

Sut y gallwn ni wella'r profiad o fyw gyda dementia? Gweithdy cymunedol

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How can we improve the experience of living with dementia? A community workshop

Outcomes from two workshops held in Holyhead and Bangor,
March-April 2023



The workshop artwork was created by Gail Gregory, who lives with dementia.

Background

As part of the 'Living with dementia: An operatic exploration to promote understanding and reduce stigma' project, we held two community bilingual workshops to understand the experience of dementia in local communities. These were held at the Ucheldre Centre, Holyhead, and Pontio, Bangor, respectively, in conjunction with productions of the new opera 'Y Bont/The Bridge'. In keeping with the theme of the opera, we asked what people thought could help them to stay connected to their local community, and what could be improved.

Who attended?

People with dementia and carers were the primary audience for the workshops, with a few people attending who delivered dementia services in the community. While some attendees were local to the workshop locations, in Holyhead we had attendees from all over Anglesey and beyond: two women living with dementia travelled from Mold, Flintshire, and Rhyl, Denbighshire, especially to attend.



Using the workshop artwork created by Gail Gregory, participants wrote their answers on postcards featuring the 'A Bridge to You' artwork with which we then built postcard bridges.

After a brief introduction, attendees were given postcards of Gail Gregory's artwork 'A Bridge to You' so that they could discuss and write down their answers to the workshop's questions.



Catherine Charlwood (centre) and Emma Quaek (left) introduce the workshop at the Ucheldre Centre, sharing Welsh and English versions of the Guide to the Living with Dementia Toolkit. Photo by Ian Smith.

What is good about your local community for people affected by dementia?

The first question was designed to understand the positive aspects as people with dementia and carers saw them. Three themes emerged:

- Nature and getting outside
- Local support groups and supportive places
- Broader support for carers

Nature and getting outside

Several people mentioned the pleasure they gained from nature:

“Close to the sea.”

“Rural aspect – beautiful sea view and quiet. Tame wildlife.”

“Cerdded am dro ar hyd lan y mor Dinas Dinlle.”

[“Walking along the seashore at Dinas Dinlle”]

Noticeably, though, there was a strong focus on when and where nature had been made accessible. The second statement above was followed by “(all out of holiday season!)”, indicating that the presence of holidaymakers changed the dynamic.

Many people focused on practical ways the outdoors was accessible to them:

“Fish & chips yn Criccieth – Bwyta wrth y lan y mor – toilets nearby!!!”

[“Fish & chips in Criccieth – Eating by the seashore – toilets nearby!!!”]

“Garden centres with cafes & toilets”

“Walks with flat, safe surfaces. Nature walks.”

“Llwybrau cerdded/seiclo/ar darmac.”

[“Footpaths/cycle paths/tarmac paths”]

Providing suitable facilities – good pathways and plenty of toilets – is really appreciated. This is something that IDEAL research on communities has also found. Town planning has an immediate effect on people affected by dementia.

Local support groups and supportive places

People could identify local groups who were helpful. Dementia Actif Gwynedd was mentioned by everyone who attends their sessions, and its effect was significant:

“Mae'r clwb dimentia Cnarfon yn agoriad llygaid efo pawb yn dangos wir caniad tuag at eu gilydd eu bod dim ond yn cymhanol ddiweddar dan nabod ein gilydd. Canu ydy'r peth dwi di cyflwgnor i'r clwb efo alawan Cymraeg a Daesneg ac bendant mae cofio alawan a darllen geiriau yn help mawr i bawb yn y clwb.”

[“The Caenarfon dementia club is an eye-opener with everyone showing true love to each other, even though they got to know each other relatively recently. Singing is the thing I bring to the club with Welsh and English tunes and remembering the melodies and reading words is definitely a great help to everyone in the club.”]

Four workshop attendees were living in communities which did not have a dementia support group, so they had set it up themselves. A couple in Newborough had set up a monthly support group, and two women living with young-onset dementia had set up DEEP groups in Mold and Rhyl, respectively. Others mentioned local day centres and care homes, but beyond dementia-specific support, people also singled out local places where they felt supported:

“[when shopping or in cafes] Staff being dementia aware and able to ‘deal’ with the person as a person.”

“Pobl cyffeillgar â dealltwnaeth o ddementia, sydd yn gweithio mewn siopa a pobl trîn gwallt.”

[“Friendly people who are knowledgeable about dementia, working in shops and hairdressers.”]

Interestingly, in both workshops, churches and hairdressers were mentioned as community spaces where your absence or a change in mood would be noticed. Hairdressing salons were also seen as a safe space in which people might open up about how they were feeling.

