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Conwy dementia listening campaign

January 2024

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

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Summary

179 people who live in Llanfairfechan in Conwy 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.
- Care workers should be experienced.
- Care and support in the right place and as close to home as possible.
- Access to information and advice.
- Care is available 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 the practical support they need.
- Care is affordable and people have access to financial help and advice.
- 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; education and training for the wider community; access to health services; and support for unpaid carers.

What community means to you.

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

- Having the care and support they need.
- 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.
- Technology and other aids.
- Financial help and funding.

Mrs X's story

I am 92 now and about 90 when Mr X got his diagnosis.

At one time Mr X was very smartly dressed and cleaned his shoes each day, he eventually got to the point where he was asking me each day what he should wear and wasn't maintaining himself as he was.

Mr X got his diagnosis of dementia in a local hospital 9 months before he died.

I first noticed there was something amiss when he went from being a very organised man. I was left to do everything he had previously done.

During this period I got very tired and down, it was like walking on eggshells, he was very unpredictable.

He would get lost, once on an appointment to the hospital, I left him in one place, when I came back, he wasn't there. I waited some time and he didn't return, I asked a nurse had he been there, the nurse said yes until the fire alarm went. Mr X was a military man and as the alarm went, he marched out of the building. Sometime later I was contacted by the police station, which was some miles away, no one could tell her how he got there. He was quite happy in the company of people in uniform, something he was very used to as a younger man.

Another instance of him getting lost was when we were on holiday, he walked out of the hotel they were staying in. He carried a card in all his pockets with address details of his North Wales address, I had forgotten to put the name of the hotel we were staying in. He was OK with crowds, but he would just follow the people around him and when the crowd disappeared he wouldn't know where to go. I tried not to let him go out on his own. Living with him had its difficulties, he sometimes forgot who he was.

One of my biggest worries was losing him when we went shopping, I did lose him at times but not for long.

The family were worried about his behaviour, he had started to get a bit more aggressive, and they were worried because of his army background that he might become violent with me, but he was always nice with me, even on the occasions that he forgot who I was. I wasn't worried as we had met and married as Christians when I was 77.

I didn't have a moments anxiety because of my faith, but at times thought I might die before him as I was so tired.

Help

Not really any extra help was offered, we continued to get out but we slowed down a lot, the responsibility stayed with me. We lived in 'a care facility' so there were professionals here who knew about the diagnosis. We already had help from a couple who do all of our shopping, this started before covid, and they continued to support us through covid and my husband's diagnosis and even now.

Community

People knew he wasn't himself, he liked to laugh, and people would still have a laugh with him, but he was a lovely chappie with those who were nice with him. We weathered it all well. The community here were supportive and waved him off to hospital when he went in on the Thursday before he died on the Tuesday, his death was quite quick, he lost weight before he went into hospital.

Professionals

As I said there were professionals around us at the 'care facility', who knew about his diagnosis. It wasn't easy to get him to the hospital the first time for his diagnosis, members of the family helped, he went two or three times I can't remember. I can't recall if any other professions called, I lived one day at a time, it wasn't too bad. One day he was at the gate of the 'care facility', half-dressed at 8 in the morning, staff noticed and let me know. Once I couldn't find my glasses for some time and eventually I looked on his face and he was wearing them.

I managed better because I was here in 'a care facility', lunch was provided and other things were taken care of so I had less to do.

Family/Children

The family did come to visit but some of them live away and weren't able to give much support.

Suggestion

Something like a Men's Shed would be good in the housing, there is nothing here for men who have done things like woodwork and do it yourself when they were younger.

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.

A Dementia Listening Campaign steering group was set up and included local councillors from Llanfairfechan Town Council and Conwy County Borough Council (the Older People's Champion), and Council representatives from Library Services. In addition, representatives from the Community Wellbeing Services, Older People's Services, HR and Equalities, Quality Standards and Commissioning and third sector representatives from Community and Voluntary Support Conwy (CVSC) and Age Cymru.

- The population of Llanfairfechan community council area is 3,545 (2021 Census) and the number of completed surveys by 31st December 2023 was 179 with the majority of these being paper versions.

We would like to acknowledge the support and help provided by Llanfairfechan Town Council, Llys y Coed Extra Care Housing, Llanfairfechan Community Library, and the Dementia Listening Campaign steering group. This report shows how effective Communities can be in shaping the services that are required. Active engagement was undertaken by Officers and Community groups to ensure resident's views were listened to and noted. The findings are invaluable as to how such a community can be developed to the benefit of everyone. This work will now be built on and further developed as per the feedback received.

We would like to thank everyone who took part and special thanks to the residents of Llanfairfechan for taking time to give their views.

We held 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, Carer's Trust, and Age Connect.
- People with lived experience and their unpaid carers to seek their views on dementia care locally and to better understand the local service provision.

- Local community activity groups.

All these conversations were recorded on the listening record sheets or people took the questionnaire and contact details away to respond in their own time.

