

Denbigh dementia listening campaign October 2023

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

















Contact us

North Wales Regional Partnership Board

County Hall, Wynnstay Road, Ruthin, LL15 1YN

Email: northwalescollaborative@denbighshire.gov.uk

Phone: 01824 712432

Website: www.northwalescollaborative.wales

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Summary

Over 200 people who live in Denbigh 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.

- People have the best quality of life they can and are loved.
- People are treated with dignity, 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.
- 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.
- People have the practical support they need.
- Communities are dementia friendly, inclusive, and accessible.
- People have access to treatments, medicines, and therapies.
- Care is affordable and people have access to financial help and advice.
- Care workers should be paid well, and have good training and terms and conditions.
- Services work together to provide integrated care that meets people's needs.
- We also need research into cures for dementia.

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 budgeting and benefits; transport; support with wider health needs; information and advice; support for carers.

What community means to you.



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

- Having the care and support they need, including paid care.
- Supportive and flexible health services.
- Support for carers.
- Local groups and community support.
- Transport.
- · Creating a dementia friendly community.
- Accessible services and environments.
- Valuing care work.
- Making help easier to access.
- Financial help and funding.
- · Technology and other aids.
- Research into treatments and interventions.
- Accommodation.
- Safeguarding and confidence.

Miss C's story

Hi, my name is Miss C. I retired to live in Rhyl eight years ago after being a general nurse for 15 years – which I loved. Two years ago, I was diagnosed with Early Onset Vascular Dementia.

It took me a long time to actually be diagnosed with vascular dementia, let alone to get support, and understanding of what was happening. I felt let down and not listened to. I had to fight for five years to get my diagnosis. I was moved from GP to the memory clinic, to the psychiatrist, back to GP, back to the clinic. I knew there was something wrong with me, obviously, by being a nurse and I knew my own body, I knew it wasn't just age and depression. It was only after someone left the memory clinic and a new Doctor took the post that I was diagnosed. He was brilliant, he just made me feel like a person and like someone was actually listening to me. He helped me understand the diagnosis and told me that I had vascular dementia because of my stroke that I had a few years before, and everything just opened up from there.

Before my diagnosis I felt let down by groups of people who were supposed to be professionals and not heard. Even now, I know that there's plans and strategies in place for later stages of dementia, but what about the beginning? What about right now? There's very little support or strategies in place – none that I've experienced anyways.

Through Denbighshire DVSC I was asked and supported to start a Dementia group in Rhyl and to help raise awareness, because there is nothing in Rhyl for people with dementia. I don't want what happened to me to happen to others and because my dementia is vascular, I wanted to set up a group for people that are at the beginning of the journey and try to help them get the right support and send them to the right people when they need it so they don't have to wait for ages. I want to change all that because I think that it's important that people aren't waiting, because once you have got that diagnosis it's a shock and then you are just left. You're just left and that's not right. We need something to be put in place from day one. From day of diagnosis, right the way till the end.

Since starting the group I've started being invited to different events and I've met such lovely people. The support and the understanding I have now is much better

and I'm feeling listened too. I'm also understanding myself and about dementia a lot more too.

It's by chance, that this has happened. It's by chance that I get to be a part of the group and invited to events and through all that actually discover what is out there. We need more signposting to services and help available to people living with dementia. Like how the Citizen's Advice Bureau have a discretionary payment for people who have dementia and are in crisis and not got much money coming in. That could really help someone – if they know about it.

Information like that is what I try to share at my groups. I think more groups are needed, more safe spaces and dementia cafes for people living with dementia and their carers. That way we have the opportunity to support one another and share our stories and any information or resources we have. That's what we do at my group. We're in one room and the carers go in another room and they have a chat, and they have a break, so if the person who's got dementia needs their carer they are just next door but they are getting a bit of respite and they can talk to other people, other carers, and share their stories and insights. Plus, we are away from each other in a safe way which is good for all of us. But more support is needed for that group to help run it and raise awareness and more spaces like that are needed.

I know that you're all professionals and have guidelines and limited resources but we're people. We're people living with dementia, and we're the experts. We're the only ones that actually know what living with dementia is really like. So, you've got to listen to us, not us listen to you and tell us what we need. We are all different, we all have different mechanisms and how we cope with certain things and we're all going to need different support. Whoever you go and see they're going to be different than the person you saw before. Not every person living with dementia is the same so we're going to need different support. So, listen. Listen to what we say and what we think we need. Visit us, ask us what we would like to do or what we would like you to do to help us and make it happen to the best of your ability. It's as simple as that.

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, 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; and
- local community activity groups including the young onset dementia group, the forget me not project, boccia group, knitters & natters group, Merched Y Wawr (Welsh Women's Organisation), Denbigh Rugby Club and cariad craft group.

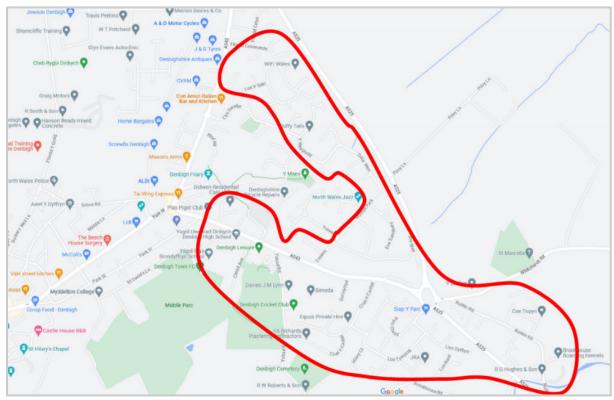
All these conversations were recorded on the listening record sheets.