Broader support for carers

Carers in the workshops also identified the positives from broader provision which came from outside the local community, but had an effect locally. This included national charities like TIDE (Together in Dementia Everyday), but also broader support schemes:

“Music/theatre. Hynt card for theatres.”

“Discount cards/carers passes e.g. Hynt, National Trust companion card.”

Hynt is a national access scheme working with theatres and arts centres in Wales. Visit <https://www.hynt.co.uk/en/> for more information.

The National Trust offer an Essential Companion card. Visit <https://www.nationaltrust.org.uk/who-we-are/about-us/access-for-everyone> for more information.

Attendees clearly valued places and organisations who had thought about access requirements, and how to make the experience of dementia easier:

“Relaxed film screenings at Pontio & Galeri.”

“Morrisons (cyn cyfnod Covid) yn rhoi amser distaw heb gerddoniaeth yn y cefndir, i fynd i siopa.”

[“Morrisons (before Covid lockdown) offering a quiet time without music in the background, to go shopping.”]

In summary, positive aspects of local communities were not restricted to dementia-specific things, nor to the local alone. Well-designed and accessible spaces, understanding people, and national schemes all played their roles in improving local communities for people affected by dementia.



Ann and Anwen consider their responses after enjoying tea and cake! Photo by Ian Smith.

What needs to be improved in your local community to help people affected by dementia?

The second question was designed to find out what needed improving within communities. Worryingly, people found this a lot easier to answer than the first question. Three themes emerged:

- Transport links
- Better signposting of information
- More awareness and understanding

Transport links

Transport – or the lack of it – was a key concern as people tried to connect with their local community. There was a strong sense that rural areas relied on transport heavily and when it was not available, this could prevent people reaching support:

“Minibus (TRANSPORT) to enable people to easily travel to centres for ‘activities’.”

“Local bus services and better connections to the bus stops.”

“Transport to and from day centres: open 9-4.30. Buses bring by 10-11, home before 2.30-3.”

This last quotation is a classic example of how a lack of joined-up services leads to an inability to use what is available: the timing of the transport dramatically reduces access to the day centre.

Reflecting what had been appreciated in the first question, there were also calls for practical help once a destination had been reached:

“More public toilets. There needs to be more to do when the weather is bad.”

“Mwy o lefydd i eistedd wrth mynd am dro i lefydd.”

[“More places to sit when walking to places.”]

“Angen ‘benches’ i eistedd yn ein pentref Bethel, Caernarfon.”

[“Need benches for sitting in our village Bethel, Caernarfon.”]

Better signposting of information

Many people spoke of their difficulties in finding information about services, or hearing of others’ struggles to find “where help is”. One person had seen our workshop advertised, but this was the only thing they were aware of and came in need of help.



There was a general sense that information or support was not easy to find:

“We need a system that works, better integration between health and social care. It’s hard to navigate. Access to social care needs to be better.”

“Mwy o wybodaeth gan GP/Gwasanaethau Cymdeithasol am gamerau/Alexa a.y.b. sydd ar gael. Pamphled syml yn nodi beth all fod yn ddefnyddiol heb i ni orfod chwilio amdanynt: Alexa, camera a ci bach tegan. Wedi chwilio amdanynt yn Alzheimer Association hunain.”

[“More information from GP/Social Services about cameras/Alexa etc. that are available. A simple pamphlet explaining what can be useful without us having to look for them: Alexa, a camera and a toy dog. Looked for them at Alzheimer’s Association ourselves.”]

“Finding information about living with dementia and signposting. Contact.”

People had had to make the effort to find out the information they needed, even though support for “living with dementia” would reduce the burden on formal services.

These requests for better signposting hide the energy cost people affected by dementia pay while searching for help. As one carer wrote,

“I want one person who can direct me to the necessary services. It is emotionally and physically exhausting chasing everyone and trying to find out what is available. [...] Individuals are wonderful but services are so fragmented.”

More awareness and understanding

Although people appreciated the understanding of their communities which was there, it was clear there is some way to go in ensuring people living with dementia are treated with kindness in the community.

Those same spaces which people had identified as positives in the first section, such as cafes, could quickly become negative if the ordering system was confusing or the staff were impatient.

“[People are] scared of how to react to the person’s ‘condition’. [... We need] better awareness in communities. Leaflets on how to approach.”

“Some sort of training or awareness courses for staff within shops, cafes etc.”

“More awareness in the community about dementia and the problems it causes – it’s not just memory loss!”

“Sharing information/awareness of dementia. Dementia friends in schools et cetera to chat.”

While many examples related to being out and about in public, there was also an expression of the understanding required closer to home:

“That people don’t pretend that the person with dementia doesn’t exist and they call to see them for a chat and give backing for the family.”

People we spoke to were keenly aware that experiences of dementia can be very different for different people:

“[We need] younger activities (people younger).”