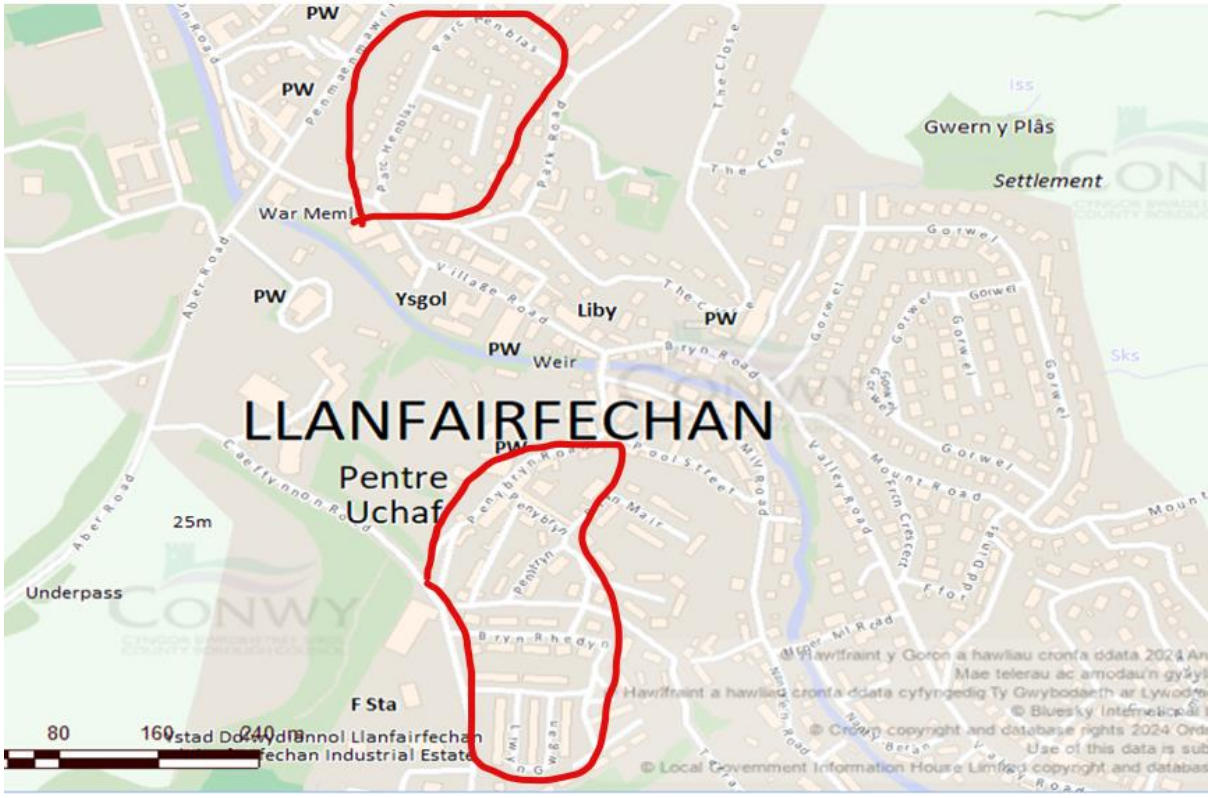
In addition, the questions on the listening record sheet were converted into an online survey and a paper copy was also available, so it could reach more people.

This made the discussion more accessible to people who wanted to be involved and/or share their views on dementia care locally but were unable to access the listening sessions.

Online surveys were shared on local Facebook groups, which included Llanfairfechan Town Council, and individuals' personal Facebook pages. Paper surveys were also delivered to housing estates in Llanfairfechan.

Conwy's focus was for people living and working within Llanfairfechan including the online survey.

Map showing the areas of Llanfairfechan where the paper surveys were delivered



Map data ©2023 Google

Information about the listening campaign, along with the online survey was shared with the following organisations and groups:

- Adult Learning Wales – Community Library
- Carer's Trust
- Community Library – Warm Hub
- CCBC Intranet & Postmaster
- Croquet Club
- Dementia Support Workers
- Falls Prevention Team
- Age Connect
- Alzheimer's Society
- Coffee Morning Group
- Community Mental Health Team
- Conwy Voluntary Service Council
- Dementia Allotment Group
- Ebb & Flow Chair Yoga Group
- Hope Church
- Llanfair Arms
- Llanfairfechan Town Council
- Llanfairfechan W.I.
- Llys y Coed Extra Care Housing – North Wales Housing
- Painting Pals
- Play Sessions – Llanfairfechan
- Rotary Club
- St. Mary's & Christ Church – Food Bank
- Zumba Class
- Llanfairfechan Golf Club
- North Wales Police
- Pickle Ball Group
- Riverside Café
- Sailing Club
- U3A
- Ysgol Aberconwy

Information about the listening campaign, along with the paper copies with a QR code link to the online survey were dropped off and discussed with employees of the following organisations and shops.

