

Active Voice Annual Report 2022

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





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Jim Pearson – Director of Policy & Practice

It is a privilege to welcome vou to Alzheimer Scotland's active voice networks 2022 Annual Report. This report sets of Ri out the activities of both ementi the Scottish Dementia Working Group (SDWG) and the National Dementia



Carers Action Network (NDCAN) over 2022

This has been a transitional year as we finally began to move beyond the COVID-19 pandemic. The previous two years have been devastating for many people with dementia, their families and carers and have exposed the gaps between the aspirations of national dementia policy and people's lives. It has been a year of change too for SDWG and NDCAN, as the members embraced the opportunity to return to in person meetings while retaining the new ways of working online we all developed during the pandemic.

Sadly, during this past two years Archie Noone, Elise O'Hagan, Peter Farr and Henry Rankin, all long standing members of the SDWG, have passed away. We remember them with great fondness and thank them for the contribution

they have made in campaigning to change the lives of people with dementia and carers of people with dementia.

This report sets out the priorities of both SDWG and NDCAN and the wide range of activities the members have undertaken to support their aims. This includes contributions to research, education, and policy consultations as well as meetings with Ministers. It includes the commitment to work alongside our local teams to support a wider range of lived experience voices to be heard, as demonstrated in the contribution of members to support almost 300 people to contribute to the consultation for the fourth national dementia strategy.

Finally, NDCAN reached a milestone 10 years of campaigning in 2021 and SDWG celebrated its 20th anniversary in 2022. Congratulations, to every one of the members past and present. You have reshaped the voice of lived experience and inspired the establishment of working groups across the world. I look forward to working alongside the members of SDWG and NDCAN in 2023 as we lay the foundations for the next 20 years.

Introduction

Welcome to the **Active Voice Annual Report 2022**, which looks back at the work of Alzheimer Scotland's local and national active voice networks over the last year.

Our two national active voice groups, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) continued to go from strength to strength in their work campaigning for the rights of people with dementia and carers, influencing policy and practice at all levels, supporting research, and raising awareness to challenge stigma and change the image of dementia. You can read more about these member-led groups on pages 4 and 6.

Despite the challenges of the COVID-19 pandemic, SDWG and NDCAN members continued to remain active and involved, embracing new ways of working online and keeping in touch whilst staying apart. However, we were delighted to resume face to face meetings in 2022 and throughout the year, members embraced a mix of inperson, hybrid and digital meetings, events, and conferences. But, whilst online platforms have made participation easier, we all agree nothing beats being together in the same room. Alongside our national groups we have continued to develop our local active voice networks throughout Scotland. Ensuring that with the support of Alzheimer Scotland's Dementia Advisors, the quieter and hidden voices of those with lived experience are heard and inform our active voice work. This was particularly true when forming our response to the Scottish Government's National Dementia Strategy 4 consultation. You can read more about this on page 11.

We would like to take the opportunity to remember and pay tribute to Henry Rankin (pictured) who sadly passed away in February 2022. Henry was a member of the SDWG for many years and was Chair for four years - a role he embraced and excelled at. He was well liked and highly respected, not only by fellow SDWG members but by everyone at Alzheimer Scotland. He campaigned tirelessly to raise awareness of dementia and was passionate about improving the lives of future generations. Henry was rewarded for his hard work when he received the Lifetime Achievement Award at Scotland's Dementia Awards in 2017. He was a true gentleman and all who knew him and worked with him over the years considered it a real pleasure and a privilege to do so. He will be greatly missed.

Finally, we would like to thank everyone who has supported our active voice work throughout 2022, we couldn't have achieved all that we have without you. We hope you find this report interesting and informative.





The Scottish Dementia Working Group (SDWG)

The **Scottish Dementia Working Group** (SDWG) is a national, member led campaigning and awareness raising group, for people living with a diagnosis of dementia in Scotland. The group was set up in 2001 and has gone from strength to strength since it was established.



SDWG is funded by Alzheimer Scotland and the Scottish Government and is the independent voice of people with dementia within Alzheimer Scotland. SDWG is an inclusive group, led by, and for, people with dementia. The group has a wide membership and dedicated members of staff who support the group's activities.

Listening to those whose voices are most important

As a campaigning group led by people with dementia, SDWG represents what matters most to those who are directly impacted by the condition. No two people are the same – so those different needs and different perspectives must be heard in order that action is taken on issues that count.