“More knowledge of rarer dementias in the medical community.”

“The only things are the memory cafes [...] but are mostly for the people in later stages. I found there wasn't anything for my stage or generation. So I started up my own DEEP group LIKEMINDED, for people with dementia run by people with dementia 😊 [...] We have been going for 15 months. The group is growing by the week, and the people keep coming back.”

Dementia is an umbrella term, covering a range of conditions, ages and experiences. For those people diagnosed with dementia at a younger age, they wanted support which matched their generation and their interests: if this was not available, then individuals had set up their own groups. As one person wrote, we need “Codi ym wybyddiaeth o'r sefyllfa yn gyffriedinol” [to raise awareness of the situation in general].

In summary, people affected by dementia could easily identify areas for improvement within their communities and barriers to remaining connected. While some of these might require significant investment and systematic change, many were areas where small adjustments could create huge change.



Dory and Carol – both of whom have set up their own dementia groups – consider how to improve local communities. Photo by Ian Smith.

What do you want people in charge of dementia services to know?

The final question of the workshops was more of an open discussion, designed to get some key messages across to commissioners and people in a position to affect real change. This is all the more important as Wales creates its new, second, national dementia strategy. Three themes emerged from these discussions:

- Give us in-person possibilities #PeopleNotPaper
- Listen to the voices of lived experience
- Signpost us to information

Give us in-person possibilities #PeopleNotPaper

People accepted that things had to be moved online during the COVID pandemic but emphasised the importance of in-person contact. People commented that often they came away from services with a bunch of leaflets but no real support. What they wanted was personal contact:

“They don’t need to give us brochures of information and advice – they need to know that we want interaction with people.”

“[Provide] space for carers to come and have a safe place in their local communities to air their frustrations and meet new friends that understand. Have regular weekly coffee shops to link with others.”

The people with dementia participating were conscious that in-person interaction helped them to retain social skills and to feel connected. One easy-to-digest point we agreed on was the need for #PeopleNotPaper when it comes to supporting people affected by dementia in the community.

People in charge of dementia services, particularly in the post-pandemic era need to remember this. As one person memorably put it, “Online is ok. Real people are so much better.”

Listen to the voices of lived experience

The question ‘What do you want people in charge of dementia services to know?’ is all about what you would say if you had the ear of the people who could change your experience of dementia. One thing people really wanted was to be listened to.

For people living with dementia, this was a chance to self-advocate and make their voice heard:

“Find out what people want – don’t tell us what we need.”

“They need to give us hope and help us do what we can – not what they say we can’t.”

“We don’t just want to sit in a chair and do nothing. We want to be more active.”

Carers also wanted to be listened to, with their statements suggesting a feeling of invisibility:

“I think they should know how many people need support and attention. How many people need to be listened to.”

“To listen to the relatives of the person and find out if they are in need of support.”

As we found, people affected by dementia are ready and willing to discuss their experiences, and have lots of ideas about how to improve their communities. Commissioners and politicians need to provide opportunities for these discussions to happen.

Signpost us to information

Building on the theme of signposting information which came out as a key area for improvement, it was clear that the lack of transparency around what was – or was not – available within communities was challenging. The carer who asked “I want one person who can direct me to the necessary services” continued, revealing the consequences of not being able to find support easily: “Help is difficult to obtain it must be quicker to help people before they get desperate”.

Other people highlighted the need for guidance as dementia suddenly became part of their lives:

“What question do I ask? I don’t know what I don’t know. What do I need to know?”

“Better links to networks: who is in that umbrella? who does what? who will help me? who will help my relative? Exploring the feelings at each stage.”

Clear, up-to-date, local information which is readily available where all can find it should be an achievable goal, which would help many people.

In summary, local communities include people affected by dementia who have specific needs. They can communicate what these are and how they can be addressed, but this population does not always feel listened to. People need to be signposted to services and more in-person opportunities to connect made available.



Catherine discusses dementia with Marian.

Lessons learned

One-off workshops are important, but do not provide sustained support. It was crucial to **collaborate with people embedded within local services** so that workshop attendees who needed signposting to help could get that immediately. Emma Quaeck was an invaluable asset in this regard, with her knowledge of the range of on-the-ground dementia services in the local area.

More discussions about dementia should be taking place. Based on the workshops and the post-show discussions of the opera 'Y Bont/The Bridge', countless people want to talk about dementia, but do not always have the opportunity to do so.



Anwen and Idwal get deep into the discussion over tea and cake. Photo by Ian Smith.

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To find out more about IDEAL's work visit www.idealproject.org.uk.

You can find a wealth of resources on the Living with Dementia Toolkit at www.livingwithdementiatoolkit.org.uk.

