

Active Voice

'Local to National' Newsletter

September – December 2023

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Introduction

Welcome to the 2nd edition of our 'Local to National' newsletter which highlights some of the recent, inspiring examples of engagement by our two national campaigning groups, the Scottish Dementia Working Group (SDWG) and the National Carers Action Network (NDCAN).

The positive outcomes from our continual Active Voice engagement work ultimately benefits people affected by dementia on both a local and national scale. A key part of the engagement work carried out by SDWG and NDCAN involves talking to people on a national platform. However, local engagement work is equally important. It allows our group members to have a conversation with, and listen to, people with personal experience of dementia, and professionals within specific dementia fields.

Our members recognise there is not 'a one size fits all' approach to engagement and different approaches are essential to hear diverse perspectives and gather important information to better inform campaigning priorities and focus points.

In this newsletter we highlight how both campaigning groups embrace various forms of engagement, both local and national, to help in their efforts to implement positive change to those affected by dementia.

West Dunbartonshire

12 December: Golden Jubilee Hospital

The physical environment of a building such as a hospital can work well or create some big challenges for people living with dementia. Staff members Con Gillespie (Dementia Lead) and Rob White (Service Design & Equalities Lead) at the NHS Golden Jubilee Hospital in Clydebank recognise this, and consequently, they are taking positive steps to assess their environment with a view of making it as dementia friendly as possible.

SDWG member Tony has been involved in this initiative from the outset by giving advice and suggestions on possible improvements from his own perspective as a person living with dementia. Tony was recently joined by Anne McWhinnie (Dementia Friendly Scotland Lead) and Deborah Edgar (Dementia Advisor) for a tour of the clinical waiting areas and consultation rooms. Tony's observations and suggested improvements will now form part of the hospital's 'Dementia Friendly Action Plan' which will be implemented in stages over the next 12 months or so.



Tony (right) with Anne McWhinnie and Con Gillespie

November: Dumbarton Joint Hospital.

The Older Adults Mental Health Team at the Dumbarton Memory Clinic were redesigning their appointment letter template which is sent out to people with dementia or people going through the diagnosis process. SDWG members Tony, Stuart and Kenny assisted in this redesign by reviewing the letter and subsequently making appropriate recommendations on how to make it more dementia friendly. The group members recommendations included increasing the font size of the letter, rewording some of the text, and adding a map of the hospital layout for easier navigation. These are all examples of how simple changes can make a huge difference to people living with dementia.

West Lothian

28 November: Post Diagnostic Support (PDS) Information Day

SDWG member Stuart, and NDCAN member Maureen hosted an Active Voice information stall at the West Lothian PDS Information Day. The event was attended by people local to the area who are currently on the waiting list for PDS. In addition to facilitating the information stand, Stuart and Maureen welcomed the opportunity to raise awareness of our campaigning work and to chat to local people living with dementia and their carers about the challenges they face.



Stuart & Maureen

Edinburgh

15 September: Annual Conference

Alzheimer Scotland's Annual Conference is always a highlight in the SDWG and NDCAN calendar and this year, as always, our group members were at the heart of the day. Welcoming delegates to the conference, SDWG member Stuart spoke about the difference that Alzheimer Scotland support had made early in his dementia journey and the importance of innovative practice in helping people to live well with dementia.



Stuart



Anne

NDCAN member Anne highlighted the work of the group and the challenges that current carers have finding time to campaign for change.

SDWG and NDCAN members Christine and Bill shared their story of living together with dementia. They highlighted the support and dedication of Alzheimer Scotland staff and spoke about the opportunity they have to shape policy, practice and care through their Active Voice work.



Bill & Christine



Thea

NDCAN member Thea introduced a session which explored women's brain health and dementia. Thea emphasised that women's brain health must be a priority. She highlighted that brain health is not mentioned in the Scottish Government's Women's Health Plan, and called for data on women living with dementia to be included in the plan.

Rynagh from SDWG spoke at the final session. She shared her personal experience of diagnosis and talked about her participation in dementia research which has offered her hope and helped improve her quality of life.