GP Surgery

- Plas Menai Surgery

Pharmacy

- Boots Chemist

Care homes

- Abbeyfield Sheltered Housing
- Llys y Coed Extra Care Housing

Bryn y Neuadd Hospital

- Administrative Block
- Staff Emotional & Mental Health and Wellbeing Section
- Rehabilitation and Engineering Unit
- Training Services

Other

- Annie Fechan's Charity Shop
- Carwsel Art Studio
- Flyers posted on local billboards
- John Williams Butchers

- Nisa Local Food & Wine Shop
- Older People's Flats
- Post Office
- Seagrass Café
- Artisan Food Market
- Dementia Bus at Llys y Coed Extra Care Housing for professionals
- Luna Beauty
- Nood Food
- Pavilion Beach Café
- Prospect House Vets
- Ystafell Vanessa Sewing Shop

We held and attended the following events:

Dementia Information Day

Which included the following information stands:

- Carers Team
- Community Wellbeing Team
- Dementia Support Workers
- Dementia Allotment Society – Rotary Club
- Direct Payments
- Herbert Protocol - North Wales Police
- Llanfairfechan Library
- Llys Elian
- Mochdre Dementia Hub
- Revenues and Benefits
- Welfare Rights

A buffet was provided on the day by Riverside Café.

Community Library Evening Drop In

Resources from the Dementia Information Day were used at this event and the Dementia Allotment Society (Rotary Club) attended.

Age Connects Information Day

Which included stands such as: -

- Alzheimer's Society
- BCU – Stop Smoking & Blood Pressure Awareness
- Community Library

- Community Wellbeing Team
- Ignitese Government Energy Scheme North Wales
- North Wales Housing Tenants Association

Christmas Fayre (all day event)

We asked our Dementia Listening Campaign Steering Group to provide us with Freebies for our stand and used a Llanfairfechan Company to produce our Dementia Listening pens. We also had a Robotic cat on the stall to bring in people to complete the questionnaires and discuss dementia and how the Robotic animals help people living with dementia.

Results

179 people provided responses to the listening campaign. Most of the responses came from members of the local community or family members and friends (including unpaid carers). Most of the responses were given in English, with under 4% completed in Welsh.

Figure 1: roles of participants

Role	Number of participants	Percentage of participants
A member of the local community	125	70%
A family member or friend of someone living with dementia (including unpaid carers)	33	18%
Someone who works as a health or social care professional	21	12%
In a different role	10	6%
Someone providing paid care and support services	9	5%
Someone living with dementia	4	2%
Total	179	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 declared a different role included:

- People who were relatives of people living with dementia in the past
- IT Support Analyst
- Secretary of local club
- Retired care home manager
- Soroptimist who regularly works with older members

We had participants from a range of age groups. Around 11% of respondents were under 25 including some under the age of 18, and 11% were 75 and over.

Figure 2: ages of participants

Age	Number of participants	Percentage of participants
11 to 25	20	11%
26 to 34	10	6%
35 to 44	22	12%
45 to 54	31	17%
55 to 64	41	23%
65 to 74	34	19%
75 and over	20	11%
Total	179	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 tailored to meet each person's needs. It involves getting to know people, seeing the person, and forming meaningful connections. Support should be based on what matters to the individual so that they can continue to enjoy the things they always have enjoyed. People shouldn't have to fit into the services on offer, the services should be built around them and less 'textbook'.

Care needs to be at the level that the person requires and that they are comfortable with and should be delivered in the person's language of choice.

Care also needs to be centred around a person and their family, which is discussed more in the next section.

Good dementia care needs to be person centred – individually designed to fulfil the specific preferences of the person living with dementia- and where possible in consultation with them. (Retired care home manager and community member, age 55 to 64)

From my own experience, dementia sufferers like other people are all different so a variety of care is important. (Carer previously, age 55 to 64)

Treating the person with dementia as a person rather than just seeing dementia. (Person living with dementia, age 55 to 64)

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. They should be listened to, feel empowered and be involved in discussions regarding care, as they often know a lot about the person.

Unpaid carers need breaks from caring, so they can continue to provide care for the person. They need time to rest, time for themselves and to complete tasks outside the home, knowing the person they are caring for is safe. 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.
- Transport for themselves and the person they care for.
- Activities for themselves and the person they care for.
- Organising days out for the person living with dementia.
- Help with care in the home.
- Someone to talk to, a helpline, support group or support network.
- Knowing where to go for help, including in a crisis.

Family and friends who may not provide care or may not describe themselves as carers also need support. Support should include education around dementia, knowing who to contact, and having someone to talk to, for example support groups or support networks.

