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Wrexham Dementia Listening Campaign

February 2024

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

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Summary

88 people who live in Wrexham city centre and surrounding areas 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.
- 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.
- Regulations and escalating concerns.

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; support for unpaid carers; 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.
- Support for unpaid carers.
- Local groups and community support.
- Transport.
- Creating a dementia friendly community.
- Accessible services and environments.
- Making help easier to access.
- Access to good healthcare.
- Safeguarding and confidence.
- Financial help and funding.
- Technology and other aids.
- Valuing care work.

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.

Listening sessions were held 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 NEWCIS.
- 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 including 'Memories' two groups that are held at Happy Hedgehog Wrexham, various local coffee morning and support groups held in and around Wrexham County, groups in the Wellbeing Hub, Taith Ni Group weekly in the Wellbeing hub run by Carers Trust, Singing for the brain sessions and armchair exercise sessions.

We organised 10 pop up listening campaign roadshows in the following areas: Coedpoeth, Chirk, Rhosllanerchrugog, Ruabon, Minera, Rhostyllen, Caia Park, Queensway, Gresford and Wrexham City Centre. This enabled people to attend a local meeting in their specific area to express their thoughts on Dementia Services in Wrexham.

The listening campaign was also shared with 38 care settings within Wrexham via care home managers, to circulate to family, friends, and care staff.

All these conversations were recorded on the listening record sheets.

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 it 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.

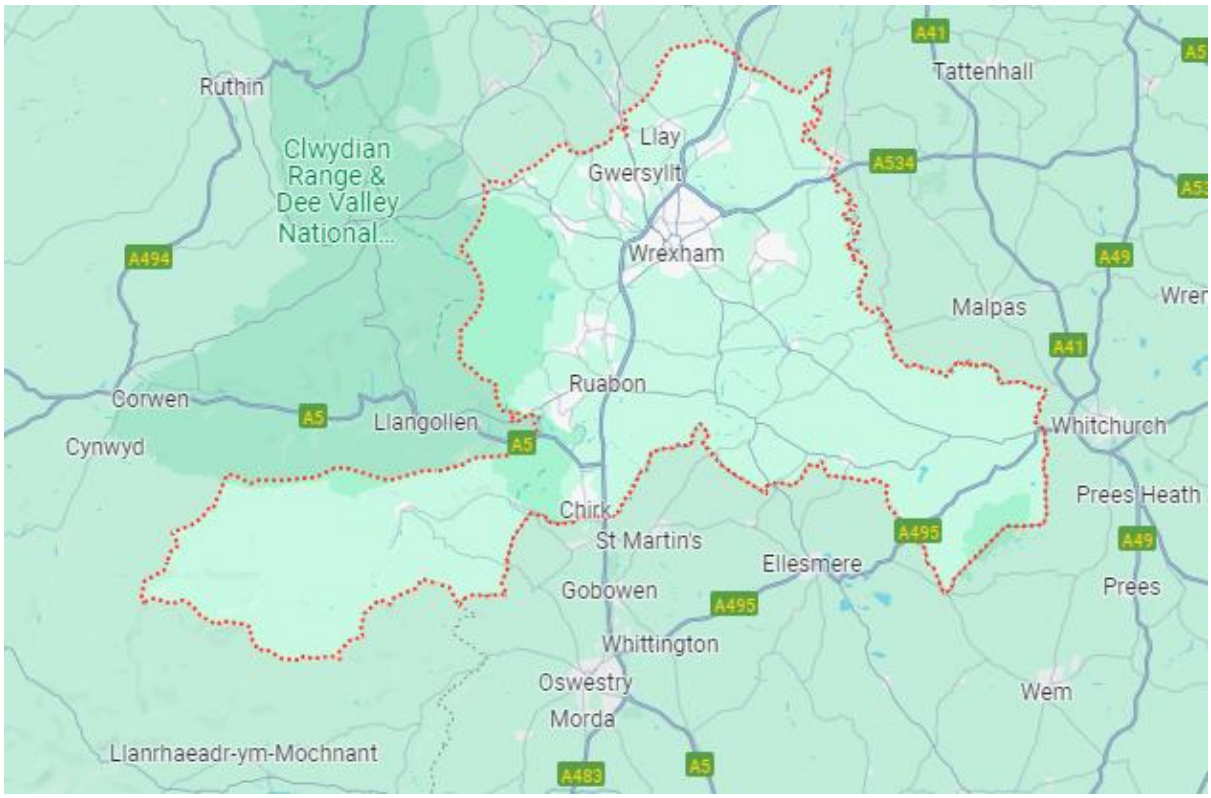
Online surveys were shared via the Wrexham County Borough Council communications team on Wrexham.com and were refreshed every few weeks, Twitter (X) and local Facebook groups, which included The Wellbeing hub, Dementia

in Wrexham Page, Local Wrexham Facebook sites that provide support and guidance to Wrexham residents, individual community agent's social media pages, via local notice boards and the through North Wales Dementia Network.

