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Anglesey dementia listening campaign

January 2024

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

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Summary

164 people who live in Holyhead 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.

- People are treated with compassion, understanding, and patience.
- Care is person-centred and based around what matters to the individual.
- People can make their own choices and decisions about their care.
- Unpaid carers, families, and friends are supported too and have opportunities for breaks from caring.
- Care and support in the right place and as close to home as possible.
- Care and support at the right time.
- Access to information and advice.
- Care is available through the Welsh language.
- Plenty of groups and activities for people to choose from.
- Communities are dementia friendly, inclusive, and accessible.
- People have the practical support they need.
- People have access to good healthcare.
- Care should be adequately funded.
- Care workers should be paid well and have good training.
- 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 to suit the individual; access to care and support; practical and financial support and help with benefits; transport; wider health care needs; information and advice; support for unpaid carers; and training and increased awareness.

What community means to you.

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

- Having the care and support they need.
- Access to good healthcare.
- Support for unpaid carers.
- Local groups and community support.
- Transport.
- Creating a dementia friendly community.
- Accessible services and environments.
- Making help easier to access.
- Financial help and funding.
- Technology and other aids.

Research methods

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

We held 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, Carers Trust, and Carers Outreach.
- 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 the local Dementia group, Knit and Natter Group, Warm Space at Milbank, Holyhead Library and Clwb Y Cob.

All these conversations were recorded on the listening record sheets.

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

Online surveys were shared on the Anglesey Council's Facebook, X 'Twitter' and Instagram pages. These were then shared by other social media accounts, including Medrwn Môn, Môn Actif and many others.

The focus of the listening work was Holyhead and surrounding areas. Other listening exercises are underway for other areas of North Wales.

Map showing the area of Anglesey where the paper surveys were delivered

Map data ©2023 Google

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

- Alzheimer's Society
- Anglesey County Council Staff via e-mail, over 1,000 staff.
- Carers Trust
- Carers Outreach
- Medrwn Môn
- Medrwn Môn mailing list
- Dementia Friendly Holyhead
- Mirli Môn Dementia Group
- Anglesey Council – Social Services
- Holyhead Community Resources Team
- Councillors
- Women's Institute County Federation Head Office
- Workforce Development – newsletter
- Town Council
- Ysgol Uwchradd Caergybi
- Business and Organisations at Holyhead

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 surgeries

- Victoria Surgery, Victoria Road, Holyhead
- Hwb Iechyd Cybi, Ucheldre, Holyhead
- Ysbyty Penrhos Stanley, Holyhead

Care homes

- Garreglwyd, Dementia Care Home, Holyhead
- Fairways Nursing Home, Holyhead

Dental surgeries

- Deintyddfa Cybi, Holyhead

Pharmacies

- Rowlands, High Street, Holyhead
- Boots, High Street, Holyhead
- Tesco Pharmacy, Holyhead

Other

- Library
- Leisure Centre
- Specsavers
- Tesco
- Morrisons
- Asda
- Standing Stones Holyhead
- Holyhead Countryside Park
- McDonalds
- KFC
- Ucheldre Centre
- Gwelfor Community Centre
- Holyhead Weightlifting Centre
- Jesse Hughes Centre

Information stands were held in the following centres to raise awareness of dementia, information on where to seek help, and conducting the listening campaign. We spoke to 109 residents at these events.

- Canolfan Milbank
- Holyhead Library
- Neuadd Llaingoch
- Clwb Y Cob

Results

164 people provided responses to the listening campaign. 109 responses came from group listening events where participants were aged 50 to 72 and were members of the community.

Most of the 55 individual responses came from family members and friends (including unpaid carers) or members of the local community. There were no responses from people living with dementia themselves.

Most of the 55 individual responses were given in English, with 15% completed in Welsh.

Figure 1: roles of respondents to online or paper survey

Role	Number of participants	Percentage of participants
A family member or friend of someone living with dementia (including unpaid carers)	30	55%
A member of the local community	18	33%
Someone who works as a health or social care professional	5	9%
In a different role	3	6%
Someone providing paid care and support services	1	2%
Someone living with dementia	0	0%
Total	55	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%.

The different roles mentioned were a person who had previously cared for a person living with dementia who has since died and a county councillor.

We had participants from a range of age groups. Around 9% of respondents were under 25, and 4% were 75 and over.

Figure 2: ages of respondents to online or paper survey

Age	Number of participants	Percentage of participants
11 to 25	5	9%
26 to 34	1	2%
35 to 44	7	13%
45 to 54	15	27%
55 to 64	19	35%
65 to 74	6	11%
75 and over	2	4%
Total	55	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?

People are treated with compassion, understanding and patience.

Good dementia care is kind, caring, understanding and patient. People are shown empathy and compassion by someone who understands the struggles they face. They should feel safe. There is good communication, making time to talk to people on a one-to-one basis, listening to what they have to say, and making time for them. Care workers are responsive, adaptable, efficient, creative, and proactive. Carers should ensure that the person is looked after well, taking care of their physical and emotional needs.

