit them best. Care needs to be flexible and adapt to the changing needs as the dementia progresses. It can help to have staff who attend regularly, to ensure the carers are familiar and trust can be established. It should be one-to-one, timely, reassuring, help to build confidence and empower the person living with dementia. Equipment should be available when needed, to help the person to stay living at home, this could include trackers to ensure the person is safe.

Rhoi amser i'r claf ddweud ac egluro ei anghenion. Peidio brysio y claf a gwneud i'r gamp deimlo yn hawdd. Dod a chi eich hun i sefyllfa y claf. [Give the patient time to tell and explain their needs. Not hurrying the patient and making the experience feel easy. Bring yourself into the patient's situation.] (Unpaid carer)

The importance of Welsh language and culture.

Care, support, services, and activities should be available bilingually.

Support for unpaid carers.

Many participants mentioned the need to support family and friends who provide care to reduce the impact on them, as a way of helping people living with dementia. This includes breaks from caring (respite care), advice, information, support groups, education on how to provide the best care, and the opportunity to attend activities with and without the person they are caring for. Some people may need support overnight, to allow the unpaid carer to get some sleep.

Cefnogi gofalwyr. Mwy o adnodd. Llefydd saff iddynt fod am y de. [Support carers. More resource. Safe places for them to be for the day.] (Health and care professional, age 45 to 54)

Local groups and community support.

This includes support groups for people living with dementia and carers along with involvement in other groups and activities of their choice for fun, friendship and to stay active. People living with dementia should be asked what they want to do, so activities match their individual interests. Suggestions include music, singing, concerts, dance, chat groups, swimming, coffee morning, exercise classes, walking, cinema, games, days out, memory boxes, arts and craft, book club, bingo, quizzes, gardening, getting outdoors, chair yoga, befriending, sensory garden, visiting friends, and gardening.

Again, these activities should be based around what matters to the individual and their family so people can choose the activities that they enjoy, be available free or at an affordable cost and be available through the language of their choice. Existing activities should be adapted to make them accessible to all, so everyone feels welcome and comfortable. Having small groups can be helpful. There should be activities for a variety of ages as some people with dementia are younger.

Activities should allow people to join in with normal life, encouraging participation in the community, but tailored to their needs. There is also a need for groups allowing people to mix with other people living with dementia or with similar issues. Some people may need support from the community or a support worker to access groups. Groups and activities need to be more widely publicised, so people know what activities are available and how to access them.

Been recently diagnosed I don't know. From working to struggling with thinking on my feet is hard. Perhaps somewhere to go to meet. It's hard mixing with 'normal people' now. Somewhere we can meet people on the same lines who know where we are coming from. (Person living with dementia, age 55 to 64)

More organised events/activities. A community dementia garden, a dementia swimming day etc. (Unpaid carer, age 45 to 54)

Transport.

Transport was raised as a particular issue with a need for improved bus services. Community transport needs to be free or at least low cost. This included the need for transport to attend events and activities as well as medical appointments. Transport needs to be safe, accessible, dementia friendly, with supervision if needed. Community cars should be used to provide transport for those where public transport is no longer suitable. Friends could provide lifts for people where they can.

Transport to and from different groups/classes – very important in rural areas. (Community member, age 55 to 64)

Creating a dementia friendly community.

Many participants spoke about the importance of understanding and acceptance for helping people living with dementia. This includes raising awareness among people, and particularly local businesses, libraries, shops, and hairdressers to create a dementia friendly community. Dementia awareness needs to include all ages, including children. The environment and services need to be dementia friendly, with safe spaces to meet and dementia friendly shopping hours.

People in the community and professionals need to know what dementia is, how to recognise it, the impact it has, how to interact with people with dementia, and how they can best support those living with dementia and their families. Educating the community can help to reduce stigma, make things more inclusive, empower the community to provide dementia care, and to better understand the needs of the person living with dementia.

Suggestions for ways to raise dementia awareness include hosting dementia awareness events and dementia bus training.

Dementia acceptance and awareness in all interactions within the community. That would require educating the people, starting as children and throughout life. Business and services conducting their activities with understanding of the needs of minority groups of people including those with dementia. Public education, raising awareness and how to interact with these people who have dementia. Many formal and informal forms of dementia involved. (Unpaid carer, paid carer, health and care professioanl, and other role, age 65 to 74)

Accessible services and environments.