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 local dementia care but were unable to take part in the listening sessions.

Online surveys were shared on Twitter and local Facebook groups, which included Caru Dinbych / Love Denbigh, Denbigh's Family, Denbigh Town Matters and the North Wales Dementia Network. A further 1,500 paper surveys were delivered to houses on the outskirts of Denbigh. Articles were posted in the Denbighshire Free Press and a local Welsh-medium newspapers/papurau bro to raise awareness.

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

Map showing the area of Denbigh 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:

- Age Connect
- Alzheimer's Society
- Caledfryn Denbigh over 350 staff members
- Carer's Trust
- Carers Outreach
- Community Arts Denbighshire Leisure
- Conwy and Denbighshire Care and Repair
- Cynnig (Disability services and support organisation)
- Dementia Aware Denbighshire Community Led Network
- Dementia Friendly Denbigh group

- Dementia Standards Five Task
 Groups with over 150 members
- Denbigh Golf Club
- Denbigh High School
- Denbigh Hwb
- Denbigh in Bloom group
- Denbigh Leisure Centre
- Denbigh Men's Shed
- Denbigh Museum
- Denbigh Rugby Club
- Denbigh Schools
- Denbigh Town Council
- Denbighshire Today
- Denbighshire Voluntary Service Council
- DVSC bulletin

- Grwp Cynefin Housing
- Making Sense Art Group
- Menter laith
- Merched Y Wawr
- MIND
- North East Wales Carers
 Information Service (NEWIS)
- North Wales Police
- Older People's Mental Health Service (BCUHB)
- Plas Pigot Country Club
- Regional and Operational Task
 Group with over 40 members

- Rotary Club
- St Mary's Church
- St Thomas's Church
- The Denbigh Workshop
- The Forget Me Not Project
- The Wings Club
- WI County Federation Head Office
- Workforce Development newsletters internally and externally
- Ysgol Frongoch and Denbigh High School
- Ysgol Frongoch Primary School

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

- Beech House Surgery, Vale St, Denbigh
- Middle Lane Surgery, Middle Lane, Denbigh
- Berllan Surgery, Vale St, Denbigh
- Bronffynnon Surgery, Bridge St, Denbigh.

Care homes

- Holland House Assisted Living,
 Lenten Pool, Denbigh
- Cae Glas Care Home, Vale St, Denbigh
- Llanrheadr Hall Assisted Living, Llanrheadr
- Y Gelli Assisted Living, Vale St, Denbigh

- Dolwen Residential Home, Ruthin Road, Denbigh
- Llys Medyg Nursing Home, Station Road, Denbigh
- Plas Eleri, Rhyl Road, Denbigh
- Awel y Dyffryn Assisted Living, Middle Lane, Denbigh

Community hospital

Denbigh Infirmary, Ruthin Road, Denbigh

Dental surgeries

The Hollies, Vale St, Denbigh

Pharmacies

- Boots, High Street, Denbigh
- Royles, Vale Street, Denbigh
- Rowlands, High Street, Denbigh

Other

- Library
- Leisure Centre
- Specsavers
- Copper Pot Café
- Ji Binc Café
- Mencap shop
- Baroque shop
- Ty Gwyrdd community shop
- North Clwyd Animal Charity shop
- Barclays Bank
- Co-operative food shop
- Post Office
- Merched Y Wawr

- Menter laith
- Hwb Centre
- Eiranfa Community Centre
- St Kentigern's
- Capel y Fron Welsh Calvinistic
 Chapel
- Bevan's
- Pure Hairdressers
- Haircraft Hairdressers
- Gift Galore
- Tony Griffiths Photo Frames

Information stands were hosted in the following supermarkets to raise awareness of dementia and where to seek help, and to promote the listening campaign.

- Morrisons
- Aldi
- Lidl

Stands were also hosted at the following events:

- Eisteddfod
- Denbigh and Flint Show
- The Royal Welsh
- Denbigh Plum Festival
- Denbigh Carnival
- Twm o'r Nant Theatre

Results

Over 200 people provided responses to the listening campaign. Most of the responses came from members of the community or family members and friends (including unpaid carers). Most of the responses were given in English, with 12% completed in Welsh.

There were only five responses from people living with dementia, so to make sure we had a fuller understanding of their views we spent a longer period of time talking directly with individuals living with dementia who shared their story in more depth with us.

Figure 1: roles of participants

Role	Number of participants	Percentage of participants
A member of the local community	91	45%
A family member or friend of someone living with dementia (including unpaid carers)	76	37%
Someone who works as a health or social care professional	38	19%
Someone living with dementia	5	3%
Someone providing paid care and support services	4	2%
In a different role	8	4%
Total	204	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 include:

- providing support to carers
- police
- housing officers
- people who have cared for people living with dementia in the past
- · retired health and social care professionals
- Llais Cymru

We had participants from a range of age groups. Around 3% of respondents were under 25, including some under the age of 18, and 9% were 75 and over.