We also had a post box available in the wellbeing hub with Welsh and English listening surveys available to complete while people were in the hub, usually when attending support groups and activities on offer there.

The focus of the listening work was in Wrexham and the online survey was open to anyone living in the county of Wrexham. Other listening exercises are underway for other areas of North Wales.

Map showing the areas of Wrexham



Map data ©2023 Google

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

- Age Connect
- Alzheimer's Society
- Community Agents in Wrexham
- Carer's Trust
- Wrexham Dementia Art Group
- Wrexham Dementia Steering Group
- Care and Repair

- Wrexham Fire Service
- Wrexham Football Museum
- WCBC Notice Board
- Wrexham.com
- North East Wales Carers Information Service (NEWIS)
- North Wales Police
- National Trust - Erddig
- St Margarets Church
- Bellis Bros Garden Centre

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

- All GP's in Wrexham

Care homes

- All care homes in Wrexham

Other

- Libraries – Main Rhosddu library in Wrexham as well as community libraries
- Leisure Centres – Plas Madoc and Waterworld
- Wellbeing Hub
- Other hubs in Wrexham area including Gwersyllt, Plas Pentwern and Glyn Ceiriog

We held a Listening Campaign event in Wrexham at the wellbeing hub on 12th October 2023. The event included 17 information and support stalls and 258 people attended the event.

The event brought together unpaid carers, people living with dementia, people living with various disabilities, professionals and volunteers from all areas and was a wonderful talking point that has been regularly spoken about afterwards.

We have used the listening survey questions as conversation starters in the dementia forums that we hold regularly in person in Wrexham, and they were fantastic and brought so many questions and answers to the table.

Results

88 people provided responses to the listening campaign. Most of the responses came from family members and friends (including unpaid carers) or members of the local community. All the responses were given in English.

Figure 1: roles of participants

Role	Number of participants	Percentage of participants
A family member or friend of someone living with dementia (including unpaid carers)	52	59%
A member of the local community	20	23%
Someone who works as a health or social care professional	13	15%
Someone living with dementia	7	8%
Someone providing paid care and support services	6	7%
In a different role	5	6%
Total	88	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:

- Volunteer
- Person centred planning coordinator
- Housing support officer
- Member of a dementia inclusive community group

We had participants from a range of age groups. Around 2% of respondents were under 25 including those under the age of 18, and 15% were 75 and over.

Figure 2: ages of participants

Age	Number of participants	Percentage of participants
11 to 25	2	2%
26 to 34	3	3%
35 to 44	11	13%
45 to 54	12	14%
55 to 64	23	26%
65 to 74	24	27%
75 and over	13	15%
Total	88	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. Everyone is different, so good care and support for people living with dementia needs to be tailored to meet each person's needs. It involves getting to know people, forming meaningful connections, and friendships. Support should be based on what matters to the individual considering their preferences and needs. People shouldn't have to fit into the services on offer, the services should be holistic and follow a wraparound care model.

Care needs vary from person to person, and can change daily, so care needs to be flexible and responsive to meet the person's needs. This includes consideration of those living with early onset dementia, whose needs and preferences may be different from older people living with dementia.

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

Safe, secure, holistic care, either at home or in specially designed supported housing. Each person should be treated as an individual and have care tailored to their own preferences and needs. Families should be involved in planning this. (Community member, age 45 to 54)

A place for people with early onset that is not in a care setting for older people, their needs are completely different. (Health and care professional, age 55 to 64)

Person centered care what matters conversation listen and understand what people living with dementia and their carers/support need. (Community member, age 11 to 17)

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, be involved in

discussions regarding health and care, and keep updated regarding their loved one's condition and care.

Unpaid carers need breaks from caring, so they can continue to provide care for the person, as caring for someone with dementia can be exhausting. They need time to rest, and time for themselves, knowing the person they are caring for is safe. Help and support available for unpaid carers should be promoted, and it should be timely, local, and easy to access. Care should be tailored to the family's needs. Support should include education around dementia, knowing who to contact, and should be provided promptly following a diagnosis. The emotional needs of unpaid carers and families should be supported, having someone to talk to, for example support groups or support networks, as caring for someone with dementia was described as 'heartbreaking'.