Rynagh

2 November: 'Tour of the labs' – exploring dementia research

In recognition of their involvement in various dementia research projects, members of both groups recently accepted an exciting invitation by Professor Tara Spires-Jones to visit the Dementia Research Institute (DRI) at University of Edinburgh. Professor Spires-Jones, who is renowned in the field of Dementia Research, is Group Leader at the DRI, Deputy Director at the Centre for Discovery Brain Sciences, and also an Alzheimer Scotland Ambassador.



Tour of the lab

The SDWG and NDCAN members were honoured to be given a guided tour of the 'Spires-Jones Lab' and were given a fantastic insight into the innovative work the DRI are conducting in the field of dementia research. Following the lab tour, members were invited to attend a team meeting where they were given the opportunity to introduce themselves before hearing from the research professors (including Professor Spires-Jones) and other key staff who all explained about the particular projects they are currently involved in.

16 November: Promoting an Allied Health Professional Human-Rights Based Approach

Our campaigning groups strive to ensure that dementia policy and practice in Scotland respects the rights of people living with dementia and their carers. It therefore came as no surprise that members of both groups were delighted to accept an invitation to present at the recent Allied Health Professionals (AHPs) learning event. The event had the overarching theme of 'A Human-Rights Based Approach to Rehabilitation for People Living with Dementia'.

Held at Napier University in Edinburgh, the event was aimed to empower a partnership approach to practice, and brought together various AHPs from all over Scotland from a range of areas including NHS, social care, and private practice.

NDCAN members Thea and Barry G, and Margaret M from SDWG, all gave personal and insightful presentations. Thea and Barry highlighted that policy suggests that carers should be recognised as equal partners in care, however in practice this is not always the case. Margaret spoke about how basic human rights which most of us take for granted, are often neglected for those living with dementia.



At AHP learning event

21 November: NHS Dementia Workforce Excellence in Acute Care

The importance of working in partnership with family carers was the key message from our NDCAN members Maureen and Barry G at this NHS staff dementia training event. Both members presented and shared their stories of the hospital care experienced by their loved ones with dementia. More importantly, they also gave their perspectives on how they would like staff in hospitals to support people living with dementia and their carers.

Margaret and Barry N (SDWG and NDCAN) also gave an insightful presentation at this event on 'living well with dementia' and spoke about various activities Margaret participates in to demonstrate how it is possible to live well following a diagnosis.



Maureen



Barry G



Margaret & Barry N

Argyll & Bute

13 September: NHS Operational Locality Meeting

This operational staff meeting was attended by various professionals in the field of dementia care from NHS Argyll and Bute. Kenny (SDWG) and Marion (NDCAN) both gave inspiring presentations at this well attended engagement session. It proved to be another fantastic example of how the members use their stories and personal experiences to raise awareness.



We were all inspired and privileged to have you all present to talk to us. You are all incredible advocates for creating awareness and breaking the stigma associated with dementia.



Carol Jones: Clinical Services Manager –
Argyll & Bute Health & Social Care Partnership

16 November: Frontotemporal Carers Group

NDCAN members Joanna and Maureen attended this peer support group for carers of people with frontotemporal dementia. Joanna and Maureen began the meeting by sharing their personal insights of being a carer and spoke about some of the challenges they had encountered. The carer group members then welcomed the opportunity to 'tell their stories' and highlight the challenges they face in their caring roles. This included issues around Power of Attorney, barriers to accessing Self-Directed Support, and the lack of respite opportunities. The meeting was emotional at times, nevertheless, there was a huge sense of unity among the carers who were very grateful that Joanna and Maureen took the time to listen, and they were encouraged by the idea that sharing their stories can help influence change.



Thank you so much to you all for coming on last night and speaking to the group. Although, this group of carers have some specific issues relating to caring for someone living with FTD, it is clear that there are commonalities in their stories... I hope the group felt that NDCAN is there to be a voice for them.



