

Dementia Gwynedd Newsletter

Dec 2024
No3

Greetings and welcome to the latest edition of the Dementia Gwynedd quarterly newsletter. The purpose of the Newsletter is provide information about what's going on in the county to help inform & support people affected by dementia. We're excited to share some of the most recent information, stories, achievements and updates with you.

Collaborations & Creativity

National Slate Museum Llanberis & Dementia Actif

In October members from the Bethesda Dementia Actif group had the opportunity to work with ceramicist Rhiannon Gwyn to create a series of personal, creative pieces inspired by the museum's Pattern Loft- which is full of stunning wooden patterns originally used to create the various items needed by the quarry. The creations formed part of Rhiannon's own work with slate and was on display at the museum in Llanberis before it recently closed for extensive refurbishments.

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We both had such a lovely time (in the craft session), Mum has spoken about it several times since, saying how much it helped her to regain confidence in being out and about with other people and took her mind off what has been a difficult time for our family. She was diagnosed with dementia in April of this year and it's felt like it's shrunk our worlds. It makes a huge difference to her just getting out now, and it also helped us both seeing people who have dementia getting on with life, having fun and being physically active. There is so much focus on the negative aspects of dementia, so being around such a friendly, lively group of people last Wednesday has helped her (and me) to feel like there is a lot of fun still to be had. I'm so grateful that programs like this exist as it is surely a lifeline for many people. Family Carer



Lived Experience

Doug Hughes is a writer producing general interest articles ranging from travel pieces to classic motoring for the English edition of The Portugal Times. Doug lives in Nefyn and was diagnosed with Alzheimers in his 50's. Here's an interesting article he wrote in 2023 whilst contemplating his diagnosis.



Am I “Living with Dementia” or am I a “Dementia Sufferer”?



In this day and age, we're compelled to mind our P's and Q's. We're living in an age that's long embraced politically correct ideology as the mainstream. Woe-betides any naysayers.

It seems I can no longer declare that I'm "suffering" from dementia. Instead, I'm meant to say that I'm "living" with it. Beats me what difference all this PC stuff is supposed to make? It's still Alzheimer's regardless of how I or anyone else choose to describe the situation. As far as I'm concerned, Alzheimer's disease is actually something that I'd obviously rather not be "living with" quite frankly. In my mind, to say that I'm "living" with it implies a sort of quiet acceptance which doesn't really describe how I view the situation.

But having said that (without making light of any dire situations others are facing), I have consoled myself with the notion that there are probably much worse things to have been diagnosed with. Truth is, at the moment, I'm not actually "suffering" per se. So I guess it's fair for me to fall in with the notion that I really am "living with dementia" - albeit reluctantly.

In the scheme of things, I consider myself to be relatively fortunate because the type of disease that has afflicted me has (so far) proved to be slow-progressing. It's noteworthy that there are umpteen incarnations of this dreaded disease and each person's symptoms will depend on the type and severity of disease. Much also depends on age, treatment, individual responses and even individual attitudes. It all adds up.

If you enjoy a spot of sympathy and a bit of the old "there, there" routine, dementia might prove to be a bit of a letdown. Very few people will initially display much by way of sympathy towards dementia sufferers because they'll often be oblivious to it. Dementia is a bit like backache, in that it goes largely unseen. It'll only be people who spend the most time with a dementia patient who'll notice any changes. Even then, young onset dementia symptoms can be quite subtle and may not initially present on a regular basis.

When people find out that I have Alzheimer's, one of the FAQs I get quizzed about is what actually prompted me to visit a physician and get a diagnosis. This isn't a very easy one to answer because, early on, I hadn't realised that there was anything amiss. I was eventually pushed to go and see my GP by others who'd noticed some changes. In fact, I'd quite arrogantly poo-hooed the notion of seeing a doctor for quite some time. To me, the suggestion that there was anything awry seemed utterly ludicrous. I only really complied in order to keep the peace and to get folks off my back. However, I had noticed that more and more people were making comments about my forgetfulness and my increasing tendency to repeat myself. Quietly, this was beginning to make me feel a little concerned.

