

Dementia Gwynedd Newsletter

Sept 2025
No 6

Welcome to the autumn of the Dementia Gwynedd Newsletter, we're thrilled to have you here! Each edition is packed with stories, tips, and updates designed to keep you in the loop with dementia support in Gwynedd. So grab a cuppa, settle in, and let's dive into what's new!

Super Group



The Dementia Gwynedd Super Group was established in April 2023. It is a vibrant and collaborative forum that brings together people living with dementia, their families, dementia professionals, and community organizations to share knowledge and experiences, foster understanding and support.

The meetings are held at the Memorial Hall in Penrhyneddraeth on a quarterly basis with guest presentations. Topics range from fire safety for vulnerable individuals, Carers Card, speech and language therapy, advocacy, research, community projects and much more.

One of the most important and thought provoking elements to the meeting is when people with lived experience share their dementia story, challenges and tribulations. Guest speaker, Susan Gallimore recently talked about caring for her late husband, Roger who was diagnosed with a rare form of dementia called Posterior Cortisol AtTrophy (PCA). Read her story on page 2.

The Dementia Gwynedd Super Group isn't just a meeting—it's a movement. It's about building a dementia-friendly Gwynedd where lived experience shapes strategy and practice. The group has contributed to the Dementia Gwynedd Strategic Plan, which outlines a shared vision for improving support and awareness across the county.

If you're curious to get involved contact:-

Emma Quaeck - emmajaynequaek@gwynedd.llyw.cymru 07768 988095

The next meeting will be on the 11th December 2025, 10:00-1:00pm - lunch included.

Susan and Roger's Story

Dealing with Posterior Cortical Atrophy (PCA), a rare form of dementia



In Susan's words :- I am going to start by listing early dementia symptoms as given by the NHS website. These include: Memory loss, difficulty concentrating, finding it hard to carry out everyday tasks, struggling to follow a conversation or find the right word, being confused about time and place, mood changes.

At first these symptoms are mild and family may not notice but for some people they will worsen. The site then looks at later symptoms for people with dementia and Alzheimer's.

However, PCA is not mentioned because of its rarity. The early signs for PCA are totally different and hard to recognise as dementia.

My husband's journey began ten years ago with many visits to the optician. This is quite common for people with PCA. Anyway, he was always grumbling about his glasses. After yet another visit he was told not to drive home as he had no peripheral vision. A stroke was suspected. We spent that afternoon at the eye hospital where they discovered colour blindness which was new. They decided his eyes were working normally. The next day was also spent having various tests and some time later an MRI. Medication was prescribed in case of a stroke. Later we were told that the MRI showed no sign of a stroke. A mystery.

Eventually, we had an appointment with the neurologist who told us that he could see an issue at the back of the brain in the area where sight is processed. We were given the name PCA and given a leaflet. Of course we had never heard of the condition. Later I looked up more information online. My husband decided not to do this. He would manage problems as they arose. The most useful information came from RDS or Rare Dementia Support which is based at University College Hospital, London. They offered information, individual support and online support groups. A lifeline. This information is really needed as many health professionals know nothing about the condition. In fact I had to give them the correct information on many occasions. This is frustrating to say the least. We all know that carers are the experts but it is soul destroying when you have to provide the correct information time and time again.

The peripheral vision issues were the beginning of a long hard journey. My husband's sight deteriorated but not in the same way as macular degeneration or other age related sight problems. So, various aids which can help sight impaired people were no help at all. His sight impairment was bizarre. It can be described as looking through a broken mirror or a jigsaw with all the pieces in the wrong place. Bright lights were an early problem and shiny surfaces especially floors, steps and escalators. As his sight deteriorated so did his spatial awareness. He found it difficult to find his way around the house or even a room.



Gradually his reading skills went, large print was more difficult than smaller print, all practical skills, use of the computer, the ability to use a mobile or a remote and eventually cutlery. Help was needed with every task. All this was happening whilst he was totally aware. He knew he had lost each skill and at times he felt sad. Most of the time he was amazingly stoic.

He enjoyed audio books, music and walking which had to be on a level surface and was guided very carefully. This was exhausting for the carer as he was six feet tall and needed some support as time went on. We did have the odd tumble and one day he gripped my hand so tightly that I flew over the top of him and landed in a heap. A kind young couple came to our rescue and luckily no damage was done. He also had several falls at home with head wounds that I dealt with.