Lindsay Voigt: PDS Link Worker – Argyll & Bute

Dundee

19 September 2023: Dementia Café engagement

SDWG members Stuart and Margaret M, and Marion Ritchie from NDCAN travelled to Dundee to attend the monthly Dementia Café which is hosted by Alzheimer Scotland at the V&A Museum. Stuart, Margaret and Marion welcomed this opportunity to meet with local people affected by dementia to promote the importance of our Active Voice work and to chat about local issues.



Dementia Café

19 September 2023: 'Stuart's Story' animation

In his capacity as a member of the Allied Health Professionals (AHP) Animation Group, SDWG member Stuart visited the Dundee Dementia Resource Centre to meet with Alzheimer Scotland student Megan Roberts. This was their first in a series of meetings to discuss their plans for an animation film featuring 'Stuart's Story'. The short film which includes 'tips' on living well with dementia is now completed and available to view on the AHP's YouTube channel.

Some of Stuart's top tips

- have a focus
- have a routine
- keep motivating yourself
- keep trying things you are struggling with
- live your life



Glasgow

7 September 2023: Global Ageing Conference

The 2023 Global Ageing Network's conference which was held in Glasgow, provided an outstanding opportunity for people to gather in a unique forum dedicated to shared learning and professional networking. SDWG Member Margaret M was invited by the CEO of Scottish Care, Donald Macaskill to present at the conference and share her personal experience of living with her diagnosis, as well as her aspirations for social care and services as she gets older.



Margaret, Wendy Rankin-Smith, Donald Macaskill

Margaret spoke about how she lives well with dementia and asked the audience to "see the person, not their age, not their illness but the whole person". She also participated in a panel discussion where she shared the work of Active Voice and how SDWG makes a difference in terms of bridging the gap between policy and practice.

Renfrewshire

2 October 2023: Filming day - Career Guidance and Dementia Research

SDWG members Kenny, Rynagh and Stuart were at the University of the West of Scotland (Paisley campus) to record an awareness raising film about working after a dementia diagnosis. The film also offers advice to employers on how to support people living with dementia to remain in their job. The film is part of long standing 'Career Guidance and Dementia Research Project' that SDWG members have been involved in with our partners at Alzheimer Scotland Centre for Policy and Practice (ASCPP). During the filming, all three group members spoke about their personal experiences of being in employment when first diagnosed and gave guidance to those experiencing symptoms of dementia in the workplace.



Kenny, Rynagh & Stuart

When complete, it is hoped the film will be able to give people living with dementia the confidence to stay in employment, and at the same time, will raise awareness to employers that in many cases, people are still able to continue working after a diagnosis.

I enjoy my work, it's part of me, and thankfully my employer has been supportive in enabling me to continue after being given a diagnosis.

Rynagh

With the right support I have no doubt I could have continued to do my job and could still be doing it today.

Kenny

Life has changed but it's certainly not over.

Stuart

Ayrshire

9 November: Consultation on the future of long-term care

Both our national campaigning groups recognise the importance of consulting with the quieter voices of people affected by dementia and welcome any opportunity to provide a platform to enable this. Representatives of both groups were delighted to get the chance to travel to Kilmarnock to help facilitate a consultation on the future of long-term care. This event was part of Alzheimer Scotland's Long-Term Care Commission. The Commission seeks to consider how policy and practice can be improved to deliver fairer, more person-centred, and sustainable care and support options to meet the long-term needs of people with dementia in Scotland. NDCAN members Joanna and Maureen, and SDWG member Stuart were joined by more than 40 local people at this engagement event, and their views and opinions will help shape the commission's report and recommendations which is due to be published in the spring of 2024.



Future of long-term care event



Joanna, Stuart & Maureen

Aberdeenshire

21 September: Aberdeen Carers Group

Most carers don't have the time or perhaps the confidence to join our national campaigning groups, therefore it can be so rewarding for NDCAN members to have opportunities to attend local peer support groups. On this note, NDCAN members Maureen and Marion were pleased to be invited to attend the Aberdeen Carers Group to highlight the Active Voice work and the hear about local issues affecting carers in the Aberdeen area.



10 October: Stonehaven Carers Group

NDCAN member Maureen attended the Stonehaven Carer Group where she gave a fantastic overview of her experiences as a carer, and the work she has been involved in as a member of NDCAN. Following on from this, there was a discussion with local carers who welcomed the opportunity to feedback on what's working well for them locally, and also what can be improved on.