Staff have the skills, training, knowledge, experience, and attributes to provide high quality care and support. They should be reliable so that the person living with dementia has continuity of care and there isn't a different care worker each day. They should be committed and visit regularly, so they become familiar to the person. There needs to be enough staff available to provide high quality care.

> Caring, patient, kind members of staff. Staff that take the time to talk and get to know the person. Carers that provide lots of activities and games to keep the patients engaged and happy. Staff that make the effort to take patients out. Staff that inform family of incidents and keep them updated regularly. (Community member, age 26 to 34)

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 flexible and tailored to meet each person's needs. It involves getting to know people, valuing them, and forming meaningful connections. Support should be based on the best interests of the person, wrap around style care, so they feel they are understood, and that their care is personal to them. People shouldn't have to fit into the services on offer, the services should be adapted to their needs, and needs should come before costs.

For people in the more advanced stages of dementia, extra care needs to be in place, care should be adapted along with the progression of their dementia. Care 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 section support for carers, family and friends.

Person centre care with the best interests of that person as priority where possible enabling them to live as independent as possible whilst also being safe and having a quality of life. (Health and care professional, age 35 to 44)

Different for every individual/family. Physical and emotional support that is adaptable through every stage and variation of illness. (Unpaid carer, age 55 to 64)

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

People living with dementia should have choices and be directly involved in discussions and decisions about their care. There should be liaison between the family and professionals, family concerns should be listened to, and they should be encouraged to be involved in their care.

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 want to be listened to and be involved in making decisions about care.

Unpaid carers need breaks from caring as it is hard work caring for someone 24 hours a day and unpaid carers often have their own health conditions. Help can be hard to find, can be limited, and is often not available.

Suggestions of ways to support unpaid carers.

- Respite care.
- Day care and day centres where the person with dementia can be cared for.
- Care provided at home or taking the person out.
- Support for friends and family.
- Someone to talk to.

- A physical space where support can be accessed.

Some participants mentioned that families should be kept updated regarding their family member and should be informed about any incidents that may have occurred when the person with dementia is under the care of someone else.

Cefnogaeth gryf i ofalwyr Digon o ddarpariaeth ar gyfer unigollion â dementia ee cynnig mwy nag un diwrnod yn Hafan Plas Crigyll Cael gweithwyr cymorth i fynd ar unigolion allan am y bore neu b'nawn, mynd â nhw am dro mewn car, ymweld â chaffi efallai. [Strong support for Carers. Enough provision for individuals with dementia e.g. offer more than one day at Hafan Plas Crigyll. Get enough support workers to take individuals out for the morning or the afternoon, take them out in the car, café visit maybe.] (Unpaid carer, age 45 to 54)

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

It's important to receive care close to home, including care packages so the person can remain at home for as long as possible. It's important that people retain a good quality of life and independence where possible, the use of technology can help this whilst helping the person to live safely at home. When residential care is needed, it should be close to family allowing them to remain part of their life. Services should be provided locally, within the community. It can help to have care provided in familiar surroundings.

Some participants felt care should not be provided by the private sector and there should be council run care homes available.

Another person commented on the good care provided at Plas Penmon.

Thinking that Dementia care is to make sure that the person with Dementia is looked after well. Being in the family setting or in homes if things have come to hard at there own home/Family and care is not enough. This means to the Dementia person it is really important that the homes are not to far away for family's to still play a part in the loved once life. (Health and care professional, age 55 to 64)

Care and support at the right time.

Dementia care needs change over time and support needs to be available at the right time in the journey, following a clear pathway. Early diagnosis and support immediately following diagnosis can help before people reach crisis point. The diagnosis process should be done as quickly as possible, and help needs to be available right away.

It can help to have a named person that the person living with dementia and their carers can contact.

Care needs to be available whenever it is needed, when families ask for it, and this should be accessible 24 hours a day seven days a week.

Immediate support on diagnosis and after care for individual and the family. (Community member, age 35 to 44)

Teulu i fod i gael gwybod pa gymorth sydd ar gael yn syth cyn cyrraedd pwynt argyfwng. [Family are supposed to be informed what support is available straight away before reaching the crisis point.] (Unpaid carer, age 45 to 54)

Access to information and advice.

Information needs to be easy to access, support will often be needed to help people navigate all the information available. Support needs to be available in many ways including in person, over the phone, and online. People need to know where to go to get advice and support, with information on what to expect and what the journey looks like following diagnosis.

Support should be available in the local community, with someone to talk to, and it should be available 24 hours a day. No-one should feel alone.

One suggestion was that services provided by the Alzheimer's Society should be available locally, to the same extent that they are in other areas of the UK.

Information on the structure and the journey to take after a diagnosis. More knowledge. Knowing who to get in touch with. Knowing where to go for support. (Community members, age 50 to 72)

Care is available through the Welsh language.

