

Active Voice

Summer Newsletter 2025

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Hello and welcome to our summer 2025 newsletter

We're pleased to share our latest newsletter, capturing highlights from the summer months and showcasing a wide range of inspiring activities, events, and contributions from across the country. In this issue, we shine a spotlight on Dementia Awareness Week, Volunteering Week, and Carers Week – each offering a unique opportunity to raise awareness, share lived experiences and celebrate the remarkable efforts of our two national campaigning groups: the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN).

Their continued campaigning, both nationally and within local communities, is instrumental in driving positive change for people affected by dementia. Through a variety of engagement methods, both groups help shape policy, raise awareness, and help strengthen support and services, ensuring that the voices of lived experience remain at the heart of everything we do.

Empowering carers – insights and support at Alloa's Brain Health & Dementia Resource Centre – by Bill Alexander, NDCAN

The Brain Health & Dementia Resource Centre in Alloa recently hosted a series of Carer Information Sessions aimed at strengthening the support network for those caring for people living with dementia. These sessions were designed to provide carers with a better understanding of the various services, resources, and sources of information available to them.

The organisers, Donna and Cherie who provided fantastic support for Christine and I, invited me to attend one of these sessions dedicated to our Active Voice work. I was very pleased to take part in this session not only as a representative of NDCAN but because Christine and I were both brought up in Alloa and had attended the Alloa Resource Centre regularly until Christine was given a daycare place nearer home. I began by sharing my personal journey as a carer and how the level of care needed by Christine had significantly increased over the past year, but we continued to live life as normally as we possibly could.



Bill at the Alloa Centre

With help from my daughter I was also able to continue my role as a member of NDCAN, and I spoke about my contribution to the campaigning work carried out on behalf of people with dementia and their carers. I stressed the importance of listening to all carers' experiences, emphasising that their voices are essential in shaping effective support and policy.

While the primary aim of the event was to inform carers about the importance of Active Voice and NDCAN's initiatives, it naturally evolved into an informal 'Have Your Say' session. This provided a valuable platform for the attendees to express their personal views on local issues affecting them and those they care for. It may be Alzheimer's Brain Health & Dementia Resource Centre in Alloa but to me it will always be the Co-op where Christine and I went for our food shop In 1969 when we were first married.

Dementia Awareness Week: 2 – 6 June

While every week feels like Dementia Awareness Week for our dedicated members of SDWG and NDCAN, this annual event always holds a special place in their calendars. This year, they marked the occasion with four engaging and impactful events, each playing a key role in advancing their vital work to raise awareness both nationally and locally.

Highlights from all four events are featured below.



Celebrating the role of friendship in dementia support - SDWG, NDCAN, and Parkinson's Dementia Working Group



We kicked off Dementia Awareness Week with an inspiring event dedicated to highlighting the crucial role of friendship in supporting people living with dementia and their carers. In line with this year's theme centred around the power of friendship, the Active Voice team was proud to partner with colleagues from Parkinson's UK to host this special online gathering.

The event brought together members of SDWG and NDCAN, along with members from the newly established Parkinson's Related Dementia Working Group – an innovative initiative designed to address the unique challenges faced by those living with both Parkinson's disease and dementia. Attendees had the opportunity to introduce themselves, share personal experiences, and discuss effective strategies for promoting meaningful social connections.

This collaborative get-together fostered a strong sense of community and shared purpose, emphasising that friendship and robust support networks are vital in creating an inclusive environment where people affected by dementia feel valued, understood, and supported.

Looking ahead, we hope this event marks the beginning of ongoing collaboration with the Parkinson's Related Dementia Working Group, as we continue to work together to promote awareness for everyone impacted by dementia.

"The groups are all wonderful and it was so lovely to hear from people and see passion for further working together – so valuable! Thank you again for the invite."