Support for the carers who are most likely to be over 65 themselves. Provision of services to enable carers to have a short time to themselves to enable them to continue their caring. (Carer, age 75 and over)

Personol – bod y gofalwr yn nabod dipyn o hanes y person sydd efo dementia, yn gwybod beth ydy eu hoffterau a ballu. Efallai gallai rhywyn ar wahan i'r prif ofalwr hefyd bod yn rhan o fywyd y person i drefnu adloniant, diwrnodau allan ayyb wedi sylfaenu ar yr hyn mae'r person a dementia yn ei fwynhau. [Personal – being a carer who knows a bit about the story of the person with dementia, knows their preferences etc. Perhaps someone other than the primary carer could also be part of the person's life to organize entertainment, days out etc. based on what the person with dementia enjoys.] (Community member, age 18 to 25)

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

and maintain ordinary day to day activities. Providing people with the opportunity to live life to the full and have a good quality of life, this could include technology to support or keep them safe.

When residential care is needed or preferred, the environment must be ‘homely’, comfortable, safe with adaptations to meet the needs of the person, and close to their family. Trying to make the environment as familiar as possible for the individual.

Dementia sufferers living independent lives with caring support – both professional support and from their family and friends –living life to the full despite suffering dementia. (Health and care professional, age 35 to 44)

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

People living with dementia should have choices, their preferences should be considered, and they should be directly involved in discussions and decisions about their care. They should be allowed to be cared for the way they want to be cared for.

Having the persons views and preference considered with all discussions. (Carer and health and care professional, age 45 to 54)

Getting down to their level caring for a person the way they want to be cared for. Showing they are still people even if they are not well. (Paid carer, age 18 to 25)

People are treated with dignity, understanding and patience.

Good dementia care is kind, caring, understanding, supportive and patient. People are shown empathy, sympathy, consideration, and compassion and treated with respect and dignity. They should feel safe. Care workers are friendly, calm, gentle, reassuring, helpful, and treat people how they would want to be treated. They should not talk down to the person or patronise them. They should go above and beyond and help keep the person living with dementia happy.

Staff have the skills, training, knowledge, experience, and attributes to provide high quality care and support. There should be continuity of care to ensure care is consistent and care workers need to have enough time to listen to the person and spend time with them, to meet both physical and emotional needs.

Patience, understanding. Supportive, knowledge of the behaviours those with dementia exhibit. Genuine passion to care for others from carers. (Community member, age 35 to 44)

Care workers should be experienced.

There should be adequate numbers of staff to provide good quality care both at home and in care homes. These services should be well managed, run effectively. It was suggested there should be a designated social worker or assessor in each area.

Staff working with people living with dementia should be trained to specialise in dementia, be professional and knowledgeable, with experience of dementia. They should be knowledgeable about the condition, behaviours those with dementia may exhibit and how to support these effectively. Staff working with people with dementia should have a passion or interest in this area, working seamlessly in the background and not drawing attention to the person being a patient.

Experienced staff working with people with dementia should be paid adequately to reflect their specialised dementia role.

Supportive, knowledge of the behaviours those with dementia exhibit. Genuine passion to care for others from carers. (Community member, age 35 to 44)

I believe that there should be a designated social worker/assessor in each locality. This should be a social worker/assessor who has specialism in this field and has a keen interest in the support network available for the person/s to access. (Health and care professional, age 65 to 74)

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

It’s important to receive care close to home, including reliable care at home for as long as possible. Services should be provided locally and within the community. Appropriate and accessible transport to care facilities, support, appointments, and activities needs to be available for those living with dementia, families, and carers. It can help to have care provided in a familiar place.

Access to information and advice

The best quality information and guidance needs to be easy to access and help to negotiate the support available will often be needed. Advice and support should be available without the need for a diagnosis and should be free and available to all. Families and those around people living with dementia need help to understand what dementia is, what to expect and what they can do to help. There is a need for education and knowledge regarding dementia.

Care is available 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.

Plenty of groups and activities for people to choose from.

Support groups for both unpaid carers and people living with dementia along with services and activities which help promote well-being, 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 consistent, local, and close to home, with transport available if needed. They should be free, or at least, affordable. Providing whatever support is needed to enable people to access activities. Suggestions include:

- inclusive community groups, for everyone not just those with dementia.
- sensory room.
- day trips out.
- music based events or entertainment.
- interaction with animals.
- support centres.
- groups for people with dementia and unpaid carers to develop support networks.
- groups such as singing, creative, art, music, and exercise activities.
- memory boxes.
- dementia villages, dementia cafes.
- activities relevant to younger people with early onset dementia.
- intergenerational activities such as with schools.
- day centres or other venues for people to meet with others and socialise.
- meaningful activities provided in the home.

- home visits, someone to talk to; and
- social worker, assessor, or someone to organise activities and days out for the person.

There was praise for services available at Llys Elian and dementia villages in the Netherlands were given as an example of good practice.