If someone needs Welsh language care, then their care and support should be provided in Welsh.

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 to help people living with dementia stay engaged and happy. It's important that these groups are local and close to home, with transport available if needed. Support should be provided to enable people to attend activities where needed. Suggestions for activities include:

- places where people living with dementia can go to socialise – pubs, hubs, community centres, or cafes.
- activities that can involve family and friends as well.
- group activities.
- people to visit people in their homes.
- volunteers offering a befriending service.
- day trips.
- day centres.
- Carers Trust support groups.
- one to one support.

There was also praise for named services including Gwelfor and Hafan (Plas Crigyll).

> Actively encourage and involve relatives/friends with care and regular activities. (Unpaid carer, age 45 to 54)

Communities are dementia friendly, inclusive, and accessible.

There's an important role for communities in understanding and supporting people affected by dementia. It includes making public places in the community safe and accessible such as libraries, community centres, GP surgeries, shops, restaurants, and cafes. Ensuring those with dementia can access community services and facilities. Participants mentioned the importance of actively involving people living with dementia, so they feel involved, included, and valued in their community.

Participants suggested ways to make communities more inclusive including providing training for communities about dementia awareness and how to support people through the different stages of dementia. Having dementia champions can help to raise awareness of dementia in the community and inform the community regarding actions that could improve the lives of those living with dementia.

Educating children in schools about dementia can help them understand the situation, however, there were conflicting opinions and not everyone is supportive of this idea. Educating the community means they can be actively involved in supporting those living with dementia and their families.

> People living with dementia should be able to access community services, facilities should be available to them that are dementia friendly that they are able to understand and cope with. Facilities should be availabe to support the person with dementia and their carer/family. The general public/shops/libraries/GP surgeries/leisure centres/cafes/restaurants etc should all attend dementia friendly training. (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 personal care, shopping or paying bills.

People have access to good healthcare.

People should have access to fast diagnosis, and be given regular check-ups, provided by a good healthcare team who do their best to not make the person distressed. GPs should provide guidance, be understanding and listen to any family concerns. If the person requires care in hospital this should be adapted to meet the needs of the person with dementia, suitable food should be provided if the person has trouble chewing and swallowing.

It was suggested that work should be done around preventing dementia, and encouraging healthy living, as there are a high number of older people in Anglesey which means numbers of people with dementia may also be high.

Faster diagnosis. Listening to concerns from family members…GP surgeries understanding that when someone has concerns for a family member this is handled sensitively. More robust measures in place so the patient concerned isn't distressed when enquiries take place. (Unpaid carer, age 35 to 44)

Care should be adequately funded.

The good dementia care described above needs to be affordable for people to access it as regularly as they need. It should be adequately funded to ensure the provision meets the needs of the community.

Care workers should be paid well and have good training.

Participants said that paying carers well will help attract more people into the profession, help to retain the workforce, and lead to better quality of care. Those working with those with dementia should be well trained, they should be dementia specialists. Some participants recommended the specific use of Admiral Dementia Nurses. There should be an adequate number of carers, support workers, and so on, to ensure the care that is needed can be provided.

Care workers trained to support those affected by dementia effectively, which involves paying a higher wage to attract and retain a high quality workforce. (Community member, age 35 to 44)

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

Participants described support which is collaborative, joined up, with joint working and good communication between different providers. It was suggested that someone such as a social worker should be allocated to a family to provide support and to help co-ordinate care between different agencies.

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

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

Chawsom ni fawr ddim efo Dad, mi gawsom ni bamffledi ond dim oedd o wir gymorth. [We didn't get much with Dad, we were given pamphlets but nothing that truly helped.] (Unpaid Carer, age 55 to 64)

My Nan suffered with Dementia for years and as a family we couldn't find support for her at all. My aunt working full time had to leave her family to sleep over every night at Nans house, and my other aunt would spend all day with her leaving a poorly husband at home and having suffered cancer and a heart attack previously herself. There was only 1 centre that would support for a few hours once a week on Anglesey. (Community member, age 45 to 54)

Does dim gofal dementia addas i bawb ar yr ynys. Teimlaf bod yr hyn sydd ar gael yn brin a dim modd i'r bobol eu mynychu os nad oes teulu i fynd a nhw. Mae prinder staff ym mhob maes o'r gofal yn creu problemau. [There is no suitable dementia care available for everyone on the Island. I feel that was is available is scarce and there is no way for people to attend unless they have family to take them. Staff shortages in all areas of care are creating problems.] (Unpaid carer, age 55 to 64)

When my brother was diagnosed with early onset Dementia in his 50's we had nowhere to go for help and support. (Unpaid Carer, age 55 to 64)

Signposting is very sketchy throughout their journey… currently no care packages available… respite care thin on ground (Health and care professional, age 55 to 64)

Hafan at Plas Crigyll provides good dementia care for those with care needs but is not readily available to everyone on the island due to distance. (Community member, 55 to 64)