Empowering Volunteers

SDWG is nothing without volunteer members. Their knowledge, experience and opinions underpin everything we do and we thank them for their continued support and commitment.

Delivering Through Teamwork

SDWG membership is based throughout Scotland. Collaborating with colleagues in all of our localities means that anyone, anywhere can contribute to, or benefit from, the work of the group.

In 2022, the group celebrated an incredible 20 years of campaigning. Throughout that time, SDWG members have worked tirelessly to campaign and raise awareness at both national and international levels. They have informed and engaged with Scotland's National Dementia Strategies, and they have worked with health and social care professionals, sharing their lived experiences to help make things better for future generations. The group have travelled across the world to spread their message, challenging stigma, and ensuring the voices of people living with dementia are heard. SDWG has gone from strength-tostrength and is now known worldwide. Visitors from countries as far away as Japan have come to Scotland to see how the group is run and upon returning home, have formed their own dementia working groups.

The remit of the Scottish Dementia Working Group is to:

- Campaign and raise awareness at a national and local level.
- Engage with, and inform, Scotland's National Dementia Strategies.
- Promote, and raise awareness among health, social care and related professions, as well as the wider public.
- Work with all stakeholders at a national and local level, including national and local government, private and voluntary providers of health, social care and housing, and other relevant bodies.
- Work with other representative groups, in particular our sister group, the National Dementia Carers Action Network (NDCAN)
- Work alongside Alzheimer Scotland to ensure coordinated and effective campaigning activities.



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The Scottish Dementia Working Group (SDWG) Priorities 2022



POST DIAGNOSTIC SERVICES

Members' lived experience demonstrates that there is still much to be done to support people living with dementia after diagnosis. The SDWG will continue to campaign for better Post Diagnostic Support (PDS).

INFLUENCING POLICY & PRACTICE

The SDWG will continue to build and develop its work aimed at raising awareness about dementia and ensuring that people living with dementia have a voice in policies and practices that are important to them.



RESEARCH & BRAIN HEALTH

The SDWG will maintain a keen interest in relevant research developments and engage in appropriate research activities.

EQUALITY & DIVERSITY



The SDWG will work to hear from all people living with dementia across the whole of society, including minority groups. It will provide them with an active voice on matters that are important to them.



TACKLING STIGMA

The SDWG will challenge stigmatising language and attitudes wherever these are encountered. It will seek to change perceptions and to raise awareness about dementia and people living with dementia where necessary.

The National Dementia Carers Action Network (NDCAN)

The National Dementia Carers Action Network (NDCAN) is a

National Dementia Carers Action Network

national campaigning and awareness raising group for carers of people with dementia. NDCAN was formed in 2011 and exists to make the voices of carers heard and raise awareness of the issues impacting on carers. NDCAN has a committee and a wide general membership that works to promote and support the rights of carers of people with dementia. Each year the group decides on the priorities that NDCAN will work on for the coming year.





Since NDCAN was formed, it has:

Influenced Government and Parliament

Meeting regularly with the Minister for Mental Health, responding to government consultations and speaking with MSPs; and participating on national boards to ensure carers voices are heard.

Helped to improve the quality of care

Working with Focus on Dementia to improve the quality of post diagnostic support and specialist dementia units to ensure that professionals know what support carers need; and, participating in the Fair Dementia Care commission to support carers as the person they care for enters the advanced stages of dementia and end of life.

Helped to train workforces

Each year helping to train health and social care professionals, including providing their own personal views and experiences of caring for someone with dementia to the Dementia Champions programme; and, contributing to the Dementia Ambassadors programme.

Raised awareness at a local national and international level

Participating at a wide range of conferences in Scotland, the UK and abroad such as Alzheimer Europe and Alzheimer's Disease International, using these opportunities to promote their work.

Helped other carers

By developing new resources for carers on a range of subjects, including early onset dementia, continence and speech therapy.

Developed a series of eight booklets

'For Carers, By Carers', explaining what has helped carers of people with dementia to get through the day and cope with difficult times.