Suggestions of ways to support unpaid carers:

- Respite care.
- Activities for themselves and the person they care for.
- Activities or care home placements close to family.
- 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.

More support for family members on how to deal with situations which is unknown to them. (Unpaid carer, age 55 to 64)

Carers contacted early after diagnosis, and offered help and guidance in their new role. Too many are left with no social worker and trying to get help. Respite is essential to unpaid carers, who can be worn and disheartened without help. (Person living with dementia and unpaid carer, 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 and continue ordinary day to day activities. Providing people with the opportunity to live life to the full, be content, have a happy life, doing things that everyone else does

and maintaining good self-esteem. Technology like clocks, trackers, and alarms could be used to help to keep them safe whilst maintaining their independence for as long as possible.

When residential care is needed or preferred, the environment must be comfortable, specially adapted to meet the needs of the person, and close to their family. Trying to make the environment as familiar as possible for the individual.

Hopefully that the person who is living with dementia is content and respected and given self esteem and encouraged to remain independent where possible and active. (Unpaid carer, age 55 to 64)

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 valued and listened to. The person and their family should be involved in planning their care and their opinions should be respected.

Individuals are supported and feel valued and listened to. That they feel like they are a person who is willing and able to do things that others are given the opportunity to do as well. (Paid carer and health and care professional, age 18 to 25)

Each person should be treated as an individual and have care tailored to their own preferences and needs. Families should be involved in planning this. (Community member, 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, consideration, and compassion and treated with respect and dignity. They should feel safe and secure. Care workers are friendly, calm, trustworthy, loving, and helpful. They should take the time to listen and talk to the person, allow them to express themselves, and become a friend. They should treat them with warmth 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. Care should be reliable, provided on a regular basis and should be consistent, so the care feels familiar to the person.

Dignity, respect choice and compassion. (Unpaid carer, age 45 to 54)

Care workers should be experienced.

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 dementia and the services available in the local area. Staff working with people with dementia should have adequate training, which is kept up to date and applied in their work.

There needs to be adequate oversight of the care provided, to ensure that good quality care is being provided.

Whereby staff are fully trained to understand the individual needs of the person with dementia and that this is monitored on a regular basis, far too often people attend training but never apply their learning in their work place and people with dementia are not listened too, seen as an inconvenience and left in the corner with no stimulation. (Health and care professional, age 55 to 64)

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

People should be given choice over their care and not be pushed into going into a residential facility if they don’t want to. Options for care should include care at home, supported living and care homes.

It is important to receive care close to home, including reliable care at home for as long as possible. Support should be provided to allow the person to stay living safely in their own home for as long as possible, this could include services such as Care Call.

Services should be provided locally and within the community. When they are no longer safe in their home, facilities should be close to family to maintain connections. Facilities should be specially designed to meet the needs of those living with dementia, they should be comfortable, and not exacerbate stress and confusion. Support should be provided to ensure a successful transition into the care home.

Deva house was mentioned as an example of a provider of excellent day care services.

Specialised, personal and above all local. Connection to family and friends is essential and the further away from home they have to receive care, particularly residential care, the more difficult that is. My sister and I have to drive 1400 miles a month each, to ensure my mum gets a visit every day. (Unpaid carer, age 55 to 64)

Being able to support the client through transition periods eg from home to care settings. (Different role, age 55 to 64)

Access to information and advice.

Expert information and guidance must be available from one place and should be easy to access and navigate. It may be useful for people to have a key worker or a named contact, who they contact for support. Help to find and apply for support will often be needed. Contact should be made with families promptly following diagnosis to provide help and guidance. Families and those around people living with dementia need help to understand what dementia is, what to expect, how to deliver good care, how to deal with different situations, and what is available in the local community. People living with dementia and their families may need help to find and access financial support, or help applying for benefits.

All information in one place suggestions of where to find financial support (need to show a process simply). (Person living with dementia, age 55 to 64)

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 are meaningful and stimulating. Access to activities should be available for the person living with dementia to attend with or without their carer. There needs to be a choice of activities so that everyone can find something they enjoy, express themselves, and experience happiness and laughter. It is important that these groups are held regularly, in local community facilities. There should be opportunities to interact with others, meet new people, make connections, and help people to avoid feeling alone.

Suggestions for activities include:

- Music.
- Brain exercises.
- Physical activity or exercise.
- Life stories.
- Reminiscence.
- Socialising.
- Befriending.