> I believe good dementia care is where we have an understanding and empathy towards dementia and its effects on the person and their family. It is important to get to know the person and involve the person and their family in local support centres and in an open environment where they feel at ease and enable the person to participate in any activities to a level that they are at ease with. I believe that there should be a designated social worker/assessor in each locality. This should be a social worker/assessor who has specialism in this field and has a keen interest in the support network available for the person/s to access. The service should be accessible and free of charge to encourage all sufferers to feel part of a larger group of friends. (Health and care professional, age 65 to 74)

Communities are dementia friendly, inclusive, and accessible.

There's an important role for communities in understanding and supporting people affected by dementia. This means not segregating or labelling those living with dementia. Community spaces should be dementia friendly, accessible, and inclusive such as libraries, community centres, shops, and cafes. Participants mentioned the importance of integrating people living with dementia into the community, in intergenerational activities rather than solely segregated services. Improved signage in communities and adaptations such as lighter carpets can help people living with dementia navigate in the community safely. Members of the community can play a part in supporting those living with dementia.

Participants suggested ways to make communities more inclusive including providing education for whole communities about dementia awareness, to aid understanding. Awareness raising should include what dementia is, what people living with dementia may experience and how they can help. This could include how they can make spaces and activities dementia friendly.

Dementia friendly community – shops etc. Inclusivity – not separating / labelling people living with dementia. Good awareness. Varied and intergenerational activities such as with schools. (Community member, age 65 to 74)

Care and support at the right time.

People should have quick and easy access to dementia assessment and diagnosis, with further support and appropriate follow up care. Early interventions should be readily available to ensure the best outcomes for those living with dementia. Care plans should be put in place which are individualised, and needs led. Ensuring support is provided at the level the person needs.

People should have access to multidisciplinary health teams, including support from an occupational therapist, and have close links with their GP practice. Good dementia healthcare should include ways to effectively identify and monitor the progression of dementia, to ensure the right level of care is provided.

Care needs to be available 24 hours a day, seven days a week if this is needed. People and unpaid carers need to know who to contact in a crisis and be able to contact them any time, day, or night.

Making a good diagnosis. Appropriate follow up care. (Carer, age 75 and over)

Timely support in times of crisis. (Carer and health and care professional, age 45 to 54)

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 help with daily tasks, help to get out and about, shopping, meal reminders, meals prepared, or personal care. They may need support adapting their home to meet their needs or locating a suitable place to live in supported living or a care home.

Care is affordable and people have access to financial help and advice.

Many participants felt dementia care should be free to those who need it. Others thought specific services should be free, such as help navigating services and

activities. Some would like care 24 hours a day, 7 days a week for those who need it. People also need help with financial activities such as renewing insurance, and banking. Some may need help with money, this may include advice on benefits.

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

Participants described support as involving a range of different people and organisations with a mix of statutory and third sector services, including family, community, multidisciplinary healthcare, and social care staff. Professional care should be integrated with community support. Good care was described as co-ordinated and collaborative.

Some people don't know what good dementia care looks like.

Some people were unsure what good dementia care looks like, and one participant was looking to find out to enable the best support for their relative with dementia.

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 open to all not labelled as being ‘for dementia’ and not just for those living with dementia. Existing groups should be adapted to ensure they are accessible and give people with dementia the opportunity to feel included, involved, and normal. Activities should be adapted accordingly dependant on the persons capabilities and the stage of dementia they are at. Groups and activities should be available to access in Welsh or the persons language of choice.

Improving access to services to make them accessible for those living with dementia, for example, easy read menus, easy read signs, and dementia friendly times in shops, cinemas, libraries, GP surgeries and cafes. Making it so people have the same opportunities and access to things as everybody else, recognising they have equal rights.

Activities mentioned included: walks, sitting in the garden, dancing, singing, art and crafts, social groups, community activities, day centres, dementia/memory cafes, meals out, days out, music, support groups, coffee club, holistic therapy, cooking, community run day centres, school performances, therapy, tai chi, fitness, memory events, fundraising, community events and a community garden.

Community sessions should be able to provide their services in an inclusive manner so that people with extra needs are not excluded. Whilst people living with dementia may need a helper or a bit of extra support to get involved, this should be accepted and encouraged. I appreciate this is easier in a smaller community and we are lucky that we live in a small and caring community. (Community Member, age 55 to 64)

The same things that are available to everybody else. (Community member, age 55 to 64)

A social setting that is not labelled. None of us like being labelled. So for instance not call it a dementia café. (Carer and community member, age 45 to 54)

Access to care and support.

Participants talked about the need for a range of support including homecare, supported living, day centres and residential facilities. The care should be age appropriate, so there need to be facilities for those with early onset dementia. It was suggested that purpose built residential care should be available, with facilities that allow the family to move in to remain with their loved one.

Some additional comments about what care should be available were that ‘everything’ should be available, ‘access to all the relevant services’ and being able to access ‘all the services available in Llanfairfechan’.

Additional suggestions regarding support for those with dementia and their families included having alert systems to help find them if they go missing, safe spaces they can go if they are confused, meals on wheels service and helplines. These services should be well marketed, so people are aware they are available.