– Anita Jeffries, Parkinson's UK



Friendship Tuesday - time to reflect and connect

Still embracing the theme of friendship, members of SDWG and NDCAN came together once again for a special online Friendship Tuesday meeting. This informal gathering offered a welcome pause from the pace of campaigning work, giving everyone a chance to relax, reconnect, and enjoy each other's company in a supportive and uplifting space.

Reflections shared during the session highlighted the deep understanding, shared passion, and meaningful friendships that have blossomed within and between the group members. It was a powerful reminder of how vital these relationships are – not only in strengthening collective campaigning, but also in promoting individual wellbeing and resilience.

"You will never feel alone when you have this group."
– Bill, NDCAN



Active Voice launches new 'Have Your Say' engagement series

To mark this year's Dementia Awareness Week, the Active Voice team proudly launched the first in a new series of nationwide 'Have Your Say' engagement sessions. This inaugural event took place at the Stranraer Brain Health & Dementia Resource Centre, offering a vital platform for people living with dementia and carers to voice concerns, share experiences, and highlight good practice. Organised by locality staff members Kelsey and Natalie, and facilitated by Stuart from SDWG along with Maureen and Lorraine from NDCAN, this session provided a valuable opportunity for the community to influence improvements in dementia care and support services.

The insights gathered will help shape the campaigning priorities and focus areas of SDWG and NDCAN, ensuring their work remains closely aligned with the real needs of those affected by dementia. All feedback from participants will be carefully collated and shared with members of both groups, who will take these messages forward in conversations with decision-makers at both national and local government levels. This forms part of their continued commitment to champion better support and services for people living with dementia and unpaid carers across Scotland. Although attendees spoke openly about the challenges they face, they also commended the continued support provided by staff at the Centre, showcasing resilience and practicality in the face of ongoing difficulties.



Active Voice at Stranraer

Visit to Stranraer Brain Health & Dementia Resource Centre - by Stuart Dougall, SDWG

Lorraine and I visited the Resource Centre on Wednesday 4 June during Dementia Awareness Week for the 'Have Your Say Event'. Lorraine and Maureen Huggins were representing NDCAN and we were accompanied by Norie and Wendy. The Stranraer Centre is just off the town centre and prior to converting into the Resource Centre it had been an 'old style' private house with high ceilings.

The 'Have Your Say' event was also based around a Tea and Blether. We had conversation starters such as:

- What are the main challenges encountered as a person living with dementia or caring for a person with dementia in the Stranraer area?
- What support works well for you?
- What do we need to build on/learn from what has been done before?

This allowed discussions to follow on topics such as:

- Do you think there is a stigma attached to dementia?
- Experiences accessing social and health care.
- Where do you go to find information about dementia?
- What areas of care and support need to be improved?
- Do you think more could be done in terms of prevention and cure?

It was apparent that the residents of Stranraer have a 'just get on with it' attitude. The saying "what you don't know, you don't know" felt relevant, as they didn't have anything to compare it with.

The Centre staff are magnificent and have such a tremendous demeanor about them. The persons attending the café are very open that if they have any pressing issues or concerns, the first port of call would be the Centre staff as they feel so comfortable with Kelsey and Natalie. Unfortunately, it felt like they are almost abandoned in their own community with the Resource Centre being their 'safety bunker' – talk about a postcode lottery! The Centre has a warm feel and calmness about it, which is undoubtedly down to the staff. Absolutely loved our visit, it's just a shame it's so far away.

"I joined the Active Voice team at the Have Your Say event in Stranraer. There was a small group of people with dementia, carers and former carers there who talked about the support available. Two things stood out to me – that they were doing a great job of supporting each other and that they could rely on the staff there if they needed advice in the future. A great testament to the work of Alzheimer Scotland."