Figure 2: ages of participants

Age	Number of participants	Percentage of participants
11 to 25	7	3%
26 to 34	16	8%
35 to 44	32	16%
45 to 54	42	21%
55 to 64	53	26%
65 to 74	33	16%
75 and over	18	9%
Total	204	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 have the best quality of life they can and are loved.

A full life where people have the best quality of life they can and have the opportunity for fun and happiness. Living in a loving and homely environment is a key part of this as well as making adjustments so people can live as independently as possible.

Good dementia care shows when the person is living the best life possible. They are happy, have a routine which suits their needs and in a familiar friendly place with friendly and patient carers who have a good understanding of how dementia affects them. (Carer, age 55 to 64.)

People are treated with dignity, understanding and patience.

Good dementia care is kind, caring, understanding and patient. People are shown empathy, sympathy and compassion and treated with respect and dignity. They should feel safe. There is good communication, and this includes talking directly with the person with dementia rather than about them, learning about them and making time for them. Care workers are friendly, reassuring and treat people how they would want to be treated. They should have the ability to step into the world of the person living with dementia to keep them happy.

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. There need to be enough staff available to provide high quality care.

Carer to be pleasant and offer a safe environment, and also engage well with the person. Treat the person like you would your own family. Get to know the person and have good insight into their hobbies, interests and family and friends. Include the person in activities, i.e. singing, talking, and all therapies on hand. (Community member, age 65 to 74)

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 what matters to the individual so that they can continue to enjoy the things they always have enjoyed. People shouldn't have to fit into the services on offer, the services should be built around them and they should have a say in how they are designed.

For people in the more advanced stages of dementia, extra care needs to be in place to make sure care workers have a good understanding of an individual's likes and dislikes, and who they are as a person. Care should be delivered in the person's language of choice and respect their cultural identity.

People living with dementia may also have other needs, such as problems with hearing or eyesight, so good care needs to take account of these too.

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-centred awareness of abilities and enabling as opposed to disabling – recognising a persons strengths and abilities and organising care and activities around the persons hobbies, past memories, giving the person the chance and the time to talk about what makes them tick (use of reminiscence aids – photos, music, cine films). All care should be focused around dignity for the person – and seeing the person behind the diagnosis. (Carer who also works in the dementia sector, 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. Good care is patient and understanding. People living with dementia should not be rushed or have other people's perspectives forced on them.

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.

Carers need breaks from caring as they say it can be intense and exhausting. Some carers may 'struggle in silence' rather than asking for help. Others find the process to get help frustrating and say it needs to be much easier to access.

Suggestions of ways to support carers.

- Respite care at local hospices or care homes.
- A place where family and friends can have time for themselves, knowing that the person with dementia is receiving specialist care.
- Day care and day centres where the person with dementia can be cared for.
- More carer days to prevent burnout.
- Support for friends and family about knowing where to go for help.

The most important thing is appropriate support for the carer / relative to enable them to continue to look after their loved one. (Community member, age 65 to 74)

So many families of someone with dementia are left to just get on with it, with no guidance or support. Many carers out there are juggling family and work commitments whilst trying to look after someone with dementia, causing them stress and health problems of their own. Free or at least affordable day centres are required to ease the burden on families. (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 reliable care at home for as long as possible, especially to keep couples living together. When living in a care home, it's important that people can retain some independence. Services should be provided locally, within the community, and include links to rural hospitals. It can help to have care provided in a familiar place.

Firstly home care is most important. My mum was kept in the infirmary against her will until she refused to eat any more. All she wanted was to be at home. (Carer, 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 from diagnosis to palliative care. Early diagnosis and support following diagnosis can help to intervene early before people reach a crisis point. The diagnosis process should be done as quickly as possible, and help needs to be available right away and not after months of waiting for an assessment.

It can help to have a named person that the person living with dementia and their carers can ask questions of as they arise, along with access to expert advice for support and education.

Care needs to be available seven days a week and often both night and day.

Emergency support should be available during all 24 hours without having to attend A&E.

Early days support and signposting to organisations that can help, and then following through making sure useful connections happen as the disease progresses. Many patients and carers will be in the older age group and need help making connections for patient and carer. (Carer, age 65 to 74)

Access to information and advice

Information needs to be easy to understand and 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. One suggestion was access to a specialist dementia nurse who could provide advice about any aspects of dementia.

One of the surveys was completed at a dementia awareness meeting where the participant living with dementia said that it was "extremely helpful - eye opening to all the care / help etc that is available in Denbighshire".

Knowing where you can get support with getting lost! Lots of organisations offer dementia support however it can be a minefield knowing who does what, and then waiting for people to get back to you can be too much and lead to crisis situations which may have been avoided had early invention been available. Being able to have respite care when you need it is key, and trying to get it should not be a stressful process. (Community member, age 35 to 44)

Care is available through the Welsh language.

Groups and activities, home care and care homes should all provide care through the Welsh language for those who need it.

Plenty of groups and activities for people to choose from.