Research &

Brain Health

The National Dementia Carers Action Network (NDCAN) Priorities 2022

COLLECTIVE VOICES OF LIVED EXPERIENCES

PRIORITY 1: CARE HOMES

Focus Area 1: Open with Care & Anne's Law Focus Area 2: Fair Dementia Care

Focus Area 3: Connection & Engagement with Action on Rights Team



Community Development

PRIORITY 2: POST DIAGNOSTIC SUPPORT

 Focus Area 1: Support past the first year
Focus Area 2: Person-centred, consistent support
Focus Area 3: Younger carers & financial implications

PRIORITY 3: WORKFORCE DEVELOPMENT

Focus Area 1: Better support for carers, including respite Focus Area 2: Dementia Focus Area 3: Dementia in hospitals



NATIONAL CARE SERVICE

Conferences & Events - 'speaking up and reaching out'

The lifting of COVID-19 restrictions saw the welcome return of in-person conferences and events, and SDWG and NDCAN members were pleased to participate in a number of these throughout 2022.

Neuroprogressive and Dementia Network

Our conference year kicked off in March 2022 with the Neuroprogressive and Dementia Network's conference, which was themed around their commitment to have Patient and Public Involvement at the centre of everything they do. The Network supports researchers from across a range of disciplines and helps deliver research across Scotland. NDCAN members Jeanette Maitland and Lorna Walker attended the conference and answered the question 'How are organisations involving people in what they are doing' - speaking as people with lived experience as carers and as active NDCAN members. They delivered a presentation on NDCAN's work and spoke about the involvement of members in research, both as contributors to research and as researchers. themselves.







Scottish Dementia Research Consortium

In May, group members attended the SDRC's two-day conference in Glasgow, themed around diagnosis and detection of dementia. Members contributed to conversations around research and brain health, taking the opportunity to ask questions of the many excellent presenters and researchers at the event.

Alzheimer's Disease International (ADI)

Members were pleased to join over 1,000 delegates representing 120 countries from every corner of the world at ADI's three-day conference in London in June 2022. The theme of the conference was 'New horizons in dementia: Building on Hope'. Issues covered included raising awareness; stigma; risk reduction; and prevention. Alzheimer Scotland's Chief Executive, Henry Simmons, gave an engaging and very well received presentation on the organisation's Post Diagnostic Support journey and our work with Brain Health Scotland. Members took the opportunity to hear from and meet with people from as far afield as China, Mauritius, Argentina, USA and from across Europe, sharing their stories and experiences and making new connections. It was clear from the event that the SDWG and NDCAN are sector leading in campaigning to improve lives, raise awareness, and tackle stigma; and in giving people with lived experience a voice in decision making.

Alzheimer Scotland Annual Conference

September 2022 saw the very welcome return of an in-person Alzheimer Scotland Conference at the Edinburgh International Conference Centre, As ever, SDWG and NDCAN members were at the heart of this event, the theme of which was 'Prevent, Care, Cure'. SDWG member Margaret McCallion and NDCAN member Jeanette Maitland opened the conference, and sessions throughout the day were introduced by group members. From the SDWG, Kenny Moffat opened a session on 'Protecting your brain health preventing dementia' and Margaret and Barry Northedge spoke about 'Innovations in care'. From NDCAN, Joanna Boddy introduced a session on 'Progress towards a cure'. Both groups had poster presentations detailing their campaigning priorities for 2022 and members took the opportunity to meet and share information with individual delegates and the many organisations at the conference. It was a wonderful opportunity for us to promote our work and celebrate the achievements of our national active voice groups.

You can watch recordings of the Conference sessions at <u>https://www.alzscot.org/</u> <u>conference22</u>



World Congress on Adult Capacity

Also in June, the 7th World Congress on Adult Capacity took place in Edinburgh under the banner "Enhancing Autonomy, Support and Protection". The event attracted



almost 300 delegates from across the world, including NDCAN member Thea Laurie who delivered a plenary presentation on 'The Carer's Experience of Supported Decision Making'. Thea spoke about the importance of ensuring that a person with a diagnosis of dementia can continue to be heard even when they cannot find the words, and of the need to support carers to work out how to do this comfortably.



Main plenary session 2 'Innovations in care' Introduced by Barry & Margaret Northedge, Scottish Dementia Working Group (SDWG)



Alzheimer Europe Conference

Our Active Voice groups were once again represented on the international stage in October 2022, at the Alzheimer Europe Conference in Bucharest. NDCAN member Elaine Deehan flew the flag for our work, along with the Head of Alzheimer Scotland's National Support Services, Jen Hall, who presented at the conference.

The event saw 544 participants from 42 countries come together under the theme of 'Building Bridges' and was another great opportunity to meet with individuals and organisations from across Europe, as well as

catching up with colleagues from closer to home, such as Dr Louise Ritchie and Dr Anna Jack-Waugh (pictured) from the Alzheimer Scotland Centre for Policy & Practice at UWS.