Participants again stressed the importance of good quality care, by professional staff, aspiring to achieve a ‘world class service’ even highlighting a need for people to be on call 24 hours a day, seven days a week. Providing care and support from the early stages, which is currently lacking, through to end of life care. Someone commented how ‘Conwy County Council’s service for dementia care is very poor, after diagnosis there is no extra support'.

Day centres – free of access charge. Benefit system that could be accessed by their carers – as there is possibly a loss of income the family may have had to incur. Purpose built Dementia residential setting that family could move into with the person but that they would have support to have a break themselves, without being away from the person. (Health and care professional, age 65 to 74)

Financial support and help with legal issues.

Unpaid carers should be able to access the benefits system on behalf of the person they are caring for. It was reiterated that there should be access to support for financial aspects and that services for those living with dementia should be free of charge. Support to help families arrange power of attorney should be available.

Education and training for the wider community.

Education facilities should be available to unpaid carers and the wider community to learn more about dementia. They should offer drop-in sessions and provide leaflets that are available in a variety of public places. Education for the whole community should include awareness, how to help someone with dementia, their needs and things that can improve the lives of those living with dementia. Unpaid carers should be able to access information on how to care for someone living with dementia and ways for them to cope.

Training covering how best to deal with someone with dementia should be provided to staff working in various settings, for example, dentists, libraries, etc. There should be a designated person in each of these public settings, who is knowledgeable and able to effectively support someone with dementia.

The local community being aware of the needs of people with dementia. Education facilities for carers and the local population. (Community member, age 65 to 74)

Help with how to care. Working with others on how they help or manage pressure. (Person living with dementia, age 45 to 54)

Access to health services.

The GP surgery should be aware that certain patients have dementia and should offer choice over the format of their appointments, for example offering face to face appointments. GP services should be easy to access, some people find apps too complicated or beyond their technical capabilities. When they phone the GP surgery, they are often on hold for long periods of time, taking them away from their caring responsibilities or disrupt routines.

Support for unpaid carers.

Support for unpaid carers was reiterated in the responses for this question too. Support needs to be available for unpaid carers to allow them to have a break from caring, get advice, talk to people in support groups, and to attend activities with the person living with dementia.

What does community mean to you?

Participants described how communities can be based around shared or common purpose, goals, interests, and values, places (such as the local area), cultural heritage, language, or be any kind of close-knit group of people. People also talked about how community is lots of different people coming together regardless of beliefs, background, race, culture, values, sexuality, age, gender, or status. There is no prejudice, just tolerance and acceptance.

Some participants said that communities meant a lot or everything to them and their community is their identity. Some specifically mentioned Llanfairfechan, with one person saying ‘everything Llanfairfechan is’. Others said that communities were dementia friendly, and people understand the impact of dementia.

Some people are not part of their local community. There was one view that getting along and helping one another is not always possible now due to people’s attitudes. One person commented how they don’t know what goes on in their community as they live ‘quietly’ on their own.

Characteristics of communities included:

- People and relationships, including family, friends, neighbours, residents, and businesses.
- Being part of a group or involved in groups. A sense of belonging, inclusion, connection, and acceptance. Feeling part of something, not alone or isolated.

A place where people know you, where things are familiar and comfortable. Feeling safe and valued and not alone or isolated.

- Working together to support and help each other in times of need and for the good of the community. Developing trust and loyalty, so support comes from trusted and familiar friends. A support network, where people take responsibility for each other.
- Practical help, such as with shopping, adaptations to the home, homecare, and activities. Volunteering to help others. Helping those who are disadvantaged, vulnerable, or have different needs, so no one is left behind.
- Knowing you can ask for help, you will be missed if you are not there, and that someone will check on you.
- Respectful, tolerant, and accepting of differences. Inclusive, making adjustments so everyone can participate in the community, everyone is included, all ages together, including people with dementia and anyone who is vulnerable.
- Bringing people together, doing things together, cooperating, and united. Having a connection, sense of belonging, feeling valued or feeling part of something.
- Opportunities for socialising, getting together and getting to know people so that people aren't isolated. Being friendly, warm, welcoming, likeminded, and connected. Sharing, learning, and listening. Knowing and caring about your neighbours.
- Fun and enjoyment.
- The public services that serve the community. The local businesses, shops, pubs, health centres, police, facilities, and services. These are supported by people, are funded, linked together and community members have some control over these services.
- Community events and activities and places to meet or drop in. These are accessible for all, everyone feels included, involved, that they can contribute, and participation is meaningful. A place where successes are celebrated.
- People want a good place to live. It is kept clean and tidy, and people help their local environment. It feels safe and secure. The needs of the community are balanced and not negatively impacted by tourism. People help make things happen that benefit everybody, improve lives, and help the community to thrive.
- A connection to the past.