DIM gofalwyr ar gael i fy nhad na chefnogaeth i r teulu iw edrych ar ei ol. Diffyg gofalwyr yn broblem erchyll ar Ynys Mon... Pobl gyda dementia i fod i gael gofal gwell yn yr ysbyty. Diffyg ymwybyddiaeth or cyflwr yn golygu bod fy nhad wedi cael profiad hunllefus yn yr ysbyty. Staff yn gweiddi arno. Sicrhau bwyd addas yn yr ysbyty- Bwyd hollol anaddas yn yr ysbyty. Rhoi bwyd fel afal cyfan/ darnau mawr o gig i berson oedd wedi anghofio sut i gnoi a llyncu. [NO carers available for my Father or support for the family to look after him. Lack of Carers is a massive problem on Anglesey…..people with Dementia are supposed to have better care in hospital. Lack of understanding of the condition meant that my Father had a nightmare experience in hospital. Staff shouting at him. Ensure suitable food in hospital. Totally inappropriate food given in hospital. Gave food such as a whole

apple / big pieces of meat to someone who had forgotten how to chew and swallow.] (Unpaid Carer, age 45 to 54)

We were let down when my father lived at home and needed help. (Unpaid Carer, age 45 to 54)

My mum has given up every aspect of her life to look after my Dad. 24hours a day. He would not be with us if it wasn't for the care my mum gives. Assisting him with EVERY aspect of daily living. (Unpaid Carer, age 35 to 44)

Prinder gofal ysbaid ar Ynys Mon, a pobl yn gorfod disgwyl yn hir amdano. [Lack of respite care available on Anglesey, people have to wait a long time for it.] (Community members, age 50 to 72)

Carreglwyd has facilities for Day Care respite. There’s none on Holyhead since Covid. (Community members, age 50 to 72)

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. Some people commented that ‘everything’ should be available, including all the things that are available to the general population.

A range of activities to suit the individual.

The importance of a range of activities was again expressed in this question. It was mentioned that there should be more opportunities for those living in residential care settings to interact with the community, participating in community events or bringing community activities to care homes. There needs to be a range of activities including dementia specific groups and general activities in the community being made accessible for all. People living with dementia should feel part of and included in their community, without stigma. Activities should be dementia friendly and appropriate for the age of the person and the stage of their dementia.

There need to be suitable facilities available in the local community such as community centres, pubs or hubs which are safe and comfortable for those living with dementia to access.

Activities should cover the differing needs and interests of people – examples included women’s groups, men’s sheds, friendship groups, therapy, the outdoors, walks, days out, social groups, events, or visits.

People should be able to attend sessions for as short a time or as long as they like, not be confined to specific times. Activities should be available in their chosen language. People living with dementia should be able to choose and only attend activities if they want to, and there should be alternatives available for people who do not like groups or social activities.

Mirili Môn was mentioned as an excellent example of a provider of these services.

Activity and friendship groups that are dementia friendly and age/stage appropriate. (Unpaid carer, age 75 and over)

Things for people to do if they’re not social and don’t like going to groups. (Community members, age 50 to 72)

Access to care and support.

Participants talked about how important it is to remain at home for as long as possible. To maintain independence equipment, technology, and adaptations should be provided to ensure home remains safe. Support at home should be provided as needed and not just in a crisis. It should be seamless, adequate, easy to access, available 24 hours a day, and delivered by properly trained staff. Support should be available for people who do not have a diagnosis.

Care plans should be detailed and personal as a one size fits all approach is not appropriate. Carers should be part of a dedicated support team and ideally the same carers should be used with regular contact, so they are familiar to the person, and can develop a relationship and trust. Care should meet all the person's needs, including physical and emotional, taking the time to talk.

When residential care becomes needed, it should provide people living with dementia a safe space, including a garden.

Some people may not ask for help, so it is important that help is offered, and regular contact is made with those not receiving support.

Gofalwyr ar gael ir person gallu byw gyda pharch yn ygymuned. Gofal gyda ymolchi, hylendid personol fel torri gwallt yn y cartref. Dylai pobl gyda dementia gael mynediad at feddyg teulu i ddod ir cartref yn hytrach na thrafeilio ir meddygfa. Dylsai pobl gyda dementia gael adnoddau iw helpu am ddim fel adnoddau iw diogelu yn y cartref. Dylsai pobl gael cymorth i addasu eu cartref ee symud gwely i lawr grisiau, stafell molchi i lawr grisia. Dylsa nhw gael cymhorthydd cymdeithasol syn gallu dod ir cartref i ofalu am berson tra maer aelod or teulu yn cael cyfle i siopa. Dylsa nhw gael cymorth gyda gofalu am eu harian/ bils ty//gwaith papur/ cymorth os yn gorfod cysylltu gyda banciau neu cysylltu gydar cyngor. [Carers available so that a person can live with respect in the community. Care with washing, personal hygiene such as cutting hair in the homes. People with dementia should have access to a GP visit to the homes rather than having to travel to the surgery. People with dementia should have free resources such as things to safeguard them in the home. People should receive assistance to adapt their homes e.g. move the bed downstairs, bathroom downstairs. They should have a social assistant that comes to the house to care for someone while a family member goes out shopping. They should get assistance to

look after their money / household bills / paperwork / assistance if they have to contact the bank or the Council.] (Unpaid carer, age 45 to 54)

Daily support where needed. Tailored help depending on the severity of the condition. A good relationship built on trust and familiarity. (Unpaid carer, age 35 to 44)

Practical and financial support and help with benefits.

