

Scottish Dementia Working Group (SDWG)

Local engagement newsletter

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SDWG & locality engagement

It would be fair to say that most of the campaigning and awareness raising work by the Scottish Dementia Working Group is carried out on a national platform, however it's equally important to point out that the members are also very much involved at a local level. This topic was highlighted recently when the group met for one of their regular 'Business Meetings' at Glasgow's Brain Health & Dementia Resource Centre. Following the usual business updates, members welcomed the opportunity to discuss the significance of their work within their own communities and how this local insight guides them with their campaigning on a national level.

Indeed, as well as being actively involved within their own communities, the SDWG members never let an opportunity pass to visit other localities to help raise awareness and to ensure they are aware of the issues specific to each particular area.

In this newsletter we spotlight some recent and positive examples of the SDWG's involvement in raising awareness and community engagement at a local level.

West Dunbartonshire

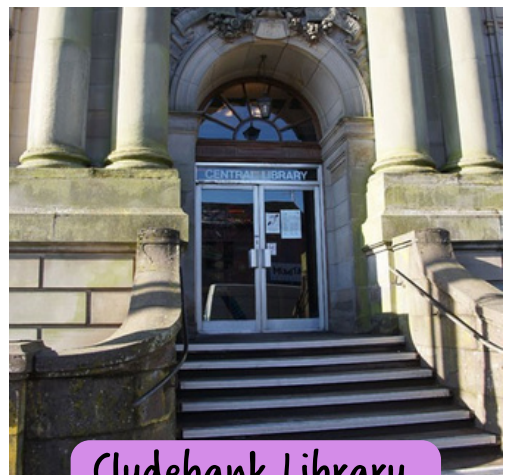
Tony was the elected Westminster MP for Clydebank (and Milngavie) constituency for 17 years. This experience, coupled with living in Clydebank, has given him an insightful knowledge of the area and an ongoing interest in its local issues.

Since being diagnosed with vascular dementia at the age of 77, Tony has been a regular visitor to Alzheimer Scotland's Clydebank Dementia Resource Centre. He currently meets there on a weekly basis with one of the Active Voice Development Officers, and whenever appropriate, the local Dementia Advisor will join the meeting to ensure Tony is kept updated on what's happening in the locality and has opportunity to provide feedback. For instance, Tony has had an ongoing involvement in the Dementia Safeguarding Scheme, and consequently, when it was launched earlier this year in West Dunbartonshire the Dementia Advisor consulted with Tony around their plans for this.

Another recent example involved Tony, along with the Active Voice Development Officer and the local Dementia Advisor, visiting the Clydebank Library to assist in their efforts to make the venue as dementia friendly as possible. Library staff facilitated a tour of their premises and Tony was able to provide suggestions for small improvements that can be considered to make the venue more accessible to those living with dementia.



Tony & Deborah at Clydebank DRC



Clydebank Library



Golden Jubilee Hospital

On a similar theme, Tony has recently been invited to visit the local NHS Golden Jubilee Hospital with a view to assist in their dementia friendly initiative.

Tony also has a passion for gardening and has linked the Dementia Resource Centre with a local gardener who is interested in volunteering opportunities. Subsequently, the gardener has arranged to do some work on the garden area at the rear of the centre with the aim of 'bringing to life' an outdoor space that can be enjoyed by those who attend the day centre.



The Every Voice Choir

West Dunbartonshire plays host to the 'Every Voice Community Choir' which was created as a therapeutic activity for people living with dementia and their carers. Tony and fellow SDWG member Danny are both actively involved in the choir whose performances locally and nationally have raised awareness of dementia and shown that people living with the disease can still enjoy an active life despite their diagnosis.

Lanarkshire

Kenny recently gave an awareness raising presentation to members of the Shotts Church Fellowship Group. Kenny (who is also a member of the church and places his faith as an important element in his life) spoke about his diagnosis and the challenges this presents, and moreover how he has adapted to live well with dementia.

The SDWG's commitment to ensuring workforce knowledge and practice are informed by people with personal experience was at the heart of a learning session with year 1 and year 2 junior doctors from Wishaw General Hospital

SDWG members Kenny, Margaret & Stuart spoke about their diagnosis journey, including their experience of receiving a dementia diagnosis whilst still in their 50s. The members also spoke about their life following the diagnosis and emphasised how they are living the best life possible with dementia, and how their work with the SDWG helps them to do so. They also took the opportunity to highlight the key things the junior doctors should keep in mind when giving a dementia diagnosis.



Kenny at Shotts Church

West Lothian

Stuart, who lives with young onset dementia is a regular visitor to Alzheimer Scotland's Red Brick Café in Livingston. The café, which is specifically for under 65-year-olds, provides a safe space for members to relax, socialise and get some advice & support. During the monthly meetings, Stuart is allocated some time to update the members on the work of the SDWG. This includes giving an overview of various projects the SDWG are involved with, and news of other national issues that may be of interest to group attendees.

Stuart has also recently taken on a role as a 'buddy' to potential new members of the Café. It goes without saying that joining a new group can be a daunting prospect for any of us, and for someone with dementia, it can also be a very unnerving and intimidating experience.