Not long after visiting my GP, and well before I actually got to see any specialist Consultants, I realised that I was failing to recognise what ought to be familiar surroundings. This often happened when I was driving my car. It felt like déjà-vu in reverse. These episodes were causing me to panic and become disorientated. On a few occasions, I even had to pull into laybys in order to catch my breath, mainly because of the anxiety I was experiencing. I dismissed the first couple of episodes as being down to fatigue but I soon noticed that these episodes were occurring more and more frequently. It was almost as if my brain was momentarily rebooting, like a faulty computer. Once back online, I could go for days without experiencing any further symptoms. I felt fine, well able to brush it all under the carpet.

When it comes to the art of self-diagnostic aplomb, I've always been in the champions' league. Who needs a physician when I can simply rely on my own wherewithal to play down symptoms or even self-prescribe? In my pre-dementia world, physicians were utterly superfluous, I barely ever paid them a visit nor did I give their profession a second thought. I was the NHS's model patient, one that made zero demands on services.

However, when it came to symptoms of cognitive dysfunction, I had absolutely no answers and my self-diagnostics started bordering on hypochondriasis. Was I having mini strokes? Did I have a brain tumor? Or was it all just an annoying figment of my imagination, fueled by all the allegations of forgetfulness and self-repetition? All of these things seemed perfectly plausible.

But, sadly not. Several tests and many scans later came the shattering diagnosis of 'early onset Alzheimer's disease.' I had attended several appointments at Liverpool's Walton Centre where both my wife and I had expected to hear the bad news on numerous occasions. But, more and more tests were required before the Consultant committed to delivering his sobering diagnosis. When it eventually came, I didn't feel anything other than total numbness. Strangely, my wife was far more shocked and upset than I was, but I guess that's a pretty standard reaction. My becoming a blubbing wreck wasn't going to solve anything.

Rather than being consumed by self-pity, my immediate post-diagnosis life was immersed by the need to sort things out in the aftermath. I had been an active property developer and still had lots of commitments. Just stopping work as per medical advice was clearly a non-option despite being told that I should immediately stop operating heavy machinery, use ladders or go up scaffolding. All that effectively meant STOP WORKING because all of the above were part of my daily routine. But, I carried on working for three more years post-diagnosis, mainly because I had so many loose ends to tie up. Despite everything, rightly or wrongly, I still felt capable of work.

When it comes to it, to say that I'm a dementia "sufferer" does appear to have a number of negative connotations, despite the fact that dementia is hardly a positive for anyone. Right now, of course, there's no cure for this progressive disease.

For me, one of the most abhorrent things to have arisen from having this condition has been my loss of interest in a hobby that I once loved. I adored messing about with classic cars. I owned several. Not so long ago, I was always one of the first on the showground, polishing and minting up my cars for various summer shows. But, I suddenly lost all interest - almost overnight. I can't explain it but I saw the cars as a chore rather than a pleasure. The enthusiasm I once had just dried up, like a barragem in a drought. So that, alongside factors like my family worrying about my long-term health, represents "suffering from dementia."

But I'm still here in a relatively fine fettle. That must mean I'm surely doing something right because it puts emphasis on the positive, that I am indeed, like it or lump it, "living" with dementia.

Community Support & Resources

Care and Support in Gwynedd - Micro Enterprises

Cyngor Gwynedd is working with local people to set up enterprises offering services that support you to achieve what matters in your home and community. This could be anything from companionship, preparing meals, support in and around the home to days out, attending social events or even helping with your pets. This is just an example of what the enterprises offer, they are flexible and will listen to what you want.

If you would like to hear more about the care and support available and to receive a list of the enterprises in your area, please contact Fran Lowden franlowden@gwynedd.llyw.cymru / 07824125642

FUNDRAISING FOR DEMENTIA

Eryri Co-Operative is a person centred service catering to individuals who require health and wellness support.