As the PCA progressed his speech became less fluent but when relaxed he could express himself quite well. He missed his independence and disliked the fact that I did everything as we had always shared jobs. Also after several years his short term memory became worse. He was aware of this and told me that his thinking was not as good as it had been. Really this self awareness made life so much harder for him.

Other issues included sundowning from late afternoon and often through the evening. He would be very restless. I asked him about it and he knew he was doing it but could not stop. We also had disturbed nights as I had to help him find the bathroom several times a night. It was exhausting. We were unable to get night care through the statutory services. In the end I paid a private care company to come once a week to let me have a rest.

We had a support lady from the Carers Trust who came for three hours twice a week. She was wonderful and they got on really well. This gave me the time for shopping or appointments or whatever. We also had some respite care.

Earlier this year whilst having respite he fell and broke his hip. There was an operation, some physio, the ward was closed due to Norovirus. Yet again I had to explain the condition to different members of staff. Six weeks in hospital followed by a week in a nursing home home where he ended his days peacefully. This is exactly what he wanted.

Susan and Roger enjoying an afternoon
in the sunshine at
Plas Brondanw, Llanfrothen in 2023
with Dementia Actif Gwynedd's
Carers Support Group



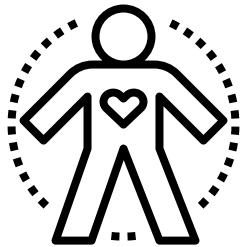
Rare Dementia Support

contact@raredementiasupport.org

www.raredementiasupport.org



Dementia Actif Gwynedd



For your weekly group exercise and social activities in your community

As well attending the various 16 weekly classes throughout Gwynedd, Dementia Actif members have been busy over the summer, here's some of the activites they've been up to.



Clwb MANtur - the mens monthly dementia group enjoying a visit the Multi Golf in Criccieth



Clwb MANtur - also had visit the amazing Maes y Plas community gardens where they harvested the onions



Intergenerational fun with the Penygroes class members and pupils from LLanllyfni school.



Day out at the National Trust venue- Plas Newydd in Anglesey in collaboration with the North Wales Fire and Rescue Service

For more information about any of the activities
07768 988095
dementiaactif@gwynedd.llyw.cymru
www.dementiaactifgwynedd.cymru

Dementia Actif Gwynedd are honoured to have been successful in achieving recognition in these prestigious awards



HIGHLY COMMENDED



Gwasanaeth Tân ac Achub
Fire and Rescue Service

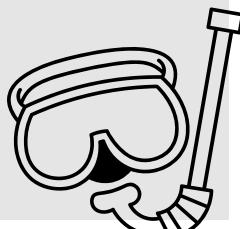
North Wales
Fire and Rescue Service
Community Awards 2025
Community
Safety Partner Award.

National Dementia Care Awards for the Category "Intergenerational projects" which recognised the work by the team for the Intergenerational Boccia Tournament. The team were shortlisted and came runners up.

"This is an outstanding and truly innovative project that stands out for its ability to bring people together to foster a strong sense of community. With a clear and unwavering commitment to improving the lives of all who live in the county. It not only addresses local needs but also inspires meaningful connection, inclusion and long term positive change"



The Dementia Actif team are proud of their team member Rachael Roberts from Tywyn, who was one of the 200 competitors who took the plunge at the World Bog Snorkelling Championships in Llanwrtyd Wells on Sunday, 24 August. Rachael braved the muddy 120-yard challenge in one of the quirkiest sporting events in the world and came in 5th fastest female and 12th overall. Congratulations Rachael!



Helpful information

Unpaid Carers Card

If you are looking after someone, the carers card offers:

- Proof of your role as an unpaid carer
- Emergency contact phone number
- Discounts and benefits at some local businesses
- Recognition of your essential role in the community

Your photo will appear on the front of the card.
Your chosen emergency number at the back.
Your card will be valid for 5 years after which you can renew it.