Support groups for both carers and people living with dementia along with services and activities which help promote well-being, in the language of their choice. There needs to be a choice of activities so that everyone can find something they enjoy. It's important that these groups are local and close to home, with transport available if needed. They should be free, or at least, affordable. Suggestions include:

- a drop-in centre for dementia patients and carers to meet people living in similar circumstances;
- places where people living with dementia can go to socialise;
- groups such as singing, dancing, moving, chatting and adapted sports activities;
- reminiscence sessions, and memory cafes;
- people to go into homes and sit with people living with dementia, to support their wellbeing as well as the wellbeing of their carers;
- dementia worker who sees people living with dementia weekly;
- giving some people (staff or volunteers) a role in community groups to make sure people living with dementia are engaged and included;
- groups for people at different stages of dementia;
- tea and coffee mornings;
- carer days;
- day trips out;
- day centres;
- one to one support; and,
- a listening service that can respond to individual needs.

There was also praise for named services including Gofal Dydd y Waen and Dial a Ride.

Darpariaeth gwbl cyfartal i siaradwr Cymraeg a siaradwyr Saesneg. Digon o weithgareddau a chyfleodd i gymdeithasu addas i'r person (e.e diwylliant cymraeg a chymreig os yw'r unigolyn a chefndir cymraeg a chymreig!). [Absolutely equal provision for English and Welsh speakers. Plenty of activities and opportunities to socialise suitable for the person (e.g. Welsh language and Welsh culture if the person is from a Welsh language and Welsh culture background!)] (Community member, age 55 to 64)

Communities are dementia friendly, inclusive, and accessible.

There's an important role for communities in understanding and supporting people affected by dementia. This means not hiding or ignoring the needs of older people. It includes safe and accessible places in the community where people can go such as libraries, community centres, dementia friendly shops and cafes, or Denbigh Men's Shed. Participants mentioned the importance of involving people living with dementia in everyday activities rather than solely segregated services. Improved signage in communities can help people living with dementia to find their way around.

Participants suggested ways to make communities more inclusive including providing training for communities about dementia awareness and reducing the stigma associated with the condition. Awareness raising should include the fact that although dementia is more common among older people, it can affect younger people too. Awareness raising can also encourage friends to stay in touch and let people know that individuals can still enjoy the things they used to even if they can't join in the same way.

To be cared for with understanding and compassion. I think the general public needs to be made aware of dementia. That the person may have forgotten some aspects of their lives, but they are a human that should be treated with kindness and understanding. Most people who are diagnosed with dementia have lucid moments and can be quite emotional when they realise they have made 'silly' mistakes. We should be more aware and supportive. For families living with dementia we should offer support and safe areas – dementia friendly cafe, shops create a safe space

where nobody has to be embarrassed or have to explain behaviours. (Carer and 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 daily help with getting up, washed, and dressed in the mornings, and ready for bed in the evening. Some people will need support with preparing meals, snacks, and hot and cold drinks to make sure they are eating and drinking regularly, and help with personal care and toileting. Others will need help with shopping. One suggestion was to have a family memory board. There's also a need to make sure people have the financial support they need, along with decent living conditions.

People have access to treatments, medicines, and therapies.

People should have access to the medications and therapies that they need along with rapid assessment and regular health checks.

I don't know, it took a long time to be diagnosed and getting medication was long winded (Carer, age 35 to 44)

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

The good dementia care described above needs to be affordable in order for people to access it as regularly as they need. Some of the participants shared what they'd like to see in an ideal world (such as care 24 hours a day, 7 days a week) or if that's not affordable, they would like the closest thing to it. People also need financial and budgeting support and advice, for example, advice around benefits.

Monetary support. Nothing else at the moment (Carer, age 65 to 74)

Rhyw fath o gyfundrefn bel mae person gyda dementia sydd mewn cartref gofal, a theulu'r person, yn gallu cael darpariaeth am ddim ar ôl rhyw amser nid yw'r gyfundrefn yn deg ar y funud... mae rhai pobl yn cael gofal mewn cartref am ddim, mae eraill sydd wedi gweithio yn galed trwy eu hoes, yn berchen ar eu ty, wedi bod yn ddarbodus efo'u harian yn gorfod talu hyd nes does dim o'u harian ar ôl... a dim

yn cael ei adael i'w plant a'u teulu. [Some sort of system where there is a person with dementia who is in a care home, and the person's family can get free provision after some time the system is not fair at the moment... some people are cared for in a free home, others who have worked hard all their lives, owned their house, been economical with their money are having to pay until there is none of their money left... and nothing is left to their children and family.] (Carer, age 65 to 74)

Care workers should be paid well and have good training and terms and conditions.

Participants said that paying carers well will help attract more people into the profession and lead to better quality of care. Good terms and conditions are also important, with enough staff available to cover shifts and reasonable working hours so that staff don't have to work 12-hour shifts in care homes. They should also be well trained and want to work in dementia care.

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

Participants described support as involving a range of different people and organisations with a mix of statutory and third sector services, including family, volunteers, charities, primary care, and social care staff. Health services need to link in with community services. These need to work together so that people can access the support, advice, and information they need without having to fight for it.

Services that a carer can access 24 hours a day, 7 days a week – not A&E. Health and social care services responding in a timely manner, so that family and dementia sufferer are not left 'in limbo' struggling to cope. Care should be tailored to meet actual needs so that sufferer does not have to fit in with only what is on offer. CHC [Continuing Health Care] process impossible to navigate with health and social care staff 'protecting' their resources. (Carer, age 65 to 74)

We also need research into cures for dementia.

There were also comments about the stage before dementia care is needed, including the need for research into cures for dementia and informing people about lifestyle changes that may help to delay or reduce the risks of dementia.