Awareness of the environment and how it affects those living with dementia, also considering other disabilities a person may have, for example problems with mobility and having dropped curbs for wheelchair access. The way signage is designed and displayed, having good lighting, quiet spaces, using plain English / Welsh, giving simple directions, using symbols or visual aids, and giving clear communication can all help with accessibility.

Plain wording and directions. Better fostering of understanding of the problems dementia causes. (Person living with dementia, age 75 and over)

Making help easier to access.

Navigating the support available can be challenging and access to support can be delayed. Suggestions for how to make help easier to access included:

- Provide a central hub to access information and support.
- Providing support 24 hours a day, seven days a week.
- Improve publicity around available support and events including how to access support.
- A phoneline for support and advice.
- Befriending or support services that can help people to access groups, support, and medical appointments.
- Using the dementia friendly logo on any events, activities, or spaces that have adapted their services to meet the needs of those living with dementia.

Knowledge of everything, we don't get to hear of these things available. Sometimes word of mouth is not good enough!!!!!!!!!!!! Dementia Actif Gwynedd are a brilliant groups of ladies – they help us so much. (Unpaid carer, age 65 to 74)

Financial help and funding.

Participants said that sometimes money is what's needed to help people living with dementia. This included direct financial help as well as support with costs such as transport and funding for services and activities. Money should be given to local effective schemes that support people living with dementia.

Access to good healthcare.

People should have access to early, quick diagnosis and intervention. There should be timely access to healthcare professionals, including support from GPs, nurses, specialist nurses, and mental health professionals. Services should be easy to access and transport to appointments should be available for those who need it.

Conclusion

Many of the people who took part in the listening campaign were replying from multiple perspectives, for example they worked in the sector but also had family members and friends living with dementia and / or were members of the community. The themes which were raised were fairly consistent between the different groups and there was a lot of agreement about what good dementia care looks like.

The purpose of this engagement was to find out what dementia care means to a community, so we spoke to a wide range of people, many of whom had experience of supporting friends or family living with dementia or professionals. There are lots of ideas and activities suggested, however, many people stressed that everyone is different and it's important that people are asked what they would like and what they need. A key part of any action plan informed by this engagement work should be to make sure that all services and support should involve the people who use them in designing them.

There was a lot of support from members of the community for an inclusive community where everyone works together to support people affected by dementia. There was also support for raising awareness of dementia and educating the community on how to help those living with dementia. This provides a great opportunity to build on the good work already taking place in Gwynedd and the surrounding area to create a truly dementia friendly community.

Appendix 1: Listening record sheet

Listening record sheet

***Listener name*:**	**What does good dementia care look like for you / your family / this community?**	**What should be available to you / your family / people living with dementia in this community?**	**What does community mean to you / You as an aging person?**	**What are the things that will help you / your family to do the things you / they want to do in this community?**
	Know how to get in touch with the right people. Get help right away.	Information about how lives are affected and what support is available. Access to other people with relevant experience.	Neighbours looking out for each other. Community events like meals in village hall. Meeting up for coffee. Sharing information about what's going on in the area.	Good health. Local transport. Village hall and the pub.
	Example row			

Appendix 2: Listening Campaign Survey

Dementia service provision

Our privacy notice is available online at www.denbighshire.gov.uk/privacy. Denbighshire County Council hosts our regional team, though we work across North Wales.

If you have any questions contact: Melanie.Sillett@denbighshire.gov.uk (Dementia Project Manager for North Wales) or call 07768 006414.

Please return completed surveys to Rachael Roberts, Dementia Actif Gwynedd, Healthy Living Bro Dysynni, High Street, Tywyn, LL36 9AE. Alternatively you can scan the QR code to complete the survey online.

If you need help to fill in the survey phone 01824 706054 or email adele.baguley@denbighshire.gov.uk

Are you responding as: (you can tick more than one)

- ☐ someone living with dementia?
- ☐ a family member or friend of someone living with dementia (including unpaid carers)?
- ☐ someone providing paid care and support services for someone living with dementia?
- ☐ someone who works as a health or social care professional?
- ☐ a member of the local community?
- ☐ in a different role?

If '**in a different role**' please tell us more

How old are you?