– Maureen, NDCAN

Lauriston Castle – celebrating the opening of our new outdoor Brain Health & Dementia Resource Centre

On Thursday 5 June, Alzheimer Scotland proudly celebrated the opening of its second Outdoor Brain Health & Dementia Resource Centre, centred around the beautifully restored lodge at Lauriston Castle, Edinburgh. Members of both SDWG and NDCAN were delighted to attend the event, enjoying the chance to explore the lodge and its surrounding gardens, now home to a variety of therapeutic and wellbeing-focused activities. The day was filled with warmth, celebration, and reflection – Rynagh from SDWG and Thea from NDCAN capture this beautifully in their personal accounts of the occasion.



opening of the Lauriston Centre

"Thursday, 5 June was a very special day... the official opening of the Alzheimer Scotland Centre at Lauriston Castle. My memory of the day is one of celebration, full of warmth, colour and light... In the fanciest tent I've ever seen, there were speeches to honour and acknowledge the effort and support of all those who made the dream come true, led by Henry Simmons. Afterwards, it was a joy to wander the cottage garden with its bus stop, phone box, activity room and colourful array of flowers and trees, and to bring all the senses into play. I'll be back for sure."

- Rynagh, SDWG

"Well done from someone who lives in Edinburgh to Alzheimer Scotland for making this important local project become a national success. The Lodge and the Forget Me Not Trust Garden are going to be a focal point for people living with dementia and their carers in Edinburgh... Walking round the tranquil but colourful garden with interesting places to rest or chat, I wished it had been around for my mum to enjoy... It was a pleasure to attend the launch and enjoy the hospitality and fun activities on offer. The speeches by our Chief Executive Henry Simmons, the Lord Provost Robert Aldridge and dementia campaigner Scott Mitchell all focused on the importance of green health and the significance to mental, physical and social wellbeing from being outdoors with friendly, supportive people."

-Thea, NDCAN

Sharing stories and perspectives at the PDS Leads Network Meeting

Members of SDWG and NDCAN continue to champion the need for improved post diagnostic support (PDS) services across Scotland. Both groups advocate for a system that guarantees every person in Scotland is offered this crucial support following their diagnosis.

In line with this commitment, Margaret from SDWG and Maureen from NDCAN recently accepted an invitation to speak at the PDS Leads Network Meeting. This network, which has been active for several years, brings together managers of PDS services from across Scotland. They meet quarterly to share best practices and stay informed about the latest developments in dementia care. Facilitated by Focus on Dementia, an organisation dedicated to improving quality of life for people with dementia and their families, the network emphasises collaboration and continuous improvement.

A key focus of the recent meeting was engaging individuals with lived experience in service development. Margaret and Maureen delivered compelling presentations, beginning with their personal stories – Margaret sharing her journey as someone living with dementia, and Maureen recounting her experience as a carer for her mother. They discussed their motivations for becoming involved in their respective campaigning groups and provided practical examples of successful initiatives they have contributed to, particularly in service improvement and workforce development.

"Thank you for sharing your story Maureen, and for becoming an advocate for dementia carers. It sounds as though you have been very proactive and are making health care services realise that people in their care have families who need support too!"

- PDS Lead

"Thank you for sharing your story Margaret, you are so brave! The lived experiences of people with dementia are so vital to ensuring development of our future services. What an inspiration – we certainly see you!"

- PDS Lead

Margaret and Maureen's inspiring stories and personal perspectives resonated with attendees, emphasising the importance of lived experience in developing effective dementia support services. Their insights truly demonstrated that that meaningful change is driven not only by policy but also by personal experience and shared commitment.

"A big thank you to Margaret and Maureen for the lovely presentations they gave today. It's so motivating for us all to hear about their work, especially the personal experiences, and why striving to make things better in PDS remains so important and worthwhile."

- Julie Miller, Healthcare Improvement Scotland

Welcoming new members to Active Voice – by Margaret McCallion, SDWG

In July, we travelled to Dundee to welcome the newest member of SDWG. This visit was a valuable opportunity to hear their experiences and welcome them to the group. As a national campaign group, we know that having members with a wide range of perspectives and experiences helps us represent the voices of people living with dementia and their carers across Scotland. We're passionate about including voices from all parts of the country and new members are always welcome to join the conversation.