As the conference took place as a hybrid event SDWG and NDCAN members were also able to participate from the comfort of their own home.

The conference also saw the appointment of new members to the **European Working Group of People with Dementia**, which celebrated

its 10th anniversary in 2022. The SDWG has been involved in, and represented on, the Group since it was established in 2012. It was therefore very welcome news when SDWG member Margaret McCallion was confirmed as Vice-Chairperson for the term 2022-2024. Margaret will very ably champion the priorities of the SDWG and ensure that the voice of those living with dementia in Scotland is heard loud and clear.









Carers Parliament

NDCAN members Marion Ritchie, Anne Tierney and Joanna Boddy attended a reception in the Scottish Parliament in November 2022 to mark 10 years of the Carers Parliament. The Carers Parliament provides a space for carers and young carers from across Scotland to tell policy and decision makers how caring affects their lives, and this event provided an opportunity to recognise how it has influenced change since it was created. The event was attended by carers from across Scotland, as well as the Minister for Mental Health and Wellbeing, Kevin Stewart MSP. In addition to making connections with the other organisations represented at the event, our NDCAN members took the opportunity to speak directly with the Minister about some of the issues faced by carers, in particular the availability of respite, and the impact caring responsibilities can have on accessing employment and developing and sustaining a career.

Influencing Policy and Practice

The SDWG and NDCAN, supported by Alzheimer Scotland, have continually contributed to the transformation and improvement of services and resources for people living with dementia and their families and carers by ensuring that the voice of lived experience is placed at the heart of everything they do.

National Dementia Strategy 4

The Scottish Government launched a 'National conversation on the future of dementia policy' on 30 September 2022 and our Active Voice groups were keen to support Alzheimer Scotland's inclusive approach to enable people with dementia and their carers to participate in meaningful engagement. The participation of people with lived experience was key to ensuring that their needs were reflected in our response to the Scottish Government.

Members of both groups facilitated a programme of public engagement sessions to gather the insight of people affected by dementia across Scotland. We supported 298 people with lived experience to have their say across 30 facilitated sessions throughout Scotland, including online sessions. Our active involvement and participation enabled a broad discussion of individuals' experiences of dementia and their views and opinions on the future of dementia policy in Scotland, and enabled guieter and hidden voices to be heard in the conversation. Participants highlighted the value of high-quality postdiagnostic support and local services, and the challenges of inconsistent service delivery and implementation.

SDWG and NDCAN were also consulted directly and had their opportunity to let the Scottish Government know what has worked well for them and, perhaps more importantly, what needs to improve. Among a range of issues discussed, SDWG members highlighted the importance of personalised interventions and spoke about the need for more practical support to be provided, particularly immediately following a diagnosis. The importance of early detection and post diagnostic support for under 65s was raised, along with the need for regular clinical reviews





and the right to an annual health check with a GP. It was felt that evaluating the previous dementia strategies in order to assess what has been delivered and achieved so far should be an important part of developing the 4th strategy.

NDCAN members and carers highlighted the lack of support and services from health & social care (particularly respite); a need for timely check-ups following initial diagnosis; and the inequality that people living with advanced dementia face in terms of access to free health care, particularly in relation to paying care home fees.

The information gathered through this engagement activity was presented to the Scottish Government to help inform the development of their Strategy. The learning from the public engagement also underpinned Alzheimer Scotland's organisational report to the consultation.

You can read Alzheimer Scotland's submissions to the National Dementia Strategy Consultation at <u>https://www.alzscot.</u> <u>org/news/our-response-to-the-scottish-</u> <u>governments-consultation-on-the-national-</u> <u>dementia-strategy</u>

Proposed Disability Commissioner (Scotland) Bill

Members from both the SDWG and NDCAN met with Jeremy Balfour MSP in June 2022 to discuss his proposal for the establishment of a Disability Commissioner in Scotland to give disabled people a dedicated champion to promote their rights and needs. It is anticipated that the role and responsibilities of the Commissioner will range from informing and influencing policy affecting disabled people to providing specific investigations of individual cases. The Disability Commissioner's role would effectively become the first and main port of call for people with a disability who are unable to resolve their issues at a service level.