☐ 11-17	☐ 35-44	☐ 65-74
☐ 18-25	☐ 45-54	☐ 75 and over
☐ 26-34	☐ 55-64	☐ Prefer not to say

What does good dementia care look like?

BWRDD PARTNERIAETH RHANBARTHOL
GOGLEDD CYMRU
NORTH WALES
REGIONAL PARTNERSHIP BOARD

What should be available to people living with dementia in this community?

What does community mean to you?

What are the things that will help people living with dementia to do the things they want to do in this community?

Thank you for taking time to complete this survey.

Please return completed surveys to Rachael Roberts, Dementia Actif Gwynedd, Healthy Living Bro Dysynni, High Street, Tywyn, LL36 9AE.

If you need help to fill in the survey email adele.baguley@denbighshire.gov.uk or phone 01824 706054.

The consultation closes on 21 January 2024.

Appendix 3: Introductory Letter

BWRDD PARTNERIAETH RHANBARTHOL
GOGLEDD CYMRU
NORTH WALES
REGIONAL PARTNERSHIP BOARD

Trigolion Tywyn,

Rydym angen eich help i wella gofal dementia yn lleol, a fydd hefyd yn helpu i wella gwasanaethau yn genedlaethol.

Efallai eich bod eisoes wedi gweld gwybodaeth am Ymgyrch Gwrando Cymunedol Tywyn. Mae hyn i gyd yn rhan o'r gwaith gwella gofal dementia parhaus sy'n digwydd ledled Cymru, a dyma'r rheswm dros ysgrifennu atoch.

Mae arolwg wedi'i amgáu gyda'r llythyr hwn a byddwn yn hynod ddiolchgar pe gallech gymryd yr amser i gwblhau'r arolwg a'i ddychwelyd i'r blwch casglu yn Byw'n Iach Bro Dysynni.

Yna byddwn yn casglu canlyniadau'r holl arolygon ac yn bwydo'ch ymatebion i gronfa ddata Gwelliant Cymru a fydd wedyn yn paratoi adroddiad ar ganfyddiadau'r arolygon gan obeithio rhoi eich awgrymiadau ar waith yn y dyfodol agos.

Diolch am eich amser a'ch cyfraniadau - mae gwella gofal dementia yn fusnes i bawb ac rydym yn gwerthfawrogi eich mewnbwn.

Cofion cynnes, Melanie Sillett,
Rheolwraig Prosiect Dementia Gogledd Cymru.

Tywyn residents,

We need your help to improve dementia care locally, which will also help improve services nationally.

You may have already seen information about the Tywyn Community Listening Campaign. This is all part of the improving dementia care work that is ongoing across Wales and this is the reason for writing to you.

You will find a survey enclosed with this letter. We would be very grateful if you could take the time to complete the survey and return it to the collection box at Bro Dysynni Healthy Living.

We will then gather the results of all the surveys and feed your responses into the Improvement Cymru database, which will then feed into a report on the findings of the surveys and hopefully put your suggestions into practice in the near future.

Thank you for your time and contributions - improving dementia care is everyone's business, and we value and appreciate your input.

Kind regards, Melanie Sillett,
North Wales Dementia Project Manager.

Appendix 4: Event posters

Friday 19th January 2024
Pendre Hall, 10:00am-4:30pm

Tywyn has been chosen as the first town in Gwynedd to hold a Listening Campaign to help shape the future of dementia care and support.

People living with dementia, carers, families, professionals and community members are invited to a day of information, activity and fun. You can come along just for the morning or afternoon ....or you're welcome to stay all day.

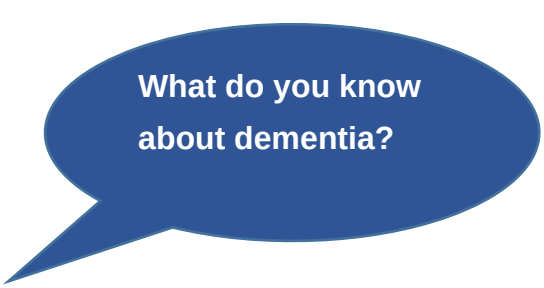
On the day :-

- **Programme of activities and presentations**
- **Stalls for information and support**
- **Have your say about what good dementia care looks like**
- **Film "The World Turned Upside down"**
- **Includes Free lunch and cuppas**