Presenting dementia patients with meaningful activities and giving them opportunities to express themselves within their limitations. (Unpaid carer, age 65 to 74)

Communities are dementia friendly, inclusive, and accessible.

There is a significant role for communities in understanding and supporting people affected by dementia. Community spaces should be dementia friendly, comfortable, safe, and welcoming. Staff working in public places such as libraries, shops, buses, and healthcare, should be educated regarding dementia. People should be mindful of those living with dementia and unpaid carers, understanding their limitations but still making them feel part of the community, and giving them a sense of belonging.

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 make things easier.

Everyone educated about how to make things easier for people living with dementia and their carers to do the day to day living easier and with dignity. This includes staff at shops, buses, libraries and all public facing services like NHS, working to make the system easier to navigate and engage well with flexibility to suit different peoples needs. (Community member and member of a dementia friendly community group, age 55 to 64)

All agencies understanding what it is like living with dementia. Many seem to have very little idea. (Unpaid carer and community member, age 75 and over)

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. People should have access to multidisciplinary health teams and have close links with their GP practice and other NHS services. Medical information about the person should be kept up to date, to ensure the most appropriate care is provided. Symptoms should not be dismissed as being dementia related and should be followed up promptly to ensure they get access to any medical assistance they might need.

Care needs to be available 24 hours a day, seven days a week if this is needed. Help should be provided immediately, and processes should not delay access to support. People and unpaid carers need to know who to contact in a crisis and be able to access that help when they need it, day or night. There needs to be adequate numbers of places in care homes suitable for those living with dementia, to ensure their care is not delayed, when and if they need it.

> Offering support at the right time and a good care package that meets the persons individual needs. (Health and care professional, age 55 to 64)

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 housework, shopping, meal reminders, meals, staying hydrated, personal care, or attending appointments. The person or their family may need help accessing support for example filling out forms.

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

Many participants felt dementia care and support should be free to those who need it. Others thought services should be well resourced. People may need help to find financial support or advice on finances and benefits that may be available. Some felt care homes should not be for profit and should be run by the local authority. There needs to be greater accountability for care homes as places often come at a large cost to people, and we need to ensure the best care is being provided.

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 multidisciplinary healthcare, social services, and social care staff. Good care was described as joined up, with continuity, and different departments talking to each other, so people don't have to repeat themselves. There should be a single referral point and any interface that people need to use should be modern and easy to understand for everyone.

Regulations and escalating concerns.

There should be a process to escalate concerns about care homes, if families feel the care is not the high quality that should be expected.

Some felt decisions regarding the most appropriate dementia care, support and services for a person should be made independent from those who provide the funding, to ensure it is based on need and not costs.

> Separate the best interests decision away from the authority that funds it otherwise the decision making will always be biased… Also better oversight of the quality of care/nursing homes. Better ways for family to escalate issues other than direct with the home who might have a tendancy to be defensive or not address the issue fully. Make providers more accountable especially when individuals are paying their own fees at upwards of £1200, a greater level of service and accountability to the individual and their family as a 'customer' should reasonably be expected. (Unpaid carer, age 35 to 44)

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

Some participants shared examples of times where dementia care is not good, and some said that they did not 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.

> We are yet to see it. (Unpaid carer, age 26 to 34)

Constantly repeating myself. Doing everything myself. It's like having a full size child. I have lost my best friend. Still having to be a wife but mostly being a mum. (Unpaid carer, age 65 to 74)

Isolated unsupported lonely. (Unpaid carer, age 55 to 64)

… It also needs to have the capacity to have enough time to give a person time to converse and listen. This is something I think is lacking in care homes. Care homes appear to have a high turnover of staff and struggle to employ sufficient staff. This coupled with what appears to be the minimum amount of training, cannot hope to provide a good quality of care. (Unpaid carer, age 65 to 74)

Heartbreaking and exhausting - it is correct when they say it is the long goodbye. I would not wish it on my worst enemy. (Unpaid carer, age 55 to 64)

Very poor, long waiting lists for support and most services now being cut. (Unpaid carer, age 26 to 34)

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, a safe environment and held in dementia friendly venues, such as community hubs. There should be a variety of venues to suit the person, not everybody wants to access day centres. Places to relax, quiet areas, and dementia friendly times for relaxed visits.

Groups and events should be suitable for the person living with dementia and the stage they are at, to allow them to be involved and included in the community. Activities should be interesting, stimulating, meaningful, and related to their interests.

Activities mentioned included: days out, singing, reminiscence choirs, social groups, community events, memory activities, drinks or meals out, music, support groups, wellbeing groups, exercise, games, holidays, cinema, and contact with others living with dementia.