In their formal response to the consultation, members broadly welcomed the proposal but expressed reservations about the scope of the Commissioner and the ability for them to represent individuals across a broad spectrum of disability. Specifically, members raised concerns that the representation of people with dementia would be diminished in the delivery of a service that covers such a wide range of disabilities and conditions and raised concerns that physical disability may take precedence over hidden or fluctuating conditions, such as dementia. Members also expressed concerns that access to support from the Disability Commissioner may be impacted by the interpretation or perception of disability and called for the inclusion of individuals who do not have a confirmed diagnosis of an illness or condition to be able to access the support of the Disability Commissioner.

The proposal subsequently received sufficient support from MSPs and was lodged in the Scottish Parliament at the end of 2022 for consideration by the full Parliament. SDWG and NDCAN members will continue to engage in the proposal as it proceeds through the parliamentary process.



National Care Service

In Autumn 2022, SDWG and NDCAN members were consulted as part of Alzheimer Scotland's process of preparing a formal response to the Scottish Parliament's Health, Social Care & Sport Committee's call for evidence on the Scottish Government's National Care Service (Scotland) Bill. Whilst welcoming the aspirations of the Bill, the response submitted by Alzheimer Scotland called for, amongst other things, a rigorous framework that provides a consistent and effective approach to meeting the needs of everyone; a clear structure for the delivery of the National Care Service that avoids ambiguity: transparent processes and continued dialogue with key stakeholders that ensures accountability; and fair and equitable representation of the third sector and people with lived experience on care boards and special care boards in order to clearly understand the needs of individuals and communities, and to identify ways to address barriers to accessing support. You can read the thoughts of SDWG members on the National Care Service consultation at <u>www.alzscot.org/sdwg-on-</u> <u>the-national-care-service-consultation</u> SDWG and NDCAN members continue to engage with the National Care Service proposals as they proceed through the Scottish Parliament.

This is just a flavour of the consultation and engagement work that our Active Voice groups undertook throughout 2022, with others including the Mental Health and Wellbeing Strategy; the Scottish Fire & Rescue Service dementia-specific guidance for staff and crews, the Scottish Government's Open with Care Oversight Group, the Dementia in Hospitals Delivery Group; and the National Dementia Strategy Implementation and Monitoring Group. In addition, members also engaged with the Minister for Mental Health & Social Care, Kevin Stewart MSP, when he visited Alzheimer Scotland's Inverness Dementia Resource Centre in July 2022.

Raising Awareness & Championing Change

Dementia Awareness Week

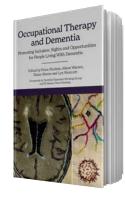
As ever, our Active Voice groups were busy during Dementia Awareness Week 2022, the theme for which was, 'Prevent, Care, Cure.'

At the start of the week plans to launch a new and innovative research fellowship programme were announced. The programme would be driven and, uniquely, decided upon by people with dementia and their families, with SDWG and NDCAN members being key to this.

Another highlight of the week was when our SDWG members gathered in Glasgow to host a Tea and Blether event with the European Working Group of People with Dementia, who joined them remotely through the wonders of the digital technology we have become so used to. Despite the distance, the tea brewed, the blether flowed, and the event was enjoyed by all involved.

Occupational Therapy and Dementia

Our Active Voice groups have always worked closely with our Allied Health Profession colleagues, and in 2022 SDWG members were delighted to have the opportunity to contribute to a new AHP publication, Occupational Therapy



& Dementia – Promoting Inclusion, Rights and Opportunities for People Living With Dementia.

Lorna Noble, Margaret McCallion and the late Henry Rankin shared their lived experiences. The front cover of the book is a copy of Lorna's embroidery of her brain and the book closes with a last word from Margaret - "no matter what the diagnosis is, always make sure you see the person as a person".



SDWG on STV

In April 2022, SDWG member Margaret McCallion appeared on STV's Scotland Tonight programme talking about her diagnosis of dementia and how she lives well with the condition. The programme was a special edition focusing on dementia and research.

Margaret spoke about her lived experience – from having memory problems, to diagnosis aged just 51, and from being told she would have to leave her job, to joining the SDWG and regaining a sense of self-worth.

You can watch Margaret's interview on YouTube at <u>https://www.youtube.com/</u> watch?v=dbzV56EnWrQ





Faith and Dementia

Faith supports many people living with dementia, and in September 2022 SDWG members met with representatives of Faith in Older People to discuss their One Step at a Time project, providing resources to help faith communities explore, develop, and take action to respond better to people with memory, disorientation, and confusion problems. Members were pleased to support the project and offered feedback on what mattered to them in relation to their faith. SDWG member, Kenny Moffat was filmed along with his local church Minister in Alzheimer Scotland's Bearsden Dementia Resource Centre speaking about the importance of faith in his life.