We met Pamela at the Bridge View café which overlooks the River Tay and had a delicious lunch and conversations as we looked forward to further collaborations.

Whilst in Dundee, we also had the chance to visit the V&A museum. We explored an exhibition titled Care, Community and Innovation in Ninewells Hospital, which encouraged us to reflect on how design and innovation can improve care environments. The exhibition also celebrated Dundee's role as a hub for medical advancements, showcasing developments in medicine, education, and research that continue to shape care practices around the world.



It's always lovely to meet potential SDWG members and their carers, and increasing the diversity and geographic locations can only strengthen Active Voice.

– Rynagh, SDWG



Rynagh & Margaret

If you are interested in becoming an Active Voice member, you can find out more details of how to get involved at the end of page 14.

Celebrating National Volunteering Week: 2-8 June

June marked National Volunteering Week, a time to celebrate the incredible contributions of volunteers across Scotland. It was a perfect opportunity to reflect on the dedication and impact of our SDWG and NDCAN members.

our tribute to the SDWG and NDCAN members

At Alzheimer Scotland, we know just how tirelessly members of NDCAN and SDWG work to improve the lives of people living with dementia. However, it's easy for people to overlook the fact that every one of these remarkable individuals gives their time as a volunteer. And their commitment isn't a one-off gesture – it's a year-round dedication to campaigning, raising awareness, and sharing their lived experience to influence real change. They give their time freely, and not for recognition, but because they care deeply about making things better for others.

Whether it's speaking at events or conferences, contributing to national policy discussions, supporting local engagement work, or helping shape and improve dementia services, their input is invaluable. They do all of this while managing their own lives, their health: and in the case of many NDCAN members, ongoing caring responsibilities.

Their passion, resilience, and sheer hard work is what drives the work of Active Voice. They are not just participants – they really are making a difference, and the reason everything we do at Alzheimer Scotland has meaning and impact. As we continue to develop and evolve as a charity, it's important to pause and recognise the people at the heart of it all.

**To every NDCAN and SDWG member
– thank you. Your voice matters, your
work matters, and we couldn't do this
without you.**



Going above and beyond – other volunteering roles

It's an absolute honour to highlight that many members of SDWG and NDCAN not only volunteer their time and energy within their respective groups, but they also take on additional volunteering roles in their spare time.

These individuals continue to support others in their communities in a variety of ways. In this article, we're pleased to share just a few examples of the contributions made by group members, focusing on the efforts of Ian, Lorraine, Stuart and Maureen.

It's worth noting that none of them were seeking recognition for their work – in fact, we approached each of them to ask if we could include their contributions in this newsletter, and they kindly agreed. Their stories reflect the spirit of dedication and commitment that runs through both SDWG and NDCAN, and we're proud to share them with you.

In Nancy's memory – Ian's journey from carer to volunteer

"Throughout the time that my wife Nancy had dementia, Alzheimer Scotland was a great help. Our local Dementia Advisor introduced us to therapeutic activities and directed me to courses for carers. At one point Nancy was confined to bed and the advisors kept in touch, and when everyone else was isolated by Covid we came back into the fold with a number of on-line activities and meetings. After Nancy died I wanted to 'pay back' Alzheimer Scotland for that support. I became a therapeutic activity volunteer and became involved with NDCAN.

"In previous years we had taken part in sponsored walks, and at Nancy's funeral we invited donations to Alzheimer Scotland. I did consider taking part in another sponsored event but felt that I would yet again be asking the same people for support. When I heard about the bucket collection at Morrisons, I felt that this was a good way for me to help raise funds by asking a different set of people. On both mornings that I took part, the Morrisons staff were very helpful and the response from the customers was excellent. Not only did they make many donations but a number of folk wanted to talk about their experience as a carer or friend of someone with dementia. I was also able to help some people who are currently experiencing the role of carer and direct them to various areas of support. All in all, a valuable and worthwhile experience for me and I hope for Morrisons customers and of course another contribution to Alzheimer Scotland's funds."