> Everything. There should be as many inclusive activities as possible. Understanding and empathy. (Health and care professional, age 35 to 44)

Access to care and support.

Participants talked about the need for a range of support including homecare, social services, day centres and residential facilities. Care and support need to be available 24 hours a day, seven days a week, and must be prompt when it is needed urgently. Help should be provided daily, as part of a routine, providing good quality and tailored support. Care homes should be local, clean, safe, with adequate staff, range of activities and have an outside space. There needs to be more dementia specific care homes.

Help should be hands on, as well as providing emotional support. Support should be offered for help shopping, a healthy diet, and housework. Care needs to be tailored

to the person, to meet their needs, using what matters conversations to develop a care plan. Care must be at the correct level and the right time and should allow the person to remain independent for as long as possible. It should be easy to access and easy to claim help with care costs if needed, it may be helpful to have one person to co-ordinate the care and support.

Some additional comments about what care should be available were that ‘everything’ or ‘everything for a happy life’ should be made accessible to the person living with dementia and their families.

Additional suggestions regarding support for those with dementia and their families included RITA being available not just in care homes but in the community, and free access to Care Call in the person’s home.

All agencies should amalgamate. There are to many and it should be streamlined. To offer correct levels of support at the correct time. Not have people going here and there hoping to find the correct support they require. (Unpaid carer, age 75 and over)

I think there is a lot of support available in wrexham, the difficulty is that as a carer I didnt know how to access the information on how to find it. (Unpaid carer, age 55 to 64)

Financial support and help with legal issues.

Financial support should be available to those with dementia and their families, including help planning finances, managing money, and accessing benefits. There should be help towards the costs of care and day services should be free to access. Help to navigate support may be needed including advice and help completing forms. Support with legal issues should be available, including help with advocacy and writing a will.

Often, a dementia sufferer will struggle along before diagnosis, and probably won't manage things like finances properly. Some sort of practical support to assess this and help work out a solution would be very beneficial. (Unpaid carer, age 55 to 64)

Education and training for the wider community.

Education facilities should be available to the unpaid carer, professionals, and the wider community to learn more about dementia. Education for the whole community

should include awareness, what to do if they come across someone who is lost or confused, recognising the early signs, and understanding dementia and how it effects a person. Unpaid carers and health and care professionals should receive guidance on good dementia care and understanding the needs of a person living with dementia. Care should be provided by specialist teams, with dementia trained and experienced staff.

Access to health services.

People living with dementia should have access to good quality healthcare, this should include specialist care that is easy to access. There should be sufficient staff to provide regular appointments or visits to monitor their condition and general health, this could include mental health practitioners, physiotherapists, district nurses, memory clinics and their GP. Dementia diagnosis should be quick, interventions should be implemented promptly following diagnosis, and a good care and support package put in place, in consultation with the person and their family. People living with dementia should have good links with their GP to ensure they are supported to access services. Services need to work together effectively to provide a seamless service, accessing so many different places can be overwhelming.

> Good relationship between GP practice, pharmacies and hospitals. Easy access to specialists when needed. Support network for carers. (Community member, age 65 to 74)

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 this should include breaks from caring, advice, training, support groups, peer support, befriending, help at home, and activities with the person living with dementia. Help should be provided immediately after diagnosis and help and advice should be available 24 hours a day, seven days a week.

Support available should be easy to access and advertised effectively. This could include information stands and drop-in centres. It may be helpful to have a central organisation to signpost and help people navigate the services that are available.

Support, there is currently limited support and help for the carers. The advice that is available is never correct. There is no financial support, and the burden is placed solely on the family. (Unpaid carer, age 55 to 64)

I think for me it is just having other people to talk to who have more experience and no what to expect in the future. (Unpaid carer, age 75 and over)

Transport.

Transport should be provided to allow people living with dementia to access appointments, activities, enjoy days out, and to local places of interest.

What does community mean to you?

Participants described how communities can be based around shared or common connections, goals, wishes, and resources, places (such as the local area, home, or workplace), or characteristic. People who come together and are like-minded.

Some participants said that communities meant a lot or everything to them, and ‘underpins their daily life.’ Community is important to them and provides them with comfort and allows those living with dementia to keep independent in their daily lives.

Some people are not part of their local community. Community does not mean anything or not very much to them. Others felt they preferred community involvement to be kept to a minimum, just being pleasant and not interfering in each other’s lives.