Cerdyn Adnabod Gofalwr Di-dâl Unpaid Carers ID Card



Enw / Name:

Eich Enw Chi / Your Name

Dyddiad dod i ben / Expiry Date:

09/06/2030

Llinell Ffôn argyfwng / Emergency phone line:

Cyngor Gwynedd: 01766 771 000

Cyngor Ynys Môn: 01248 750 057



To apply for your Carers Card, contact Carers Outreach
01248 370797
help@carersoutreach.org.uk



GWASANAETH CYNNAL GOFALWYR
CARERS OUTREACH SERVICE

LIFE

NEW

TAITH NI

GRŴP CYMORTH DEMENTIA SUPPORT GROUP



Ar gyfer Gofalwyr a'r rhai sy'n byw gyda Dementia neu broblemau cof
For Carers and those living with Dementia or memory problems



**Neuadd Goffa Bethel
Memorial Hall, LL55 1YE**



**Pob Dydd Llun
Every Monday**



12:30pm - 2:30pm

AMSERLEN

Cinio Ni : 12:30yp - 1:15yp

Cinio Blasus wedi ei danfon gan Gaffi'r Bedol, paned, a phwdin

Taith Ni : 1:15yp - 2:30yp

Sesiwn Gweithgareddau i unigolion â Dementia, a chyflwr i ofalwyr gael cyfarfod gofalwyr eraill, siarad, gwrandu a chael eu clywed yn ein cornel gofalwyr

TIMETABLE

Cinio Ni : 12:30om - 1:15pm

Delicious lunch delivered by 'Caffi'r Bedol', a cuppa, and dessert

Taith Ni : 1:15pm - 2:30pm

Activities session for individuals with Dementia, and an opportunity for carers to meet other carers, talk, listen and be heard in our carers corner



Cysylltwch â **Siân Williams** am fwy o wybodaeth // Contact **Siân Williams** for more information



07376 484 154



sian.williams@ctnw.org.uk

Dementia Support Tool



BWRDD PARTNERIAETH RHANBARTHOL
GOGLEDD CYMRU
NORTH WALES
REGIONAL PARTNERSHIP BOARD



HEDDLU
GOGLEDD CYMRU
NORTH WALES
POLICE

The Dementia Support Tool is a simple yet effective information tool to help people living with dementia, families and carers. It is a joint project between the Welsh Ambulance Services University NHS Trust, North Wales Police, North Wales Fire and Rescue Service, the North Wales Regional Partnership Board, and Betsi Cadwaladr University Health Board.

Stickers are available featuring a QR code that links to dedicated webpages full of trusted advice and support. Just scan the code with a phone or tablet for:

- Guidance for caregivers
- Support for families
- Resources for people living with dementia

You'll find the stickers in:

- Non-emergency patient transport ambulances
- Community health settings
- Various public spaces across North Wales
- **Dementia Actif Gwynedd - contact Emma 07768 988095 dementiaactif@gwynedd.llyw.cymru**

QR CODE???

Connecting patients,
caregivers and relatives
to dementia support
services



We're proud to announce this
simple yet effective tool to help
people living with dementia and
others who care for them.



Nationwide Building Society and Admiral Nurses

Dementia UK is offering face-to-face clinics with an Admiral Nurse in Nationwide Building Societies throughout the UK. In Gwynedd and nearby counties, this service is available in the Caernarfon, Bangor, Llandudno, Colwyn Bay and Aberystwyth branches - dates available on the website.

Appointments are held in a private space. People with dementia or carers don't have to be Nationwide members to access this service. You don't need to have a diagnosis to attend. Book a free confidential appointment for advice and support including:

- getting a diagnosis
- understanding symptoms and changes in behaviour
- practical tips for carers
- choosing a home or residential care
- emotional support



To book an appointment Text the word APPOINTMENT to 07478 724000 and you will get a call back. Or go to <https://www.dementiauk.org/information-and-support/how-we-can-support-you/admiral-nurse-clinics/nationwide/#locations>

The logo for hynt, featuring the word 'hynt' in a bold, black, sans-serif font inside a yellow right-pointing triangle.

What is hynt?

Hynt is a new national access scheme that works with theatres and arts centres in Wales to make sure there is a consistent offer available for visitors with an impairment or specific access requirement, and their Carers or Personal Assistants. Contact hynt to find out who it's for; what it provides; and how to become a member.

If you need support or assistance to attend a performance at a theatre or arts centre then you may be eligible to join hynt.

Call - 01446 401744.

E-mail - info@hynt.co.uk

Website - <https://www.hynt.co.uk/en/>



Changing Seasons

If you're supporting somebody living with dementia, the Alzheimers Society suggests these 7 ways to help make sure they're safe and comfortable during the colder, winter months.

1. Make sure the person is dressed appropriately

People with dementia won't always remember to dress appropriately for colder weather, so it's important to help make sure they're wearing the right clothes. Layers are key to keeping warm, and the best materials for maintaining body heat are cotton, wool, or fleecy fibres.