Cyn edrych ar sut olwg sydd ar ofal dementia da - mae angen mwy o fuddsoddiad yn yr ymchwil i drio dod o hyd i wellhad i'r gwahanol glefydau sy'n achosi dementia. Nid yw i weld yn cael yr un buddsoddiad a chyhoeddusrwydd ma ymchwil i gancr a chlefyd y galon yn ei gael. [Before looking at what good dementia care looks like more investment is needed in research to try to find a cure for the various diseases that cause dementia. It doesn't seem to get the same investment and publicity that research into cancer and heart disease gets.] (Health and care professional, age 55 to 64)

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

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

My mum has just moved into an EMI [specialist dementia] residential home and is 91. I have moved her from Essex as I live in North Wales. I have struggled to get help with making that decision from agencies and in finding a home, and was left to my own devices and the internet. It has been extremely stressful and difficult. (Carer, age 55 to 64)

Not as good as it was 30 years ago, constant cuts and the whole country are feeling it. (Community member, 65 to 74)

Social care is broken when it comes to dementia. Paying lip service but no action. (Carer, 65 to 74)

I don't know. I am caring for my mother (82) who has a mild form. I cannot get a doctor's appointment – unavailable while in lockdown and unhelpful. Mum will not attend a previously uncaring doctor's practice. I have reached out to a group but they have nothing that will help our particular needs. Doctors are particularly unhelpful. (Carer, age 55 to 64)

What should be available to people living with dementia?

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

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

There was a lot more detail given in answer to this question about a wide range of activities that should be available that may appeal to different people and would provide opportunities to meet with like-minded people. Some people said that 'everything should be available'.

Activities mentioned included: adapted sports and games activities, art, befriending services, bowling, bubbles, cinema, coffee mornings, community groups, clubs, crafts, cultural opportunities, dancing, day trips, drop-in centres, entertainment, exercise groups, fishing, friendship groups, going to the theatre, just sitting and chatting, knitting, music including listening to music from the past, memory bags, books and boxes (some are available in libraries now), memory cafes, moving, multisensory activities, nature club, outdoor activities and trips, peer groups support, places to meet, reminiscence sessions, rugby, sewing, singing, specialist centres and hubs, support groups, swimming, tea dances with afternoon tea, walking groups and warm places.

Or as one person living with dementia described it: "help to do normal things that you used to be able to do before".

Again, people stressed the importance of support being based around what matters to the person living with dementia, and inclusion in the local community so that people can keep doing the things they enjoy and continue to mix with people who don't have dementia, not just attend dementia-specific groups. People need practical and emotional support. Activities need to be available at the right time of day – not too early and not too late, be free or affordable and available in Welsh for those who need it.

Other suggestions included community champions, support workers to help people engage with activities, activities for Black, Asian and Ethnic Minority (BAME) community members, a 'dementia village', and improving the way buildings and

communities are designed so they are more accessible to people with dementia, such as improving access to the beach.

There was a counterpoint to all these activities though, as a community member said:

People should feel able to live as they did previously did before their diagnosis – so if they didn't really get involved in groups etc before they shouldn't now be expected to go to them. Perhaps it is the carer who needs to get out and respite care needs to be available for the person living with dementia. (Community Member, age 35 to 44)

Access to care and support.

Participants talked about the need for a range of support from care to stay at home, supported independent living such as at Awel y Dyffryn, Denbigh, through to specialist dementia care homes and hospices as needs change. There should be a range of options and choice of accommodation along with day care opportunities. Carers provided by the local authority were also mentioned.

Care is both to support the person living with dementia and the friends and family who care for them. Overnight support can be very important to help carers continue, as otherwise they become too tired from lack of sleep. Some suggestions were more small, local care homes 'that can provide the right support and stimulation to help people stay safe', respite care 'at least three times a year' and a buddy system to help with shopping. Also available should be help with things like hairdressing and chiropody, shopping, cooking, diet, and food services. Support workers can help with daily life tasks and attending appointments.

Participants stressed again the importance of having enough well-trained care workers to provide consistency of care and enough Welsh speaking staff. Care workers need to understand dementia and the people they are supporting and treat them well. They also talked about the need for a range of care staff, for example one participant shared that their husband would only respond to male carers.

Dylai fod mwy o ddarpariaeth ar gyfer cadw pobol yn eu cartrefi eu hunain. Dylai bod mwy o ddarpariaeth ble mae gofalwyr yn gallu cadw golwg ar bobol efo dementia yn ystod y nos, tra bônt yn cael aros yn eu cartrefi eu hunain mor hir â phosib. Dylai fod mwy o 'sheltered housing' tebyg i'r hyn a gynnigir yn Awel y

Dyffryn, Dinbych. Nid oes hanner digon o ddarpariaeth yn enwedig i bobol sydd wedi bod yn berchen ar eu tai eu hunain. Dylai fod mwy o ofalwyr sy'n siarad Cymraeg. Dylai fod mwy o ofalwyr a mwy o oriau o ofalu. Mwy o gartrefi henoed a chartrefi i bobol efo Dementia yn Ninbych a Dyffryn Clwyd I'r bobol hynny sy'n methu byw yn annibynnol gyda chymorth fel eu bod yn cael aros yn Ninbych ac yn eu cynefin yn lle bod rhaid iddyn nhw fynd i fyw i gartref mewn cymuned wahanol ble does neb yn eu nabod.