Lean on Me - Winter Campaign 2022

Our Active Voice groups are always central to Alzheimer Scotland's awareness and fundraising campaigns, and this was certainly the case with the 2022 Winter Campaign. The campaign focused on the 'Every Voice' Community Choir and two of its members,

Tony and Ángela Worthington. Tony, a former MP, is also a very active and involved SDWG member, with Angela's support. The song of choice for the campaign was Bill Withers' Lean on Me, and the message was that with the help of



our supporters, Alzheimer Scotland can be somebody to lean on.In the campaign Tony spoke about the connections he has made through Alzheimer Scotland, the support he receives from his Dementia Advisor, and how his work with the SDWG has allowed him to continue to campaign and to influence policy.



The importance of early detection of Alzheimer's disease

The Davos Alzheimer's Collaborative (DAC) launched a project on Healthcare System Preparedness for Early Detection of Alzheimer's. Scotland is a flagship for this work and in November 2022 two SDWG members, Margaret McCallion and Margaret Northedge, along with her husband Barry Northedge, had the opportunity of sharing their experiences with Project Lead, Alison McKean. Their conversations, which were recorded, considered matters such as early and accurate diagnosis, their experience and the impact of diagnosis and what helped them following diagnosis. You can find out more about the DAC and watch the conversation with Margaret and Barry Northedge at

https://www.brainhealth.scot/dac

Improving the quality of health care for patients in Scotland

The Scottish Intercollegiate Guidelines Network (SIGN) aims to improve the quality of health care for patients in Scotland by reducing variation in practice and outcome, through the development and dissemination of national clinical guidelines containing recommendations for effective practice based on current evidence. NDCAN member, Marion Ritchie, represents our Active Voice groups on this programme of work and in 2022 presented on the 'Carer Lived Experience'. Marion shared her story and spoke about the importance of carer education, the stages of grief and anticipatory grief, and stressed the need to offer appropriate services to help with grief at all stages of the dementia journey. Marion welcomed the recommendations and best practices produced in the SIGN guidelines which had raised awareness of the grief processes, and supported further investigations and improved help for carers in the future.

Hearing from the quieter voices

Our Active Voice groups are committed to hearing the quieter voices from across Scotland so in June 2022 NDCAN members Marion Ritchie and Joanna Boddy met with members of Alzheimer Scotland's Young Onset Carers group in Livingston, to learn about the issues faced by unpaid carers in order to better inform their campaigning and awareness raising work. Also in June, SDWG member Geoff Orry attended the launch of a Mens Monthly Peer Support Group in Renfrewshire, which provided a great opportunity to share information about SDWG's work and to explore the importance of meeting others and being part of a network for support and friendship. SDWG members also attended the Alzheimer Scotland West Highland Silver Lining Group in May to share their work and connect with some of those hidden and quieter voices living remotely. They travelled to the V&A in Dundee in November to join the local Alzheimer Scotland community café and engage with local people around dementia supports and services. In August, members from both Active Voice groups joined colleagues from across Alzheimer Scotland's localities to share their lived experiences and promote the importance of local engagement in order to hear from the guieter voices of those who are living with dementia, their families and carers.

This is just some of the work that our Active Voice groups were involved in during 2022. From participating on Boards, Working Groups and Delivery Groups to working closely on research projects with colleagues from Brain Health Scotland and the Alzheimer Scotland Centre for Policy and Practice. They've participated in initiatives to deliver dementia education and information to the workforce of the future and have championed better dementia policy, practice and awareness raising at every opportunity. And, importantly, they always made time to just catch-up, take stock, and keep in touch –

from the SDWG's regular 'Feel Good Friday' catch-up to the Active Voice Christmas get together which set them up well for what they expect to be another busy year in 2023!!



A carer's experience

In November 2022 NHS Borders held an awayday on the theme of 'Compassionate Care'. NDCAN member, Maureen Huggins, participated in the event and presented on 'A Carers Experience'. Maureen spoke about the impact that acute care and hospitals can have on persons with dementia and highlighted the importance of dementia education for staff and volunteers. The event also considered the 'ABC of Compassionate Leadership', the 'A' representing 'Autonomy: Having a voice, influencing decisions, being listened to, being trusted' and it was highlighted that NDCAN is an excellent example of this.









Prevent. Care. Cure.

For more information on both Active Voice groups:

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