With this mentoring role, Stuart will arrange to meet prospective new members and provide comfort and advice, and moreover, offer appropriate support to help build the person's confidence.



Glasgow

Patricia is a regular attendee of Alzheimer Scotland's Glasgow Football Memories Group. The group are currently at the heart of a project with Abertay University, and a design team, to create a Virtual Reality (VR) experience around Football Reminiscence.

To make this an immersive and realistic experience, Patricia and fellow group members have decided to use assets and memorabilia from the Scottish Football Museum at Hampden Park, for instance they will use the original seating from the national stadium for users to sit on whilst experiencing the VR. The group have also been at the forefront of discussions around themes for phase 1 of the project and have agreed on an initial 3 'taster' experiences that will take people on a journey from travelling to the match on a bus, to going through the turnstiles into the stadium, to cheering on their team from the stand.



Patricia at Hampden with Football Memories group

This first phase of the project is anticipated to be launched in September to tie in with the 150th anniversary of Scottish Football. In addition to co-designing the VR experience, members of the Football Memories group will also feature in a film which is being specifically made to capture the project's progress and the story along the way.

SDWG members Margaret and Tony M regularly attend the Young Persons Café at Alzheimer Scotland's Bridgeton Resource Centre. This Café exists to offer a place to meet other people who understand and are affected by Young Onset Dementia, and to learn more about dementia. Attending the Café provides Margaret and Tony opportunity to hear some of the issues affecting people with younger onset living in the Glasgow area, and at the same time, gives them a valuable insight into local support and services.

SDWG recently facilitated a 'Coffee with a Cop' day at Glasgow's Brain Health & Dementia Resource Centre. The aim was to bring the group members and others affected by dementia in the Glasgow community, together with community police officers to discuss relevant issues and learn more about each other. The idea not only allowed the attendees to see the police are approachable, but also gave an opportunity to raise awareness about dementia and discuss various initiatives that are available to help people live safely with dementia. One unexpected outcome from the 'Coffee with a Cop' day relates to the 'Dementia Safeguarding Tag' scheme – a partnership between Alzheimer Scotland and Police Scotland. SDWG members had expressed their feelings that the term 'Tag' was inappropriate for this purpose and is an example of the negative language they are trying to eliminate when people talk about dementia. It was pleasing to note that Police Scotland have taken on board the feedback and have since involved the SDWG members in renaming this safeguarding scheme.



SDWG members who are involved in Alzheimer Scotland's Long-Term Care Commission (LTC) recently visited the organisation's Croftspar Place – a supported accommodation service. The LTC focuses on considering alternative models of care, therefore the visit to Croftspar was arranged to provide some additional insight into one such alternative to a care home setting which has been designed for people living with dementia.

SDWG member Tony recently presented at an engagement event which was attended by key Glasgow stakeholders including professionals from Health & Social Care. Tony spoke about his dementia diagnosis, gave an insight on living with dementia, and intimated that being part of SDWG has helped him stay focused and in a routine



Tony at Glasgow engagement event

Stirling

Christine & Bill Alexander (SDWG & NDCAN members respectively) took their campaigning and awareness raising message to Stirling. Both visited Stirling Central Library for the launch of a new Alzheimer Scotland partnership to establish dedicated Dementia Information Hubs in over 120 community libraries across Scotland. The partnership seeks to build on the many years of working with local libraries in our localities and will help us reach more people living with dementia across Scotland.



Christine & Bill at Stirling Library

Christine & Bill spoke about their own personal experience and of the importance of being able to access dementia information, services, and activities locally. Christine and Bill are also regular visitors to their local Dementia Resource Centre in Alloa which includes meeting up with their peers at the Dementia Café. They both agree that attending the café is an opportunity to get to know others in their locality and hear more about local issues. In Bill's words, "it's the little things we hear locally that can help us to make a real difference nationally".

Ayrshire

SDWG member Stuart Dougall was delighted to be invited to join the weekly Coffee & Catch-Up Group in the Kilmarnock Dementia Resource Centre to chat about our active voice work, his lived experience, and what membership of the group means to him. Stuart spoke about his journey following his diagnosis of dementia at the age of 58, and his current work with the SDWG, including his participation in current research activities and awareness raising of young onset dementia to help tackle the stigma people with dementia face.



Stuart at Kilmarnock DRC

Highlands

Margaret lives in Drumnadrochit on the banks of Loch Ness. Living in such a remote area of Scotland gives her a fantastic insight into some of the unique challenges people living with dementia face due to being geographically isolated, particularly as she has got to know many of the local dementia community through her association with the Dementia Resource Centre in Inverness.

Margaret has also been actively involved in supporting staff training at Raigmore Hospital in Inverness. This initiative saw Margaret attending meetings with key staff members to share her personal experiences, and to ensure the nursing staff have the knowledge and skills to support patients living with dementia.

Margaret and her husband Barry were pleased to be able to participate in a recent National Care Service "Making Sure My Voice Is Heard" session in Strathpeffer. The event, organised by the Scottish Government, explored issues around accessing social care support and had a particular focus on issues faced by people in rural and remote locations.



Margaret & Barry at Strathpeffer

"Enabling and promoting the diverse voices of people with dementia and carers to campaign for, promote and uphold rights and drive change."