Many people mentioned the need for financial support, help with direct payments, and help with benefits. There is a need for some people to have support looking after their money, paying bills, completing paperwork, contacting the council or the bank. There is a need for someone to advocate for help for the person with dementia. Also, there needs to be enough adequate housing. Other practical care needs mentioned included bathing, personal hygiene, haircuts at home, and meals on wheels.

Transport.

Transport, including accessible and low-cost community transport, was frequently mentioned, along with the need for assistance to help people get out and about and access appointments and the activities listed above. Transport needs to be dementia friendly as it was mentioned that public transport can be scary for people with dementia, and taxis are different each time and don't have the time or patience that is needed.

Activities/groups with transport; Walking and following directions became a challenge very early in the diagnosis, public transport was scary and was not an option. Taxis were ok in the beginning but drivers did not have the time, patience or understanding when getting in and out and later down the line this also became difficult because it was a different colour car or driver each time. (Unpaid carer, age 55 to 64)

Wider health care needs.

There's also a need for more support for wider healthcare needs and to improve access to healthcare for those living with dementia, recognising they can have additional health needs such as issues with mobility. More hospital staff should specialise in dementia. There is a need for more staff such as psychiatrists, community psychiatric nurses, and crisis teams, working full time to provide consistency. GP services should provide home visits for those with dementia. Health

services should work collaboratively, with good communication, to ensure a seamless service with a single point of access.

> Full time consistent Psychiatrists and CPN's in CMHT at Cefni, better communication between all services, a single point of access to services (where the people there can signpost and have all info to, support ,help instead of people being left to flounder. (Health and care professional, age 55 to 64)

Information and advice.

People should have access to clear and jargon-free information and advice about:

- the diagnosis, disease, and where to go to get help.
- services available and how to access support locally.
- funding that is available.
- activities and events that are available.

Information and advice should be available in various formats including face to face. Suggestions for how information and advice should be available included via meetings, drop-in services, and a one-stop-shop.

> Easier access and information on what is available to look after someone with dementia – one stop shop. (Paid carer, age 55 to 64)

Support for carers.

Support needs to be available to carers too. There needs to be help available around the clock, with consideration for those who need to work who often don’t sleep due to caring responsibilities. It was mentioned that there was a need for more than is currently available. Carers are often elderly themselves and can be “frail and exhausted”. Support should be provided without delay and be sufficient to prevent carers reaching crisis point. Carers should also have access to emotional support to help them come to terms with the diagnosis and the ongoing pressures of being a carer for someone living with dementia.

There should be access to day centres to provide respite care for carers, giving them a chance to have a break from caring. Hafan Plas Crigyll was mentioned as a good provider of day care services.

Families should receive help to write profiles for their loved one, to help services better understand the person they are caring for.

Plas Crigyll (day unit) da iawn - Ella mwy o ddyddia i roi brec i teulu/gofalwyr mynd a nhw am dro - Cerddad neu am banad - Ella rhyw fath o ty dementia - Lle saff gyda gardd i fynd a nhw i roi brec i'r teulu a rwbath iddyn nhw gael mwynhau. [Plas Crigyll (day unit) is very good – maybe more days to give family / carers a break and take them out – for a walk or cuppa – maybe some kind of dementia house – A safe place with a garden they can spend time which would give the family a break and would be something they can enjoy.] (Carer previously, age 45 to 54)

Training and increased awareness.

The community needs to be dementia friendly, with its members aware of dementia and understanding the needs of those living with dementia. Training should be provided to carers, health and care professionals, children in schools, and the general community. Training should include what dementia is, how to identify it, how to support families and people with dementia, the dementia pathway, and the Herbert protocol. Having more dementia champions and awareness events in the community could help to increase awareness.

What does community mean to you?

Participants described how communities can be based around shared or common interests, passions, experiences, attitudes, values, needs, conditions, cultural heritage, language, or be any kind of close-knit group of people who get along. Many referred to a place or proximity, such as the local area, neighbourhood, village, town, Anglesey, Wales, where we live, or the same home.

Some participants also said their communities are important to them, and they are everything. One described community as ‘the heart of our village’. Others didn’t feel part of a community, one said it meant ‘nothing’. Another person commented that community is different for everybody. One comment mentioned how community worked well during the lockdowns (Covid).