There should be more provision for keeping people in their own homes. There should be more provision where carers can keep track of people with dementia at night, while they are allowed to stay in their own homes as long as possible. There should be more 'sheltered housing' similar to what is proposed at Awel y Dyffryn, Denbigh. There is not half enough provision especially for people who have owned their own houses. There should be more Welsh-speaking carers. There should be more carers and more hours of care. More older people's homes and homes for people with dementia in Denbigh and Vale of Clwyd for those people who are unable to live independently with support so that they can stay in Denbigh and in their local environment instead of they have to go and live in a home in a different community where no one knows them.

(Carer, age 65 to 74)

Financial support and help with budgeting and benefits.

Many people mentioned the need for this financial support and help with budgeting and benefits, and one suggestion was less paperwork required to apply for benefits.

We are very lucky in Denbigh area to have Gofal Dydd y Waen and Forget me Not sessions. These are both excellent services which rely on donations for funding. (Carer, age 35 to 44).

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.

Wider health care needs.

There's also a need for more support for wider healthcare needs and to 'work with GP surgeries to improve a person's experience'.

Weekly visit by nurse or carer to keep an eye to see if they are coping. Somebody to check if their appliances are working - fridge, heaters etc. Hearing aid checks – most of my friends are stone deaf, leading to confusion, but they won't face up to it. (Community member, age 75 and over)

Information and advice.

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

- the diagnosis, disease, symptoms, treatment and where to go to get help;
- services available and how to access support locally;
- aids and equipment to help at home;
- safe places for people living with dementia;
- activities that are available; and,
- legal advice and advocacy.

The quote below is an example of how it can be difficult to find the information you need at the right time.

Have you heard about 'water jellies'? It's water in an edible jelly invented for people with dementia who don't drink much – but i had to find out through research on the internet. How about combined food because some people prefer to nibble all day rather than one large meal? (Carer, age 55 to 64)

Other suggestions for how to share information and advice included a local phone link or national helpline or hotline with 24-hour advice and out-of-hours help available, link person and dedicated doctors to hand who specialise in dementia care, a hub or drop-in place where families can get support and advice and make connections, and posters in dementia friendly shops.

Another suggestion was:

An event such as this today which shows what and who is available in this community to provide support and help. (Person living with dementia, age 65 to 74)

Support for carers.

Support needs to be available to carers too. People also mentioned the need for training and advice for family members, carers, and other community members or volunteers about how to support people living with dementia including training for staff through their employers such as local shops. Also, that carers need support including peer group support to help make the caring role sustainable, such as 'a safe space for carers to share coping techniques.'

Another suggestion was:

Enough money to allow carers to have a morning or afternoon free daily to do whatever will give them rest, or something completely different – with the happy knowledge that the person with dementia will be content and safe, or maybe doing nothing. (Carer, age 75 and over)

What does community mean to you?

Participants described how communities can be based around shared or common interests, values and beliefs, places (such as the local area), needs, cultural heritage, history, race/ethnicity, language, religion, or be any kind of close-knit group of people who get along.

Some participants also said that communities meant a lot to them and gave examples of the strength of the community in Denbigh, such as Denbigh in Bloom and Denbigh Plum Fest. Some said that community was everyone and everything. Others that communities were inclusive and welcoming of people living with dementia. There was also a view that community is separating because people of different ages don't mix, that some people don't want to meet with others, and to some people community doesn't mean a lot.



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. Collective understanding. Feeing safe and valued and not feeling alone. Contentment. People going about their lives in peace. Creating a community feel.
- Working together to support and help each other and for the good of the community. Sharing. Building relationships so people can help each other.

- Practical help, such as with shopping or cleaning and other everyday chores and activities. Volunteering to help or give people lifts places. Receiving care close to home and having the right support locally. Support for carers.
- Knowing you can ask for help. Somewhere you can reach out to for support, advice, and services.
- Respectful and accepting of difference, equality, and diversity. Appreciating
 people. Non-judgemental, peaceful, and non-threatening. Making adjustments so
 that everyone can participate in the community including shopping and social
 activities. Including everyone including disabled people, people with dementia
 and anyone who is vulnerable. Having dementia friendly spaces and safe spaces.
 Feeling welcomed.
- Bringing people together, camaraderie and community spirit. 'Cariad difesur abundant love'.
- Opportunities for socialising and providing good company so that people aren't isolated. Being friendly. Being heard and providing a listening ear. Knowing your neighbours and speaking to them. Getting to know people in a natural way.
- Friends, family, neighbours, and other networks of support. Family and friends
 that are close by, help at the end of the phone or everyone being involved in each
 other's lives while still having some independence.
- Fun and enjoyment.
- The public services that serve the community. The local businesses, shops, pubs, services, resources and amenities and the way we support each other. Good transport.
- Community events and activities and places to meet. Opportunities to get involved and participate.

Examples of communities include a church group, mother and baby groups, warm spaces including the warm hub in Henllan, regular craft fairs and craft groups, singing together, school, chapel, Denbigh infirmary.