For more information and to book your place :-
Call Rachael 07976 622591
Or use the QR code

Appendix 5: Wales Listens Campaign Example Questions

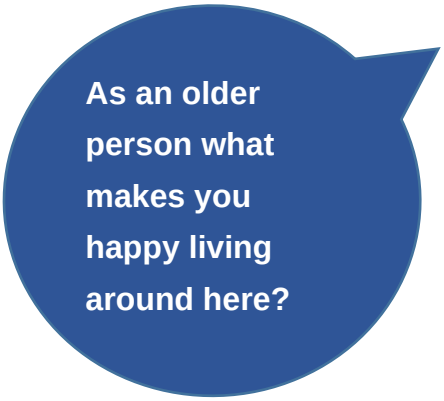
Example questions that can help you to have conversations with people in your community and gather their stories

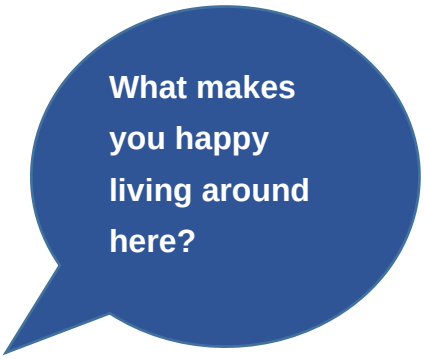


What does good dementia care look like around here?

What is strong within this community, what good things happen around here?

Who are the people in the community that support it?





As an older person what's the best thing about living around here?

What's the worst thing about living around here as an older person?

What does community mean to you as an aging person / as a young person

What helps you live in this community?

What will help you to live in this community?

What is it like to live in this community with dementia?

What do you think should be available in the community if you are an older person / person living with dementia / caring for somebody with dementia?

Appendix 6: Email

Pobl Tywyn	People of Tywyn
Mae gwella gofal dementia yn fusnes i bawb • Mae angen eich help i wella gofal dementia yn lleol. • Mae'r Ymgyrch Gwrando yn rhan o'r gwaith gwella gofal dementia. • *Y cyfan ry'n ni'n ei ofyn yw ichi gwblhau arolwg byr o 4 cwestiwn.* • Bydd eich adborth yn helpu Llywodraeth Cymru i lunio gofal dementia yn y dyfodol. Cliciwch yma https://online1.snapsurveys.com/hn3zyi i weld yr arolwg ar-lein. Gellir darparu copïau papur hefyd, cysylltwch ag Adele Baguley ar 01824 706054 neu drwy e-bost Adele.baguley@denbighshire.gov.uk Mae gennych tan 21 ain o Ionawr 2024 i'w gwblhau. Diolch i chi am eich amser a'ch cyfraniad – gyda'n gilydd gallwn wella gofal dementia i bawb yn lleol a Chymru gyfan.	**Improving dementia care is everyone's business.** • Your help is needed to improve dementia care locally. • The Listening Campaign is part of the improving dementia care work. • *All we're asking is for you to complete a short survey of 4 questions.* • Your feedback will help the Welsh Government shape future dementia care. Click here https://online1.snapsurveys.com/hn3zyi to access the survey online. Paper copies can also be provided, please contact Adele Baguley at 01824 706054 or via email Adele.baguley@denbighshire.gov.uk You have until 21st January 2024 to complete the survey. Thank you for your time and contribution – together we can improve dementia care for everyone locally and across Wales.

Appendix 7: Programme of events at Tywyn

- Thursday 18th January 2024 – virtual Dementia Bus experience at Byw'n Iach Bro Dysynni, Tywyn 10:00-1:00 & 1:30-4:30pm
- Friday 19th January listening campaign event and raising awareness about dementia at Neuadd Pendref, Tywyn 10:00am - 4:00pm

Programme

10:00	Meet and greet
10:15	Melanie Sillett – Regional Dementia Project Manager Introduction to the listening campaign
10:30	Dawns i Bawb- interactive dance performance
11:15	Break
11:30	"What's it like to live with dementia?" Question and answers session - Ysgol Penbryn pupils and Teresa and Glenda who both live with dementia
12:15	Paul Jordan, North Wales Police Herbert protocol
12:30	Totaleigh- sing along session
13:00	Lunch
14:00	Film – "The World turned Upside Down"