One of the founding members, Gwenda Hughes also arranges community events and recently included fundraising events - Cuppa Mornings and two Memory Walks, one being a trek to the summit of Yr Wyddfa, by foot and train. The sum raised has now exceeded £2,300, which has smashed her original target of £500 and all for the Alzheimer's Society.

"Thank you so much for everyone who has been part of the events that I have arranged. I never thought that I would raise such an incredible amount, everyone has been so kind so thanks a million to everyone for supporting me"- Gwenda

Contact 07999 453676 info@eryricoop.cymru



ERYRI
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ERYRI
CO-OPERATIVE



Reading Well for Dementia

Recommended books chosen by people living with dementia, carers & health professionals. Contact your local library for more information:-



- Bala - 01678 520014
- Bangor - 01248 353479
- Barmouth - 01341 280258
- Bethesda - 01248 600737
- Blaenau Ffestiniog - 01766 830415
- Caernarfon - 01286 679463
- Criccieth - 01755 522256
- Dolgellau - 01341 422771
- Nefyn - 01758 720873
- Penygroes - 01286 880427
- Porthmadog - 01766 514091
- Pwllheli - 01758 612089
- Tywyn - 01654 710104

THE READING AGENCY

Available at your local library

Reading Well for dementia

reading-well.org.uk

Recommended books chosen by people living with dementia, carers and health professionals.

THE READING AGENCY
ARTS COUNCIL ENGLAND

Libraries Connected

© The Reading Agency
Modern Library
England and Wales

Gwynedd Dementia Centre & Hubs

The Dementia Centre and hubs forms part of the Memory Support Pathway to support & guide people with dementia and their family and friends.

Monday - Bangor Centre - 10:00am - 4:00pm

Tuesday - Criccieth Centre - 10:00am - 4:00pm

(1st Tuesday/month Lunch - 'Cinio Ni' at the Prince Of Wales, Criccieth)

Wednesday - Bangor Centre - 10:00am - 4:00pm



The Dementia Centre will also visit various Community Hubs each month at Caernarfon, Blaenau Ffestiniog, Barmouth, Llanaelhaearn & Porthmadog.

To find out more contact:- ffion.travis@ctnw.org.uk 07376 484154

Clwb Mantur

Clwb Mantur is a group for men living with dementia and in particular for those with young onset dementia. The group meet once a month at various locations to take part in social activities and have the opportunity for peer support. This project is a collaboration between BCUHB & Dementia Actif.

Activities so far have included, a visit to the Ffestiniog Railways workshops at Boston Lodge in Porthmadog; Outdoor activities with the Dref Werdd at Gwaith Powdwr natur reserve in Penrhyndeudraeth; Afternoon tea in Portmeirion and a Sporting Memories session and games at the Porthmadog Football Club.

Contact Emma 07768 988095 for more information.



Dementia Gwynedd Directory

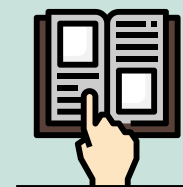
What do you think?

It is important for people to stay connected when they have a diagnosis of dementia. Having an active social life can reduce stress, reduce isolation, brighten mood and keep relationships strong. To help make this a little easier for people to know what's going on in the community, we are in the process of creating a Dementia Gwynedd Directory which will include information about appropriate community activities & groups in your area.

The Directory will be available online and as a hard copy booklet.

We would appreciate any ideas about what to include in the Dementia Gwynedd Directory, please contact Emma:- 07768 988095

emmajaynequaeck@gwynedd.llyw.cymru





My House of Memories APP

The My House of Memories app, co-created with people living with dementia, is a digital collection of museum and everyday objects from across the decades that have been brought to life with sound, music and descriptions. The app is available in Welsh & English and allows people living with dementia and their carers to explore pictures of objects together and find things that resonate with them, encouraging connections and conversations.