Characteristics of communities included:

- Being part of a group or involved in groups. A sense of belonging, inclusion, and acceptance. Feeling part of something. A place where people know you, where things are familiar and comfortable. Feeing safe and happy and not feeling alone.
- Working together to support, help, care, and look after each other, with people’s best interests at heart and to create a better community. Looking out for each other, for example neighbourhood watch. Collaborating, everybody having a role sharing their skills. Building a social resource.
- Practical help, such as helping people attend activities, or giving people lifts. Support and respite for unpaid carers.

- Knowing you can ask for help or advice, and where to get it. Somewhere you can reach out to for support, advice, and services. ‘A hub of knowledge and information’. People feel confident to give and receive help.
- Accepting people regardless of their conditions or abilities. Non-judgemental, and understanding. Making adjustments and helping people to get out, so everyone can participate in the community, removing any barriers. Supporting vulnerable people and their families.
- Bringing people together, strength and togetherness.
- Opportunities for socialising and providing good company so that people aren’t isolated. Being friendly. Getting out, seeing people, having conversations, and communicating. Knowing your neighbours and speaking to them. Getting to know new people, being interested in them, and making friends. Meeting regularly, creating a good atmosphere, enjoying food together.
- Friends, family, neighbours, residents, carers, volunteers, and other networks of support. Family or friends that are close by but knowing you don’t always have to rely on family. Some participants described the people in a community as a ‘unit’, ‘body of people’, ‘faces’, ‘everybody’, ‘general public’ and ‘unique family’.
- The public services that serve the community. The cafes, shops, NHS, support agencies, and libraries. Access to good transport.
- Community events, groups, clubs, and activities, with opportunities to stay active and facilities to meet such as libraries, and community centres.
- The environment is safe and is well kept.

Two people described communities for those living with dementia. One described how communities should have set patterns, where roles are clear, and things run like clockwork. Another described how people with dementia can feel confused by their community, especially if they were previously in a different place.

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

Pobl yn edrych ar ôl ei gilydd. Lle mae pawb yn teimlo'n ddiogel. [People looking after each other. Where everyone feels safe.] (Unpaid carer, age 55 to 64)

An essential social resource that shares my passion for protecting my language and culture. (Unpaid carer, age 45 to 54)

It should be where I am safe ,where I know and look out for neighbours and visa versa where I am able to ask for help if I need, where people know where to get it. (Health and care professional, age 55 to 64)

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

Having the care and support they need.

Care should be person-centred, regular, the best possible, and delivered as promised. Care should be provided in their home allowing the person to remain independent, and to stay in their own home for as long as possible, with extra consideration for those living in rural areas. It includes physical, emotional, and practical care, including eating, bathing, dressing, shopping, gardening, and talking. This should be from dedicated dementia trained staff based on the values described in the section 'what does good dementia care look like?'. People should have confidence in the care being provided, someone suggested care should be approved by a body or organisation.

People to visit those who can't get out to visit groups. Some people may need befrienders, community members, or care co-ordinators to help them navigate support, attend groups and appointments, or get out and about. People also mentioned day centres as well as accessing local groups and community support.

Care and support should be provided by a supportive network of services, that communicate with each other, including council, health, and voluntary sectors. All services should be available in Welsh.

> This question is too personalised, to be honest, the person centred care plan should reflect this if the pathway is delivered as promised. (Unpaid carer, age 45 to 54)

Access to good healthcare.

Those living with dementia and their unpaid carers should have easy access to healthcare, with face-to-face appointments available. Health care should work to ensure the person maintains or develops good physical health where possible. There is a need for more health and social care professionals, and they should be available across all local areas.

Support for unpaid carers.

Unpaid Carers were described as the most important thing to help those living with dementia and it was stated some unpaid carers are 'on their knees' providing care

around the clock, so it is essential that they receive the support they need to continue this vital role. This includes breaks from caring (respite care, day centres, etc), someone to call, support groups, and drop-in centres. Care and support should be available 24 hours a day and it should be local. Advice should be provided so families know where to go for help, how best to support their loved one, and what to expect through the various dementia stages. Support should be offered to unpaid carers as they are often afraid to ask for help. One suggestion was that care plans should include the needs of the unpaid carers, and unpaid carers should be listened to when developing plans and throughout their care.

Feeling supported. Respite. Better to seek advice from those suffering with dementia and their carers, Im fortunate that I don't know anyone directly, just friends who provide 24 hour support to loved ones with the disease and are on their knees, and find it so hard to ask for help. (Community member, age 55 to 64)

Local groups and community support.

This includes support groups for people living with dementia and carers along with involvement in other groups and activities of their choice for fun, socialising and to stay active. Support should be provided for people to join, get to, and participate in these activities. Groups should be local, warm and welcoming, encourage people to join in, and regular. Suggestions include outside activities, events, elderly social groups, lunch club, afternoon tea club, bingo, singing, cooking, creative arts, walks, dancing, and support groups.