– Ian, NDCAN

Maureen – supporting NHS volunteers in Dumfries and Galloway

"During Volunteering Week in June, which coincided with Dementia Awareness Week, I was invited to support a recruitment drive for NHS volunteers in Dumfries and Galloway. As part of the campaign, I recorded a video for Facebook outlining the various volunteer roles available and encouraging others to get involved.

"Our goal is to have two volunteers on each of the eight acute wards at Dumfries and Galloway Royal Infirmary every weekday evening, while also expanding our presence in Stranraer's Community Hospital and the region's four Cottage Hospitals.

"In the video, I shared my personal motivation for volunteering: to help reduce stress and anxiety for patients living with dementia. Our Dementia Consultant, Wendy Chambers, estimates around 50% of patients in the Royal Infirmary have dementia, meaning that all ward volunteers will encounter individuals affected by the condition during their shifts.

"To support this, a small group of us deliver dementia awareness training for all new volunteers. This helps them better understand dementia, appreciate the challenges of the hospital environment, and learn how they can contribute to making a patient's stay less distressing.

"Being a ward volunteer isn't always easy, but it has given me a deeper appreciation of the pressures faced by healthcare staff, and I hope that, in some small way, I've helped make a difference to the patients I've met."

– Maureen, NDCAN

Team Dougall - volunteering with heart at the finish line - by Lorraine Dougall, NDCAN

Stuart and I were invited by the fundraising team to assist at the Edinburgh Marathon, following our involvement in last year's Supernova Forth Bridge event. Alzheimer Scotland had a presence in the charity village at the finish line of the Edinburgh Marathon, where participants could enjoy complimentary hot/cold drinks and snacks. Additionally, sports massage students offered massages to runners as part of the post-race support. As the event featured both half and full marathons, we arrived on site early to start welcoming the participants and to personally thank them for their incredible accomplishment.

One of the first visitors to the tent was Dr Anna Jack-Waugh (Alzheimer Scotland Centre for Policy and Practice, University of the West of Scotland) and Wendy Chambers (AHP Practice Education Lead in Dumfries and Galloway) who had completed the half marathon and were beaming with energy and pride.

We then made our way to the finish line to welcome the Alzheimer Scotland runners, to express our heartfelt thanks on behalf of the charity and guide them back to the tent for refreshments and/or an optional massage.

It was deeply humbling to hear, first hand, the many reasons and personal stories from the participants, the raw emotion as they crossed the line was just amazing to witness. Each conversation was a moving reminder of the profound connection people share with Alzheimer Scotland and the meaningful causes that inspired their run.

I was genuinely struck by how many male runners broke down in tears as they crossed the finish line - a poignant testament to the sheer physical and emotional toll of the race, and the immense personal triumph it represented for each of them.

Stuart with Dr Anna Jack-Waugh
and Wendy Chambers



Lorraine with Alzheimer Scotland
mascot Buddy

From lived experience to practice - working toward a dementia friendly Golden Jubilee Hospital

Recently, SDWG members Tony and Tommy met with Con Gillespie, the Dementia Lead at the Golden Jubilee National Hospital in Clydebank. This visit was part of the hospital's ongoing commitment to becoming more dementia friendly, with a focus on enriching the experience for patients and visitors with dementia and their carers. Tony and Tommy are actively involved in this initiative led by Con, where they share insights from their lived experiences with dementia. Their contributions aim to help the hospital develop a safe, therapeutic, and welcoming environment. This includes thoughtful considerations of environmental factors such as lighting, colour schemes, artwork, and access to outdoor spaces - elements that can significantly promote wellbeing and reduce confusion among patients.

In addition, Tony and Tommy are supporting practical adaptations like clearer signage and contrasting details to improve navigation and independence for people with dementia. While considerable progress has been made, they acknowledge there is still work to be done. A report outlining achievements and future plans will be released soon.

