

**“Be brave. Remember that it’s the people with dementia who are the experts. If you see something acting as a barrier, get rid of it!”**



**Emma Quaeck is the Dementia GO Project Manager, a physical activity and support scheme for people living with dementia and carers. She is also a Dementia Friends Champion and Chairperson of Porthmadog Dementia Friendly Communities.**

## **What is Dementia GO?**

It started as an extension to the National Exercise Referral Scheme (NERS), a series of exercise classes which people with a diagnosis of dementia could be referred to. The response to these initial classes was absolutely phenomenal. We started with classes in three leisure centres which you could only take part in by referral, and we now run classes in 14 venues, which we have opened up not only to people living with dementia, but also people who may be worried about their memory, carers, or older people who find the level of class appropriate for them. The classes are partially based around strength, balance and falls reduction, but the real focus is on having a laugh. We hardly ever use the word exercise or talk about health, but we talk a lot about fun. Every class we do finishes with a cup of tea and some biscuits, and the opportunity to chat - that’s really important!

Putting on physical activity classes for people with dementia was a new area for almost all of us working here. I realised that we couldn't put on classes without first raising people's awareness of dementia. When you're working with people with dementia, it's really important to make sure that their whole experience is positive, from the moment they leave home to when they leave the class and head back home. It's not just about the actual class.

We ran Dementia Friends awareness sessions for over 100 leisure centre staff, and provided specialist training for our exercise instructors. I wanted to make sure that everyone who came into contact with participants with dementia had a basic awareness. It's just as important that your receptionists know how to support people living with dementia as the instructors themselves.

All the staff have been amazing, they're really good at adapting to people's needs on the spot. I actually think our leisure centres and classes are now more inclusive, and we're seeing more activities being put on for older people, which is fantastic.

## **What made you want to start classes for people living with dementia?**

My mother had Alzheimer's for 17 years, and I was with her from the diagnosis to the end. I've seen how it affects people, and how it affects the whole family. I'd seen her in the community and in a care home setting, and I'd seen how people reacted. I'd seen people crossing the road to avoid my Mum, worried about what she would say or how she would act. I'm not judging them, I know it's often because people just don't know how to respond.

So many people with dementia feel excluded from everyday life. My Mum was always such an active person, I wish that something like this was available when she was alive. She would have loved it.





## What are the benefits for people taking part in the classes?

In one of the classes we usually start people off playing table tennis, something a lot of them won't have done since they used to go to the youth club as kids. This lets them have some fun, but also gets them stretching and moving. You can see their coordination improve as the weeks go on. We then start to introduce them to other forms of exercise to help improve strength, balance and stamina, to help them to be able to continue to live independent lives. When you're working with people with dementia, you can't be too precious about the plans you might have made in advance. You have to be responsive to the people on the day, be flexible and go with the flow. It's so important that the activities are fun, as well as functional.

When you get it right, you can see the joy in people's faces, and the sparkle in their eyes when they're involved. For that moment, nothing else matters to them. The challenges and difficulties that they face in their everyday lives fade away. When people tell us that coming to the classes has improved their quality of life, you can't ask for any greater encouragement, it's priceless.

The classes also help people get out and about, to meet people and to make new friends. There are two couples who go to the classes in Caernarfon. They didn't know each other before, but they've now become such good friends they go round to each other's houses every Wednesday and play board games. One of the gentlemen who has dementia has always been a really keen gardener. He's been to the other couple's house and helped them put up a greenhouse in their garden. The classes have completely changed their lives, they now have a reason to get out of the house, and to do things together.

## **Do you have any plans to build upon the success of Dementia GO?**

We've started putting on bigger community events, bringing all the different groups together, which are fab. We've organised three dance-a-thons. Over 160 people came to the most recent one we organised, which is phenomenal. Russell Grant came along and took part, which helped raise loads of publicity. The events are a day out for people, a reason for them to get out of the house, an excuse to dress up in the best clothes, and have some fun.

We also ran a Boccia tournament. Boccia's a form of bowls that you can do seated. It's a recognised Paralympic sport, and anyone can play. We had so much interest. Different groups from all over North Wales got involved, such as the MS, Stroke and Parkinson's Societies, not just people who come to our classes. We're now seeing local Boccia clubs start up, and we're going to make the tournament an annual event.

I want us to start working more closely with other organisations and groups. I've been talking to Age Cymru Gwynedd a Môn. They have 'Age Well' centres in quite a few rural areas locally and already run some exercise classes. I want to support them to make sure their classes are inclusive for people with dementia, sharing some of the lessons that we've learnt. As people's dementia progresses, we need to support them to stay physically active wherever they're living. I'm starting to work with Gwynedd Council Residential homes. We will be supporting care home staff to empower their residents to be more active.

## **Do you have any advice for anyone thinking of running activities for people living with dementia?**

Never forget the vital role that carers play in the lives of people with dementia. While our classes have been targeted at people with dementia, they've become a kind of unofficial support group for the carers, who get a chance to meet up and chat during and after the classes. We've had carers keep coming to the classes even when the person with dementia they were caring for can't come anymore. Having their experience on hand is invaluable, and it's so good to have their ongoing support.

Don't try and do everything on your own. Link up with other groups and organisations around you. There's so much support and help out there if you just ask. Look for potential partners who are doing similar things. Get people involved, and get to know the people in your community, as that's where you'll get your best ideas from.