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

Unigolion, teuluoedd, cyfeillion a chyd-weithwyr yn dod at ei gilydd i gymdeithasu a chefnogi ei gilydd ym mhob agwedd o fywyd. Mae cymuned wledig, er y pellter ffisegol, yn un clos a chariadus ac yn gwerthfawrogi gallu pwyso ar ei gilydd. Yng Nghymru, credaf bod cymuned wledig yn unigryw Gymreig a Chymraeg ei natur. [Individuals, families, friends and co-workers come together to socialise and support each other in all walks of life. A rural community, despite the physical distance, is close-knit and loving and appreciates being able to lean on each other. In Wales, I believe that a rural community is uniquely Welsh and Welsh in nature.] (Community member, age 45 to 54)

Community a small knit group of people who know each other and watch out for each other. (Person living with dementia, age 55 to 64)

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 shopping and attending appointments. 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 drop-in centres, memory cafes, dementia villages, or community hubs, to provide safe spaces to meet with others.

Having a single point of access for getting help and advice, so people know where to go for support and can easily find out what is available, this should be widely publicised. Advice should be available regarding risk, and support should be provided for example alarm systems, to help keep the person safe in their home. A helpline or someone people can call 24 hours a day, seven days a week, if they have an emergency should be available.

Additional comments included that social care needs to be better integrated within the farming community.

Provide support and care to live in their own home and support to go out for daily activities. (Health and care professional, age 45 to 54)

We need a needs-built dementia village around all of North Wales and very soon as dementia and Alzheimer's are on the rise. ACT NOW NORTH WALES!! (Carer, health and care professional, and community member, age 45 to 54)

The importance of Welsh language and culture.

Care, support, socialising, and activities should be available in Welsh. There should be sufficient staff to provide services in the medium of Welsh. The people who provide care and support should know the area and the people.

Cymdeithasu yn y Gymraeg, sgwrsio, canu a symud yn eu mamiaith. [Socialise in Welsh, chat, sing and move in their mother tongue.] (Community member, age 45 to 54)

They know the area and the people. (Person living with dementia, age 55 to 64)

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, someone to talk to, and the opportunity to attend day centres and activities with and without the person they are caring for.

A day unit for people living with dementia to attend, carers welcome but respite provided. (Carer, age 55 to 64)

Increase availability of day services to reduce impact on family carers. Dementia villages. More areas / accessibility to day services to include wider community. (Health and care professional, age 26 to 34)

Local groups and community support.

This includes support groups for people living with dementia and unpaid carers along with involvement in other groups and activities of their choice for fun, friendship and to stay active. Suggestions include music, concerts, dance, chat groups, dolls, swimming, afternoon tea, exercise classes, walking, theatre, games, days out, memory lane trips, craft, entertainment, memory books, and history talks.

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. Some participants commented that they prefer integrated activities rather than dementia specific groups.

> Perhaps open a little cafe in the village so that carers and the person with dementia can talk to others in the same situation. If possible short walks if able so that they get fresh air / exercise. When I was a league of friends member I remember asking a gentleman if he would like to go to the theatre and he said No!! but can I go and watch Wrexham play football!! (Community member, age 75 and over)
>
> Support them. Interact more with them. Don't treat people differently because they have dementia. Include them in things. (Health and care professional and community member, age 55 to 64)

Transport.

Transport was raised as a particular issue within this area, some mentioned there being no public buses available in the area. This included the need for transport to attend events and activities as well as medical appointments. Transport needs to be accessible for those living with dementia, as public transport is often not suitable. A suggestion included having volunteers who can provide lifts for people.

> Mae trafnidiaeth yn broblem ddyrys yma. Does dim un gwasanaeth bws, bellach, yn rhedeg yn ein cymuned ni a chyda chostau byw ar gynnydd, dementia yn effeithio ar unigolion hŷn, gan amlaf, mae diffyg trafnidiaeth yng nghefn gwlad yn ynysu pobl. [Transport is a thorny issue here. No bus service now runs in our community and with the cost of living on the rise, and dementia affecting older individuals, for the most part, the lack of transport in the countryside isolates people.] (Community member, age 45 to 54)
>
> Accessible travel- public transport is not good enough. (Community member, age 26 to 34)

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, schools, and banks to create a dementia friendly

community. The ‘Dementia Friends’ scheme was specifically mentioned and the idea of having dementia champions, to increase dementia awareness.

People in the community need to know what dementia is, the impact it has, and how they can best support those living with dementia and their families.

Several responses for this question were blank, stated that they didn’t know, or said that they weren’t informed enough to comment, which perhaps also highlights a need for greater awareness in the community for how to help people living with dementia.

Staff awareness in local shops to help identify customers who have memory impairments. (Retired care home manager and community member, age 55 to 64)

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, vision, hearing. The way signage is designed and displayed, having bright coloured doors or points of interest, dementia-friendly crossings and dementia-friendly flooring can all help with accessibility. Making sure there are a variety of ways to access services, to suit all, for example having print as well as online forms.