Again, these activities should be based around what matters to the individual and their family so people can continue to do the hobbies and interests they previously enjoyed. Recognising everyone is different, so there needs to be activities to suit everybody.

Venues and buildings are needed that are accessible for those living with dementia. These venues should be local and easy to access, including village halls, community centres, and hubs.

Anglesey needs more activities for the elderly to get together, e.g. lunch club, afternoon tea club, and fun activities like a bingo, singalong. Dementia can be a very lonely disease. (Unpaid carer, age 45 to 54)

Being part of a community and having a dementia friendly community is very important. Friends, family, and neighbours can help people to keep doing the things they enjoy. People mentioned carers, members of the community, or befriending to reduce isolation and to support people to attend local groups.

Many people mentioned the importance of transport to be able to access this kind of support and days out.

Gweithwyr cefnogi fel bod modd i'r bobol sydd gyda dementia allu mynd allan i'r gymuned/am dro/cymeryd rhan mewn gweithgareddau. Trafnidiaeth ar gael i gludo'r bobol sy'n byw gyda dementia i'r ganolfan a'r gweithgareddau. Mae diffyg mawr yn y gwasaneth yma ym Môn. [Care workers so that people with dementia can go out into the community for a walk / take part in activities. Transport available to transport those living with dementia to the centre and activities. There is a big lacking in this service in Anglesey.] (Unpaid carer, age 55 to 64)

Transport.

Transport was raised by many participants as key to helping people living with dementia, one person stating transport as being a 'big issue' in Anglesey. The provision of transport included the need for transport to attend events and activities as well as medical appointments.

Transport suggestions

- Dedicated transport for those living with dementia.
- Affordable transport or support with transport costs.
- Improved public transport, increased frequency and coverage, not just main roads, and towns. Someone gave an example of Morawelon as having good transport links.
- A bookable minibus service.
- Enough taxis to meet the needs of the local area.
- The 'Post Bus', which involved the post service combined with a bus service, was mentioned as a system that worked well.

Providing transport and support for people to attend events can also help provide a break or respite for unpaid carers too.

Minibuses sy'n mynd trwy'r pentref Dwi'n lwcus gallu dreifio a dreifio yn y nos Dwi'n banned o dreifio yn y nos, angen help gyda trafnidiaeth gyda'r nos Pobl yn dibynnu ar y bws i nol pensiwn ond dim bysys ar gael Post Bus yn dda o'r blaen (fan bost a bws mewn un) Post ar amser Dwi'n iawn tra allai dreifio. [Minibuses that drive through the village. I'm lucky to be able to drive and drive at night. I'm banned from driving at night, need help with the evening transport. People depend on the bus to go and get their pension but no buses available. Post bus used to be good (post van and bus in one). I'm ok while I can drive.] (Community Member, age 50 to 72)

Dedicated transport available to all not just those on the main roads or larger towns. (Community member, age 55 to 64)

Creating a dementia friendly community.

Many participants spoke about the importance of understanding and acceptance for helping people living with dementia, reducing stigma and being 'stared at'. This includes raising awareness among people of all ages, and particularly schools, chapels, pubs, libraries, and workplaces to create a dementia friendly community. Education and training should be provided regarding the following areas:

- Awareness of dementia, identifying it, symptoms.
- How dementia impacts the person and their family.
- Types and stages of dementia.
- How everyone can best support or handle someone living with dementia.
- People with dementia are important to the community and can still contribute.

Other things that can help the community be dementia friendly include keeping to a routine and ensuring places remain familiar to the person living with dementia. Places and people should be welcoming and inclusive, as someone commented 'dementia can be a very lonely disease'.

Support from all, eveyone needs to understand how they can support people living with dementia. Lots of training for all to understand how they can help. (Health and care professional, age 55 to 64)

To raise awareness of what Dementia actually means to individuals and how it affects their daily lives and that of their family and carers. (Community member, age 18 to 25)

Accessible services and environments.

Improving access to the physical environment, facilities, and venues for people, making sure places are accessible, including banks, councils, GP surgeries, and post offices. Being accessible includes running events and meetings at a time that suits people, for example not just first thing in the morning. Making sure services are not just available online so they can be accessed by those who do not have access or do not want to go online, providing face to face appointments, that are close to home. The environment needs to be safe and adequate lighting should be provided.

Less pressure to go online. If I'm not online I feel disconnected. I got help to use the NHS app, but I'm not interested. I want to speak to a human. (Community member, age 50 to 72)

Making help easier to access.

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

- someone to help them navigate and signpost to the support available.
- Services to provide support without people having to ask or to follow up, as some find it hard or are scared to ask for help.
- improve advertising and communication around available support and events using a range of methods. Some people mentioned they don't go online and don't want to.
- someone to 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.
- support available immediately after diagnosis, not having to wait.
- making it easier to apply for support, again not just online.
- making support available across the island, not just in towns.

More information immediately following diagnosis of what support is available and where to find it. (Unpaid carer, age 55 to 64)

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 for everyday expenses such as transport and food, and funding for activities, care, and staff such as Admiral nurses.