Characteristics of communities included:

- People and relationships, including family, friends, neighbours, villagers, professionals, extension of family or everyone.
- Being part of a group or involved in groups. A sense of belonging, feeling part of something, togetherness, not alone or feeling at home. Groups welcome all, with times to suit everyone and information about the group being shared.
- Working together to support and help each other in times of need and pulling together or pooling resources to provide the best services. Developing trust, being kind, caring and supportive. A support network, where people take

responsibility for each other, looking out for the young, old, vulnerable, and carers. People with different skills and capabilities supporting one another.

- Practical help, such as with shopping, prescriptions, and taking people out. Providing information and advice about activities suitable for those with dementia.
- Knowing you can ask for help, somewhere to go, and that there will always be somebody there on a bad day.
- Respectful, non-judgemental, and accepting. Inclusive, recognising the diversity of people's needs, equal opportunities, all ages together, everyone is a valued member.
- Bringing people together, in it together, collective, integrated, and united. Having a connection, sense of belonging, in harmony, and being there for others, particularly those living with dementia and their families.
- Opportunities for socialising, getting together, interacting, networking, and engaging so that people are not isolated. Having a space or place to meet up and have a 'cuppa and a chat.'
- Living life to the full, and opportunities to grow or develop.
- The public services that serve the community, where there are professional staff who are well trained. The community has full support from the council.
- Community events, activities, and places to meet or drop in. Events and activities are run by the community, there is a variety of activities to choose from, and they are available to everyone. Places where positive agendas are discussed.
- People want a good place to live. It feels safe and secure. People do things in the interests of everyone, to improve the lives of others.

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

A group of people in the same area with similar goals and wishes. (Unpaid carer, age 65 to 74)

Where people with a like thinking but with different levels of capabilities and skills come together to support and help each other by looking after the needs of people who require it. (Unpaid carer, age 45 to 54)

Not a lot as the person I am caring for is not very social. (Unpaid carer, age 65 to 74)

Community under pins our day to day life. (Community member, age 55 to 64)

In reality, I don't see much by way of community apart from neighbours asking after my mother. People use community care like there's some sort of structure there to provide it but that's generally not the case, and with dementia, most people are ill equipped to offer any useful support anyway. I think 'local' probably a better goal than 'community' when it comes to dementia support. (Unpaid carer, age 55 to 64)

A sense of belonging and not feeling isolated with people you can trust around you and to feel able to ask for help from the community if needed. (Volunteer befriender, age 65 to 74)

Care and support for everyone equality for all opportunities to support one another and grow. (Community member, age 11 to 17)

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, who understand dementia, based on the values described in the section ‘what does good dementia care look like?’

There should be support to take people out for appointments and activities, and to complete day to day tasks such as preparing food and taking medications. There should be practical hands-on help in the home, someone to check on them, with sufficient staff levels to allow time to get to know the person and for staff to be able to provide the level of help required. People should know there is always someone there if they need them.

When day care is no longer sufficient, specialist supported living or care homes should be available close to their family.

Information and resources should be available, to help keep the person safe and to make life as enjoyable and happy as possible.

More Dementia carers who know how to deal with the person and make their life enjoyable and happy like it was before they had dementia. (Unpaid carer, age 55 to 64)

My mother went downhill during a prolonged stay in hospital and was moved directly into residential care in Colwyn Bay (the only available space even though we're all from Wrexham) so didn't really have to manage outside that environment, but if we want people to do the things they want to do in the community, I think adequate care provision to let them remain in the community in the first lace, rather than shipping them 50 miles away would be top of my list. (Unpaid carer, 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. They need time to themselves to meet their own needs, to look after their mental health and to get support for their own health needs. This includes breaks from caring (respite), care in the home, support to navigate services, and support networks. Unpaid carers need to know the person they care for is safe when they are not there.

> Having experts who develop new systems and procedures and activities. Having additional support from people that can initiate and facilitate a rota week by week. This would ensure carers and family have direction for their loved ones whilst they could go about and get more of their own needs completed helping the family and carers mental health. (Unpaid carer, age 45 to 54)
>
> This is a difficult one for me, as the person concerned is totally reliant on me, and I also have my own health concerns! But sometimes it's more important just to be there for them and to listen to them. (Unpaid carer, age 55 to 64)

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 with interesting and varied subjects. Suggestions include photography, pet therapy, befriending, trips out, singing, art groups, coffee mornings, wellbeing, colouring, social groups, community events, mental stimulation, and physical activity.

Again, these activities should be based around what matters to the individual and their family so they should be tailored, dementia friendly, and support to access should be provided. Not everyone wants to do things with other people, so it is important that activities are available on one-to-one as well as groups, there should be activities available online as well as in person.