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

A whole community where they pull together and embrace the needs of people who live with dementia (Health and care professional, age 55 to 64)

Everyone supporting each other. Lots of activities and events - Denbigh is good at this! Getting everyone involved. (Community member, age 45 to 54)

Friendly and knowledgeable neighbours. My neighbour made me aware of this event! (Person living with dementia, age 65 to 74)

This is a hard one. Having had the community of being a life-long chapel member – although depleted – is still a time of meeting and sharing so much of everyday living and dying. (Carer, age 75 and over)

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

Having the care and support they need.

This includes sufficient and affordable paid care and support for people in their homes. It includes personal care where needed including personal assistants, one to one support, nursing support and agency care. This should be from trained staff based on the values described in the section 'what does good dementia care look like?'. There was also a view that not all family and friends are equipped for a caring role, which is why paid care can be so important.

People to visit those who can't get out to visit groups. Some people may need befrienders or support workers 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.

A trusted person who has built a relationship with the dementia patient so that the patient can participate in what they would like to do. Having a dementia worker would help people do what they would like to achieve. (Carer, age 35 to 44)

Supportive and flexible health services.

Good supportive health services are important. These should be flexible to meet the diverse needs of people living with dementia. For example:

It is also hard to get ready sometimes for the mornings so flexibility around times and around appointments. Consider the person when appointments are booked. I can't get my wife to an early morning appointment an hour away, it's not practical. (Carer, age 75 and over)

Support for carers.

Many participants mentioned the need to support family and friends who provide care as a way of helping people living with dementia. This includes breaks from caring (respite care), systems in place so they can continue to care, and social and emotional support so that they don't become isolated. Another suggestion was meals on wheels as a way of taking the pressure off family and friends who provide care. Sharing ideas for encouraging people living with dementia to eat and drink. One suggestion was classes to help carers with food ideas.

Systems in place so carers don't have to give up their jobs – support packages in place (Community member, age 75 and over)

Support for carers so that they can have help to take their loved ones to places. (Carer, age 75 and over)

Local groups and community support.

This includes support groups for people living with dementia and carers along with involvement in other groups and activities of their choice for fun, friendship and to stay active. Suggestions include interactive reminders of the past including music and films, arts and crafts, dancing; walking, gardening, singing, reading, puzzles, knitting groups, social clubs, places to go and chat with people with and without dementia, safe places to go like cafes or local shops, days out to places people went when younger, going to church or chapel, gardening, dedicated dementia events in cinemas and cafes, painting, tea dances, relaxation, groups based around shared interests, shopping, library services, men's sheds,

Again, these activities should be based around what matters to the individual and their family so people can choose the activities that they enjoy, and be available through the language of their choice.

My husband didn't want any community involvement. Horrified at the idea of quizzes, art and singing. He had been a successful businessman and chair of local committees. (Carer, age 75 and over)

There were also a lot of comments about the importance of being part of a community and the importance of having a dementia friendly community. Friends, family, and neighbours can help people to keep doing the things they enjoy. People mentioned volunteers and befriending services to reduce isolation and also 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.

Having an open mind, not being too restrictive, letting people make mistakes, integrating young and old on a regular basis, making the community more safe for everyone. (Carer and health and care professional, age 35 to 44)

Joining a group that helps the well-being of people with dementia, like Alzheimer's sessions that are able to help the patient or relative to sing, listen to music, or dance and communicate together to not feel alone. Art groups and walking groups are good to help stimulate and relax people (Carer, age 65 to 74)

Transport

Transport was raised by many participants as key to helping people living with dementia. This included the need for transport to attend events and activities as well as medical appointments.

Transport suggestions

- Better support for people who don't have a car or who no longer have a driving licence.
- Free or low-cost transport or support with transport costs.
- Improved public transport, particularly from villages.
- Dementia-friendly buses and transport including the importance of a 'helpful driver'.
- More door-to-door transport which could be provided by volunteers, including groups that offer a door-to-door pick up service.

- Dementia friendly bus/taxi services.
- Community transport scheme, including suggestion that this 'is linked to the memory clinic and activities in the community'.

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

Community transport that picks up in neighbouring villages e.g Denbigh Flexibus only goes to Henllan – we need transport in Trefnant, Ruthin etc. Door to door service. (Community member, age 55 to 64)

Put the town bus back on a timetable. It appears to only be available on an app on a mobile phone. (Community member, age 75 and over)

Creating a dementia friendly community

Many participants spoke about the importance of understanding and acceptance for helping people living with dementia. This includes raising awareness among people of all ages, and particularly local business and transport providers, to create a dementia friendly community. Suggestions included use of the sunflower lanyard or a 'dementia band' that people can wear to show they may need additional support, community events to help raise awareness of how people can help, holding dementia awareness week, an 'adopt a family' scheme to support people who don't have family themselves, and dementia friendly training for staff working with the public such as in shops or spaces to sit in shops,

There was a particular issue around the importance of understanding and acceptance from friends so that people can stay involved in their communities and keep doing the things they enjoy. For example:

Acceptance – I know of someone stopped membership of golf club because he has dementia – he can still play golf!! (Care worker, age 55 to 64)

Keeping people with dementia in their own community instead of shutting them away out of sight. (Carer, age 55 to 64)

Accessible services and environments

Improving access to the physical environment, facilities, and venues for people with physical disabilities or impaired mobility is important, for example shops and hairdressers. Being accessible includes running events and meetings at a time that suits people, for example the time of day when they're most alert, or to allow people time to get up and ready. The way signage is designed and ideas like making sure people have name badges can help with accessibility.