You can save your favourite objects to a digital memory tree, digital memory box or timeline. The My House of Memories app also has a 'My Memories' feature, which enables users to upload their own photos.

Download the My house of Memories App via the [iTunes store](#) - for iPads, iPhones and iOS devices and [Google play](#) - for android devices

<https://www.liverpoolmuseums.org.uk/house-of-memories/my-house-of-memories-app>
<https://www.liverpoolmuseums.org.uk/house-of-memories/cymru/house-of-memories-cymru>



BBC Music Memories <https://bbcrewind.co.uk/>

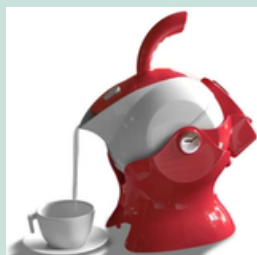
This website is designed to use music to help people reconnect with their most powerful memories. Evidence shows that music can help people - including those living with dementia - to feel and live better. Create a playlist and then export it to Spotify to listen to your tracks in full, or sit back and listen to a Memory Radio show.

Helpful Products for around the home

The Alzheimer's Society have a wide range of products to help people living with dementia and their carers around the home. The helpful products are designed to make life easier and more comfortable, while supporting independence and safety. They include reminder clocks, simple phones, lighting, products to help in the kitchen and bathroom, personal care aids, clear signage, and easy-to-use gardening tools. Visit their website for more information:-

<https://shop.alzheimers.org.uk/collections/help-around-the-home>

Or contact Ffion Travis at the Dementia Centre for information about different products :- ffion.travis@ctnw.org.uk 07376 484154



For more information about anything relating to this newsletter please contact Emma Quaek 07768 988095

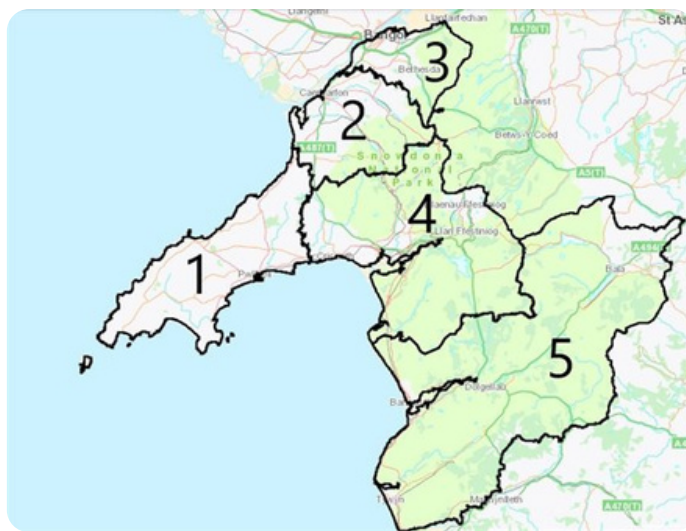
USEFUL TELEPHONE NUMBERS

Cyngor Gwynedd's Adult Services

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

Emergency Out of Hours 01248 353 511

<https://www.gwynedd.llyw.cymru/en/Residents/Health-and-social-care/Adults/Adults.aspx>



The Wales Dementia Helpline is open 24/7 to offer support, advice and signposting relating to dementia, covering all of Wales.

 Call 0808 808 2235

 Email dementia@helpline.wales



USEFUL
TELEPHONE NUMBERS



- Memory Support Pathway - 01492 542212
- Dementia Actif Gwynedd - 07768 988095
- Carers Outreach - 01248 370797
- Age Cymru Gwynedd & Mon - 01286 677711
- Care & Repair Cymru - 029 2057 6286

Organisations working together to help support people affected by dementia



Byw'n lach



For information contact :-
Emma Quaek - Dementia Gwynedd Co-ordinator
✉ emmajaynequaek@gwynedd.llyw.cymru ☎ 07768 988095