There should be suitable facilities available to host activities, these should be dementia friendly and accessible. Dedicated facilities, dementia hubs, community centres, or a single place to access all services (activities, advice, support, education). The Wellbeing Hub was mentioned as an excellent provision.

Enabling support workers to assist. Allowing adequate respite for unpaid carers. Support with digital technology allowing people living with dementia to attend groups / activities virtually to complement other in person activities / social groups. Wellbeing Hub has amazing facilities helping people to live as independently at home for as long as possible. (Health and care professional, age 35 to 44)

A Dementia hub which is fitted out and equipped to meet the needs of dementia sufferers and their carers. This place must have easy access by public transport and must have adequate parking for those who come in vehicles This place could then be the centre for activities and also be a place of support information and education for carers. (Unpaid carer, age 75 and over)

Transport.

Transport was raised as being important to help those living with dementia. Places need to be accessible on public transport, and there needs to be adequate parking. Dementia friendly, accessible transport should be provided to access events, groups, and services. Some participants felt transport should be free.

Free transport to events/groups/services in the community. (Health and care professional, age 35 to 44)

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 about dementia among people, particularly businesses, shops, cafes, restaurants, cinemas, and theatres to create dementia friendly venues and a dementia friendly community. The ‘Dementia Friends’ scheme was specifically mentioned along with community initiatives to be held regularly to increase 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.

Creating safe spaces and a dementia friendly community can help the person living with dementia feel welcome, included, not judged, not different or useless and be a part of the community. Having a community who cares can make all the difference to someone living with dementia.

Transport availability, being accepted in the community even though they have a different outlook to the world. Support to educate others on dementia and how they can help people that live with dementia in their communities. (Paid carer and health and care professional, age 18 to 25)

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. Considering building entrances, and the issues with depth perception people with dementia have can help make an environment more accessible. Making sure services are accessible and relevant to the person accessing the service. Having signs to indicate whether premises are dementia friendly/accessible.

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:

- Ensuring access to a speedy diagnosis.
- Local directory of services.
- Signs for dementia friendly spaces.
- Map of where to find dementia friendly places and activities in the local area.
- A single place to go for help and advice, like a wellbeing hub, dementia hub or drop-in centre.
- More cohesion between services, with streamlined processes to accessing services.
- Making it easier for people to volunteer.
- One-to-one support to access groups and activities.

Familiar sign to represent a safe dementia space. Maps to help to find out where they are. Opportunity to continue to be part of local communities. (Carer, age 45 to 54)

Access to good healthcare.

Prompt access to diagnosis should be available, followed by regular check-ups to monitor the progression of their dementia and identify other health needs. Access to

Easy access to GP services should be provided, with support to access appointments and GP's aware of services that are available to signpost people to.

> Get the whole system streamlined. Ensure that GPs are fully aware of what is available. My GP is not. Put yourselves in the position of a carer And see how you get on… (Unpaid carer, age 75 and over)

Safeguarding and confidence.

The importance of safeguarding people living with dementia to keep these vulnerable individuals safe in their community.

Financial help and funding.

Participants said that sometimes funding is what is needed to help people living with dementia. This included funding social care, carers, activities, day centres, projects, and transport. Funding needs to be long-term to allow the continuation of support.

Technology and other aids.

The provision of equipment can help those living with dementia. Support with digital technology can help people attend activities online if they choose to.

Valuing care work.

Improving the salaries of care workers, can help to recruit and retain staff, this would help provide a consistent, and quality service for those living with dementia.

Conclusion

Many of the people who took part in the listening campaign were replying from multiple perspectives, for example they were unpaid carers, worked in the sector but also were members of the local community. 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 is important to have choice over care and support, to ensure it meets the needs of the person 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 Wrexham 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 Wellbeing Hub, Crown Buildings, 31 Chester Street, Wrexham, LL13 8BG 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 Wellbeing Hub, Crown Buildings, 31 Chester Street, Wrexham, LL13 8BG.

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

The consultation closes on 31 January 2024.

Appendix 3: Introductory Letter

BWRDD PARTNERIAETH RHANBARTHOL
GOGLEDD CYMRU
NORTH WALES
REGIONAL PARTNERSHIP BOARD

Trigolion Wrescam,

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 Wrecsam. 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 yr Hwb Llesiant.

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.

Wrexham 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 Wrexham 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 The Wellbeing Hub.

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

Wrexham Dementia Listening Campaign

Do you live with Dementia or are you supporting someone living with Dementia in this area?