Helping someone with dementia choose what to wear is important. Help them to make their own choices, make sure they are clean and comfortable, and to express their own identity and personal style.

2. Keep the room warm

Try to make sure any rooms that are occupied during the day are kept warm – it's a good idea to aim for around 20 degrees Celsius

As well as putting the heating on, things like draught-proofing, thermal curtains and roof insulation can help maintain a consistent temperature. It's also worth keeping a blanket within easy reach of a person with dementia, so they can grab it if they're feeling chilly. At night, a hot water bottle or electric blanket can help keep the bed warm.

3. Encourage regular movement

Keeping active can help to boost circulation and help keep someone with dementia warm. It's a good idea to encourage the person to move around at least once an hour.

If walking is difficult or extreme weather conditions make it hard to go outside, simply getting the person with dementia to move their arms and legs, or wiggling their toes can be helpful.

4. Make the most of natural daylight

Decreased sunlight can cause someone with dementia to feel increased anxiety, confusion, and even depression during the winter.

You can help by making sure they're exposed to natural daylight when possible. Get outside when you can – a quick walk around the block or even just sitting outside in the garden for a few minutes can do wonders.

Sundowning and dementia - Sometimes a person with dementia will behave in ways that are difficult to understand in the late afternoon or early evening. This is known as 'Sundowning'. At home, make sure curtains are open during the day to let in as much light as possible. You could also position the furniture so that the person with dementia is sitting near a window. As natural light starts to fade, make sure lights and lamps are turned on.

5. Stick to a routine

A big change in routine can cause someone with dementia to become confused or agitated. If you do have to make changes to someone's routine in winter – for example, changing nap times or daily walks due to limited daylight – try to do them slowly and gradually.

6. Be careful in icy or snowy weather

Perception issues can make it difficult for someone with dementia to see icy patches on a pavement or understand that snow can make a surface extra slippery.

If you're out for a walk in icy or snowy conditions, make sure you're supporting the person with dementia carefully. Encourage them to take smaller steps and walk more slowly than usual.

7. Eat and drink regularly

Keeping warm uses up a lot of energy, and a warm house can increase the risk of dehydration. It's important to make sure someone with dementia is eating regular meals and drinking enough fluid during the winter.

Snacking throughout the day can help keep energy levels up, and warm drinks can help keep them at a comfortable temperature. They should avoid drinking alcohol as it makes you feel warm, but actually draws important heat away from vital organs.

<https://www.alzheimers.org.uk/blog/how-support-somebody-living-dementia-cold-weather>

CYNGOR GWYNEDD

Keeping your house warm

Help is available if you're finding it difficult to keeping your house warm. You might be eligible to have work done on your house such as improve insulation or a new heating systems through schemes such as Nyth and Eco 4.

To find out more visit Gwynedd Council's website or contact to see if you are eligible or need advice

<https://www.gwynedd.llyw.cymru/en/Residents/Costau-Byw/Keeping-Warm.aspx>

Email - tloditanwydd@gwynedd.llyw.cymru

Phone 01766 771 000 (ask for the Energy Advisor)



Warm Spaces - Is your house cold? Fancy a chat or a cup of tea?

A number of locations across Gwynedd offer a warm welcome for anyone to come in for a warm shelter, chat and a cup of tea.

Phone 01766 771 000 or scan the QR code on the right to find out where the nearest Warm Space is to you.



Winter Whispers by Catherine Pulsifer

Winter whispers secrets to the hearts,
Each person listens in their own way,
Kids dance and laugh in the snow's embrace,
While some seek warmth, hibernate and wait.
For others, winter's chill is a friend,
A time for joy, for cocoa and play,
So let us honor each unique view,
And find harmony in winter's varied hue.



Would you like to help to make a real difference to the future of dementia care, diagnosis and treatment.

Your brain today could be tomorrow's breakthrough: Why every mind matters in changing the future of dementia.

Dementia is one of the biggest health challenges we face today. There are around a million people currently living with dementia in the UK. This is estimated to increase to more than 1.4 million by 2040! Research offers hope by helping us understand what causes the disease, develop effective treatments, improve care and hopefully one day find a cure. Taking part in a research study can take many forms.