Technology and other aids.

Technology and aids can help people around the house and keep them safe. Examples given were fire alarms, personal alarms, and home security.

Conclusion

Many of the people who took part in the listening campaign were unpaid carers but there were no responses from people living with dementia, so it would be important to make sure their voices are heard when designing any services for them. The themes which were raised seemed fairly consistent between the different groups that did participate and there was a lot of agreement about what good dementia care looks like.

The purpose of this engagement was to find out what dementia care means to a community, so we spoke to a wide range of people, many of whom had experience of supporting friends or family living with dementia. 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, including activities for individuals who do not like groups. 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.

An issue that was raised repeatedly by many participants was the need for more consistent local provision of services across Anglesey, including better provision of transport. There is a need for improved access in more rural areas outside of towns.

There was a lot of support from members of the community regarding awareness of dementia, learning more about dementia, and how best to support people living with dementia. With a community willing to help those living with dementia be included within the community this provides a great opportunity to build on the good work already taking place in Anglesey 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: ebangeal@ynysmon.llyw.cymru (Dementia Officer, Anglesey Council) or call 01248 752957.

Please return completed surveys to Gwelfor Community Centre, Ffordd Tudur or Holyhead Library, Stanley Street. Alternatively you can scan the QR code to complete the survey online.

If you need help to fill in the survey phone 01248 752957 or email ebangeal@ynysmon.llyw.cymru.

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 Gwelfor Community Centre, Ffordd Tudur, Holyhead, LL65 2DH or Holyhead Library, Market Hall, Stanley Street, Holyhead, LL65 1HH.

If you need help to fill in the survey email ebangeal@ynysmon.llyw.cymru or phone 01248 752957.

The consultation closes on 31 December 2023.

Appendix 3: Introductory Letter

BWRDD PARTNERIAETH RHANBARTHOL
GOGLEDD CYMRU
NORTH WALES
REGIONAL PARTNERSHIP BOARD

Trigolion Caergybi,

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 Caergybi. 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 Caergybi neu Gymuned Gwelfor Canolfan.

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.

Holyhead 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 Holyhead 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 Holyhead Library or Gwelfor Community Centre.

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

CYNGOR SIR YNYS MÔN ISLE OF ANGLESEY COUNTY COUNCIL

DEMENTIA ACTIF MÔN

Ymgyrch Gwrando Caergybi
Holyhead Listening Campaign

Llyfrgell Caergybi / Holyhead Library
Dydd Llun / Monday - 27/11/2023
10:00 - 14:00

Dewch draw i roi eich adborth ar y gymuned a Gofal Dementia

Come over to give your feedback on the community and Dementia Care

GWELLIANT CYMRU IMPROVEMENT CYMRU

MEDRWN MÔN

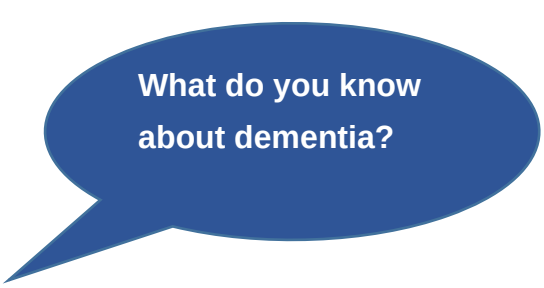
BWRDD PARTNERIAETH RHANBARTHOL GOGLEDD CYMRU NORTH WALES REGIONAL PARTNERSHIP BOARD

Ynys Môn Oed-Gyfeillgar Age-Friendly Anglesey

www.ynysmon.llyw.cymru
www.anglesey.gov.wales

Appendix 5: Wales Listens Campaign Example Questions

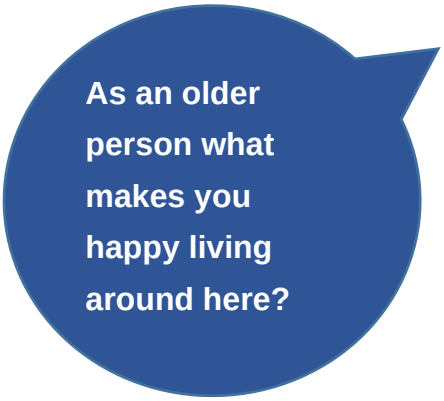
Example questions that can help you to have conversations with people in your community and gather their stories



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 Caergybi	People of Holyhead
Mae gwella gofal dementia yn fusnes i bawb	**Improving dementia care is everyone's business.**
• 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.	• 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.
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	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
Mae gennych tan 31ain o Rhagfyr 2023 i'w gwblhau.	You have until 31st December 2023 to complete the survey.
Diolch i chi am eich amser a'ch cyfraniad – gyda'n gilydd gallwn wella gofal dementia i bawb yn lleol a Chymru gyfan.	Thank you for your time and contribution – together we can improve dementia care for everyone locally and across Wales.