Come along for a chat and a drink and let me know your thoughts on Dementia Support in Wrexham.
Drop in –

Wednesday 13th September 2023
Chirk Parish Hall
Chirk
LL145NA

10am-3:00pm

Led by Kate Evans Person Centered Planning Dementia Coordinator - WCBC
Katea.evans@wrexham.gov.uk or call 01978 298608 with any questions

Wrexham Dementia Listening Campaign

Do you live with Dementia or are you supporting someone living with Dementia in this area?

Come along for a chat and a drink and let me know your thoughts on Dementia Support in Wrexham.
Drop in –

Thursday 21st September 2023
Old Carnegie Library, Coedpoeth LL113TD

12.00pm–2:00pm

Led by Kate Evans Person Centered Planning Dementia Coordinator – WCBC
Katea.evans@wrexham.gov.uk or call 01978 298608 with any questions

Wrexham Dementia Listening Campaign

Let's Talk Dementia

Do you live with Dementia or are you supporting someone living with Dementia in this area?

Come along for a chat and a drink and let me know your thoughts on Dementia Support in Wrexham.
Drop in –

19th September 2023
Gresford and District War Memorial Trust
Memorial Hall, off High Street
Gresford, Wrexham LL12 8PS

10am–11.30am

Led by Kate Evans Person Centered Planning Dementia Coordinator – WCBC
Katea.evans@wrexham.gov.uk or call 01978 298608 with any questions

Wrexham Dementia Listening Campaign

Let's Talk Dementia

Do you live with Dementia or are you supporting someone living with Dementia in this area?

Come along for a chat and a drink and let me know your thoughts on Dementia Support in Wrexham.
Drop in –

Friday 6th October 2023
Rhos Library
Princes Rd, Rhosllanerchrugog, Wrexham LL14 1AB

10am–12:00

Led by Kate Evans Person Centered Planning Dementia Coordinator - WCBC
Katea.evans@wrexham.gov.uk or call 01978 298608 with any questions

Wrexham Dementia Listening Campaign

Do you live with Dementia or are you supporting someone living with Dementia in this area?

Come along for a chat and a drink and let me know your thoughts on Dementia Support in Wrexham.
Drop in –

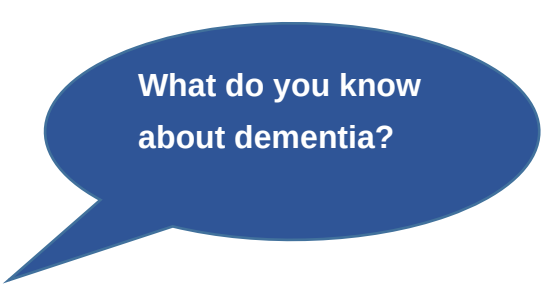
Thursday 28th September 2023
Parish Hall, Vicarage Hill, Rhostyllen, Wrexham LL14 4AR

9.30–11.30am

Led by Kate Evans Person Centered Planning Dementia Coordinator – WCBC
Katea.evans@wrexham.gov.uk or call 01978 298608 with any questions

Appendix 5: Wales Listens Campaign Example Questions

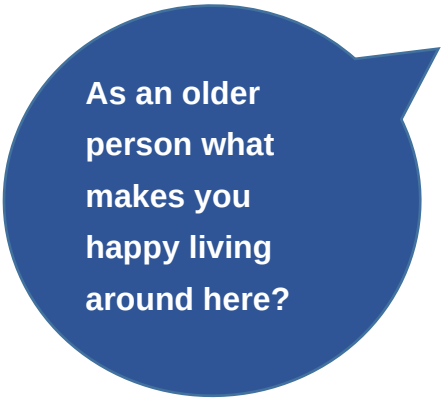
Example questions that can help you to have conversations with people in your community and gather their stories

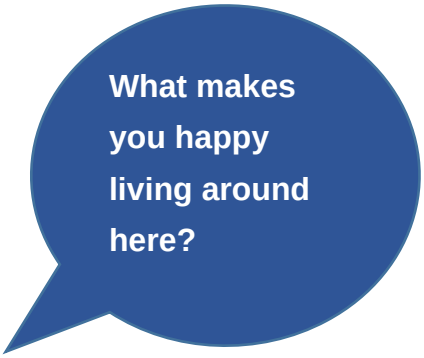


What does good dementia care look like around here?

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 Wrecsam	People of Wrexham
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 e-bost Adele.baguley@denbighshire.gov.uk Mae gennych tan 31ain o Ionawr, 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 January 2023 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: Listening campaign post box