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 single point of access so people have access to all the services available to them that they need.
- Providing support prior to receiving a diagnosis and ensuring speedy diagnosis.
- Improve publicity around available support and events using a range of methods. It’s not enough just to advertise on social media or online.
- Befriending or support services that can help people to access groups, support, and medical appointments where they may not have the confidence to go by themselves or need other support to attend.
- Places to go for help and advice, like community hubs or drop-in centres.
- 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.

Put the dementia friendly logo on events that have been specifically reviewed for this client group. Communication – advertising in lots of ways (not just online). Not making everything online - needing to complete e-forms etc. (Carer, and health and care professional, age 45 to 54)

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. There's also a need for information and advice about the financial support available as well as legal advice for relatives. There were also suggestions that fundraising events could be held to raise money.

Technology and other aids.

Technology and aids can help people around the house and keep them safe. Examples given were cooking aids, reminders, and alarms.

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. The themes which were raised seemed fairly consistent between the different groups and there was a lot of agreement consistency 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. There are lots of ideas and activities suggested, however, many people stressed that everyone is different and it's important that support is focused on what matters to each individual and their family. 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. Also, to raise 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 Llanfairfechan and the surrounding area to create a truly dementia friendly community.

Appendix 1: Listening record sheet

Listening record sheet

Send scanned sheets to PHW.ImprovementCymruDementia@wales.nhs.uk

***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 Llanfairfechan Library, Village Road, Llanfairfechan, LL33 0AA. 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 Llanfairfechan Library, Village Road, Llanfairfechan, LL33 0AA.

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

The consultation closes on 31 December 2023.

Appendix 3: Introductory Letter

BWRDD PARTNERIAETH RHANBARTHOL
GOGLEDD CYMRU
NORTH WALES
REGIONAL PARTNERSHIP BOARD

Trigolion Llanfairfechan,

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 Llanfairfechan. 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 Llyfrgell Llanfairfechan. 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.

Llanfairfechan 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 Llanfairfechan 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 Llanfairfechan Library. 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

GWELLIANT CYMRU IMPROVEMENT CYMRU

BWRDD PARTNERIAETH RHANBARTHOL GOGLEDD CYMRU NORTH WALES REGIONAL PARTNERSHIP BOARD

citizens uk

PEOPLE OF LLANFAIRFECHAN

Llanfairfechan has been chosen as the **FIRST TOWN** in Conwy to help shape the future of dementia care.

'Llanfairfechan Community Listening Campaign'

- putting local people at the centre of the discussion around dementia care;
- share stories about the community and what is important to help to shape how local people with dementia are cared for;
- ensure people with dementia have the best possible experience of living in their own home and participating in community life.

INFORMATION EVENT

A number of information stands will be available offering advice and support – with free refreshments

WHERE: Town Hall Llanfairfechan

WHEN: Wednesday 27th September 2023 10am – 2pm

Any questions Email - pauline.roberts@conwy.gov.uk or michelle.freeman@conwy.gov.uk

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'Llanfairfechan Community Listening Campaign'

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- share stories about the community and what is important to help to shape how local people with dementia are cared for;
- ensure people with dementia have the best possible experience of living in their own home and participating in community life.

DROP IN EVENT

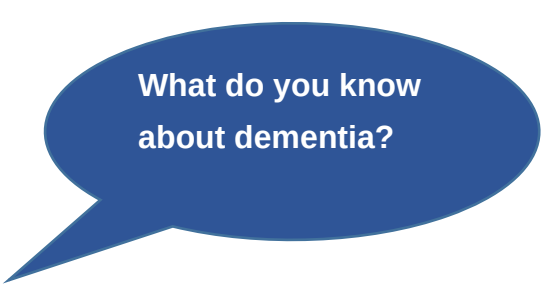
We will be offering advice and support on various subjects – with free refreshments

WHERE:
Community Library
Llanfairfechan
WHEN: Wednesday 11th October 2023
3pm – 6pm

Any questions Email - pauline.roberts@conwy.gov.uk or michelle.freeman@conwy.gov.uk

Appendix 5: Wales Listens Campaign Example Questions

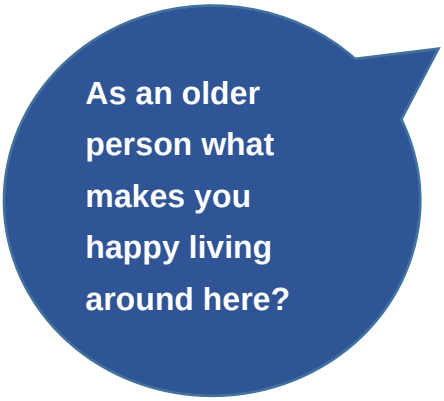
Example questions that can help you to have conversations with people in your community and gather their stories



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 Llanfairfechan	People of Llanfairfechan
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 31ain o Rhagfyr, 2023 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 31st December 2023 to complete the survey. Thank you for your time and contribution – together we can improve dementia care for everyone locally and across Wales.