Webinars

The shift towards using online platforms has made webinars more attractive to SDWG and NDCAN. Using this technology, the members of both groups can now tap into larger audiences compared to in-person events, and furthermore, geographic restrictions aren't a barrier. Some recent examples showing how member participation in webinars can be a very useful campaigning and awareness raising tool are highlighted below.

28 September: Who are Alzheimer Scotland's Active Voice?

As a follow up to their Annual Conference, Alzheimer Scotland hosted a series of webinars. SDWG and NDCAN members were pleased to be given the opportunity to facilitate one of these webinars which focused on our Active Voice work. The webinar began with a presentation on the importance of involving the voice of lived experience, and was followed by SDWG members Patricia and Kenny, and NDCAN member Joanna, having a conversation about their personal experiences of dementia and the work they do to campaign and influence policy and practice.



24 October: 'Occupational Therapy and Dementia' book webinar

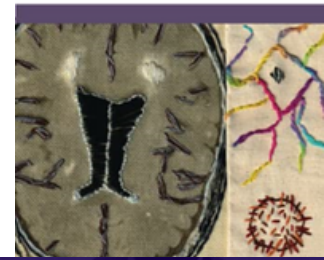
This webinar highlighted an informative new book that has been produced by our Allied Health Professional (AHP) colleagues. The publication, which includes a foreword by SDWG Member Margaret M, examines how core elements of occupational therapy may support a person living with dementia through valued activity in continuing engagement, sustaining their identity and sense of purpose. During the webinar, Margaret read her contribution to the book which closed with her plea to “always see the person as a person”.

Occupational Therapy and Dementia

Promoting Inclusion, Rights and Opportunities for People Living With Dementia

Edited by Fiona Maclean, Alison Warren, Elaine Hunter and Lyn Westcott

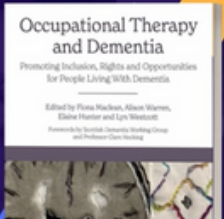
Forewords by Scottish Dementia Working Group and Professor Clare Hocking



OCCUPATIONAL THERAPY AND DEMENTIA WEBINAR

JOIN THE EDITORS IN CONVERSATION WITH THE AUTHORS OF THE FOLLOWING CHAPTERS:

- Wendy Rankin and members of the SDWG – Chapter 2 – The Voices of People Living with Dementia
- Chris Roberts, Jayne Goodrick & Alison Warren – chapter 3 – Always Looking for a Solution
- Elaine Hunter – chapter 5 – The Role of Occupational Therapy in Promoting Lifelong Brain Health



Looking to the future...



25 October: AHP Driving and Dementia Webinar

The AHP (Allied Health Professionals) Dementia Webinar in October focused on 'Driving and Dementia'. Stuart from SDWG played a key part in this webinar by delivering a presentation on the importance of driving from the perspective of his own personal experience.

7 December: Sign Guidelines Webinar

NDCAN member Marion spent well over two years assisting in the development of the new SIGN guidelines on the assessment, diagnosis, care and support for people with dementia and their carers.

As a part of the launch, Marion was delighted to co-host a webinar to promote and explain the content of the evidence-based guidelines which cover the diagnosis of dementia, post-diagnostic support, non-pharmacological distressed behaviours, grief and dementia, changing needs, and palliative approaches.



Marion

Winter campaign - 'We're all in'

Alzheimer Scotland's winter campaign for this year focuses on dementia research and celebrates the idea that each of us, in our own unique way, can contribute to the multifaceted landscape of dementia research. The 'We're all in' campaign features personal video messages from SDWG members Kenny and Rynagh who share their insights into the importance of research and what participating in research means to them.

I'm involved in research because I'm a reader, I'm curious. Not knowing things is not for me...and research is a great way of getting to know things.

Rynagh



Research is not only about medicines and cures. It's about the condition – what causes it, what the risk factors are, understanding how to live well with it, what the opportunities are.

Kenny

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