Examples include studies looking at prevention or new ways to diagnose the condition; drug studies trialling new treatments; and surveys aiming to improve the quality of life for people with dementia and/or their carers. The different types of studies that recruit through Join Dementia Research include:

- Brain scans
- Drug/medication trials
- Focus groups
- Lifestyle programmes
- Online and offline questionnaires
- Physical tests/assessment
- Talking Therapies
- Thinking and memory tests



To register go to : <https://www.joindementiaresearch.nihr.ac.uk/>

Or for more information call Alzheimers' Research UK 0300 111 5 111
9am to 5pm, Monday to Friday. Please mention Join Dementia Research at the start of your call

Memory Bags

available to borrow from your local library



Bringing memories to life -
a new collection of Memory Bags

How about reliving the past by borrowing a bag from
our special collection - for free!

Browse our online catalogue or ask a member of
library staff for assistance.

The collection includes -
Sensory bags for people with visual or hearing
impairments

Memory bags filled with books, pictures and
fascinating objects from past eras

For more information -
01286 682663



Moira & Idwal

Moira and Idwal live in Caernarfon. Idwal was diagnosed with vascular dementia six years ago and at the time, Moira said she was left to get on with it after the diagnosis, “the consultant just said ‘oh yes your husband’s got vascular dementia’, and I really wasn’t ready for that. I hadn’t really thought about dementia”

Moira and Idwal were given a big pile of leaflets and were then left to their own devices.

About a year later and by chance, Moira found out about Dementia Actif Gwynedd and since then they have been supported by the team. Idwal enjoys the weekly exercise class at Byw'n Iach Arfon in Caernarfon, where he also attends to the community garden in the summer months. Moira also goes along to the class for a cuppa, singalong and a chat at the end of the class. They both attend the Clwb Clebran (quiz and reminiscing group) on a Monday in Bangor, the monthly Boccia League in Porthmadog. Moira is an active member of the Dementia Carers group who meet up online every fortnight. They both also enjoy the various outings and trips that are organised and recently had a visit to Plas Newydd in Anglesey.

Your Story



Idwal : I like coming to the classes to see other people and it keeps me fit and active.

Moira : And if Idwal is happy then I am happy !

Useful Contact Numbers

Contact your local Byw'n lach facility for information about Active For Life gentle physical activity sessions



Arfon, Caernarfon - 01286 676451

Bangor - 01248 370 600

Bro Dysynni, Tywyn - 01654 711763

Bro Ffestiniog, Blaenau - 01766 831066

Dwyfor, Pwllheli - 01758 613437

Glan Wnion, Dolgellau - 01341 423579

Glaslyn, Porthmadog - 01766 512711

Pafiliwn, Barmouth - 01341 280111

Penllyn, Bala - 01678 521222

Plas Ffrancon, Bethesda - 01248 601515

Plas Silyn, Penygroes - 01286 882042

Cyngor Gwynedd's Community Adult Teams

1. Llŷn Area - 01758 704099
2. Caernarfon Area - 01286 679099
3. Bangor Area - 01248 363240
4. Eifionydd & Meirionnydd North Area - 01766 510300
5. South Meirionnydd Area - 01341 424499



- Memory Support Pathway - 01492 542212
- Dementia Actif Gwynedd - 07768 988095
- Wales Dementia Helpline - 0808 808 2235
- Carers Outreach - 01248 370797
- Alzheimers Helpline - 0333 150 3456
- Age Cymru Gwynedd & Mon - 01286 677711

Organisations working together to help support people affected by dementia

YMMDIRIEDOLAETH
GOFALWYR
Gogledd Cymru
Gwasanaethau Gofal Croesffydd

CARERS
TRUST
North Wales
Crossroads Care Services

BWRDD PARTNERIAETH RHANBARTH
GOGLEDD CYMRU
NORTH WALES
REGIONAL PARTNERSHIP BOARD

Alzheimer's
Society
United Against
Dementia

PRIFYSGOL
BANGOR
UNIVERSITY



BWRDD IECHYD PRIFYSGOL
BETSI CADWALADR
UNIVERSITY HEALTH BOARD

GIG
CYMRU
NHS
WALES

Byw'n lach
Gwynedd Oed Gyfeillgar
Age Friendly Gwynedd

Gwynedd a Môn
age Cymru

Dementia
Actif
Gwynedd

Dementia
North Wales
Memory Support Pathway

bywyd
LIFE
GWAJANAETH CYNNIAL GOFALWYR
CARERS OUTREACH SERVICE

CYNGOR
GWYNEDD