Valuing care work

The importance of valuing care work, providing good training for staff and better pay was stressed again as something that will help people living with dementia too.

Making help easier to access

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

- Provide a single point of contact that's easy for people to access and talk to.
- Services to provide support without people having to ask or to follow up.
- Improve publicity around available support and events using a range of methods.
 It's not enough just to advertise on social media or online.
- Befriending services that can help people to access groups, support, and medical appointments where they may not have the confidence to go by themselves or need other support to attend.
- Good planning and communication between service providers.
- Places to go for help and advice.

Simple instructions, signage, and posters. Modern world is difficult for most elderly to navigate, but particularly those with dementia for who the simplest task is a challenge. (Carer, age 45 to 54)

Financial help and funding

Participants said that sometimes money is what's needed to help people living with dementia. This included direct financial help as well as support with costs such as transport and funding for services. There's also a need for information and advice about the financial support available as well as legal advice for relatives.

Technology and other aids

Technology and aids can help people around the house and keep them safe. Examples given were dementia clocks and choice boards with picture symbols so people can choose what they need to do.

Research into treatments and interventions

More research is needed into treatments and to make sure that evidence-based interventions are available to support people living with dementia and their families.

A great deal of research needs to be done so that there'll be treatment before dementia has developed and advanced. That means a great deal of money – which must be made available now (Carer, age 75 and over)

Accommodation

Specialist accommodation to keep people living as independently as possible, within their own community. An example given was 'Grwp Cynefin' in Denbigh where people can talk/keep company to others to stop loneliness and get help when needed'. (Community member, age 26 to 34)

Safeguarding and confidence

The importance of safeguarding people living with dementia to prevent issues like financial abuse or targeting for theft. This can include the importance of systems to protect people to help raise confidence to keep going out and about, for example, to protect people from getting lost.

Conclusion

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

The purpose of this engagement was to find out what dementia care means to a community, so we spoke to a wide range of people, many of whom had experience of supporting friends or family living with dementia. There are lots of ideas and activities suggested, however, many people stressed that everyone is different and it's important that support is focused on what matters to each individual and their family. This was highlighted by a couple of participants who reminded us that some people don't want to be involved in activities and groups, and that's OK too. 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. This provides a great opportunity to build on the good work already taking place in Denbigh 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.
	Exam	ple 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 Denbigh Library, Hall Square, Denbigh, LL16 3NU. Alternatively you can scan the QR code to complete the survey online. The consultation closes on 13 October 2023.

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

Are you responding as: (you ca	an tick more than one)	
someone living with dementia	a?	
a family member or friend of	someone living with demen	itia (including unpaid carers)?
someone providing paid care	e and support services for s	omeone living with dementia?
someone who works as a he	alth or social care profession	onal?
a member of the local comm	unity?	
in a different role?	•	
If 'in a different role' please tell	us more	
How old are you?		
11-17	35-44	<u> </u>
18-25	45-54	75 and over
26-34	55-64	Prefer not to say
What does good dementia care	e look like?	



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 Denbigh Library, Hall Square, Denbigh LL16 3NU.

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

The consultation closes on 13 October 2023.

Appendix 3: Introductory Letter



Trigolion Dinbych,

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 Dinbych. 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 amgau 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 Dinbych.

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.

Denbigh 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 Denbigh 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 Denbigh Library.

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

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

Kind regards,

Melanie Sillett,

North Wales Dementia Project Manager.

Appendix 4: Event posters



PEOPLE OF DENBIGH



'Denbigh Community Listening Campaign'

DENBIGH has been chosen as a town in North Wales to help shape the future of dementia care, Improving dementia care is everyone's business.

'You told us - We listened.'

Join us to hear what the people of Denbigh have told us:

- How we can help people living with dementia to do the things they want to do in this community
- What should be available to people living with dementia in this community
- · What does good dementia care look like
- What does community mean to you

We want to put local people at the center of the discussion around dementia care.



WHERE;

Eirianfa Community Centre, Denbigh WHEN:

Tuesday 21st November 2023
9:00am—2:30pm (Buffet lunch included)

To book a place at the Denbigh Dementia Community Listening Campaign Event,

SCAN THE QR CODE Or call Adele Baguley on

01824 706054/ 01824 712432

email Adele.baguley@denbighshire.gov.uk



Appendix 5: Wales Listens Campaign Example Questions





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

What do you know about dementia?

What's the best thing about living around here?

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 makes you happy living around here?

What's the worst thing about living around here?

What makes you happy living around here?

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 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?

Where do you go locally to meet others?

What are the things that will help you to do the things you want to do in this community?

What are you passionate about?

What can you give to your community?

What would you like in your community?

Appendix 6: Email

Pobl Dinbych

Mae gwella gofal dementia yn fusnes i bawb

- Mae angen eich help i wella gofal dementia 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/h

n3zyi i weld yr arolwg ar-lein. Gellir darparu copïau papur hefyd drwy gysylltu âg Adele Baguley ar 01824 706054 neu e-bost

Adele.baguley@denbighshire.gov.uk

Mae gennych tan 31^{ain} o Hydref, 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.

People of Denbigh

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/h

n3zyi 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 October 2023 to complete the survey.

Thank you for your time and contribution – together we can improve dementia care for everyone locally and across Wales.