This collaboration highlights the power of combining lived experience with professional expertise to promote a more inclusive and supportive environment. Hopefully the initiatives at the Golden Jubilee Hospital will stand as an inspiring example of dementia friendly practices that can be adopted across all healthcare settings.



Tony and Tommy

Career guidance and dementia research project - a collaborative research journey - by Kenny Moffat, SDWG

Over the past five years, I've had the privilege of being part of a collaborative research project with colleagues from the UWS Alzheimer Scotland Centre for Policy and Practice (ASCPP). The project, titled 'Guidance for Life, Work and Career', examines how dementia and employment overlap, aiming to better understand how people living with dementia can be supported to continue working and planning their careers.

In July 2025, our research team met in person with Professor Louise Ritchie and Research Assistant Connor McDonald to review the key findings and recommendations for the final report, which will be published later this year.

Key to the success of the project was the meaningful involvement of people living with dementia at every stage. Members of the Scottish Dementia Working Group (SDWG) played a vital role - from contributing to the initial funding application in 2019 to shaping the final report. Their insights and lived experiences have been central to the research.

I'd like to give a special mention to the SDWG members who have worked alongside me throughout this journey: Margaret Northedge, Barry Northedge, Margaret McCallion, Rynagh Flynn, and Stuart Dougall.

We look forward to sharing the final report soon and hope it will help inform employers and organisations about how to better support people with a dementia diagnosis in the workplace. Our goal is to promote understanding, challenge assumptions, and encourage inclusive practices.



"Please focus on what we can do, not what we can't."

- Margaret, SDWG

"Career guidance should be considered as part of post diagnostic support plans for people diagnosed with dementia who may benefit."

- Kenny, SDWG

Carers Week 2025 - celebrating unpaid carers and championing equality

Carers Week took place from 9-15 June, with this year's theme, 'Caring About Equality', shining a spotlight on the challenges and inequalities faced by unpaid carers across Scotland and beyond. Carers Week is an important opportunity to highlight the realities of caring, celebrate the invaluable contributions of carers, and push for better support and recognition.

To mark the occasion, we invited members of NDCAN to share their thoughts and reflections on caring - and they truly delivered. Their powerful quotes were featured across our own and Alzheimer Scotland's social media channels throughout the week, helping to amplify the voices of those with lived experience. Indeed, many of these quotes will continue to be shared in future campaigns and communications throughout the year.

"My friend said to me "...oh no I am not a carer. I just look after my mum and dad who both have dementia. And then there's my aunt who is in a care home. I do all her finances and visit her twice a week. I am not a carer - I am just a daughter and a niece". In fact, she had retired early to be near her family in order to care for them. It involved an impact to her pension plus moving back from England to Scotland."

- Thea: NDCAN

"The fact that I used to be a nurse was a huge help. However, balancing my parenting role, full time work, and my ever-increasing caring responsibilities was exhausting. As a result, my health suffered."

-Ailsa, NDCAN

"Never underestimate the benefits that a thirty-minute coffee can bring to a household where someone has dementia. It could change the whole dynamic within the household for the better."

- Frank, NDCAN

"You don't stop being a carer even when circumstances and situations change. Keep being your loved one's voice as you know them best."

- Fiona, NDCAN

"Always keep a diary of events, medication, meetings with professionals, their names and outcomes."

- Mary, NDCAN

"At times I get so weary of having to repeat things and organise everything. Then I feel guilty and that I'm a failure, but I read somewhere - the only time you've failed is if you don't try once more."

- Joan, NDCAN

"'Age is just a number' goes the saying. Until you care for someone with young onset dementia and age becomes a barrier to accessing the scant support services that exist."

- Gillian, NDCAN

Promoting workforce development through student engagement

In their continued dedication to workforce development in the health care sector, SDWG and NDCAN are always pleased to engage in meaningful opportunities that provide students with lived experience and insights. Recently, this commitment was showcased when members of both groups participated in an online session with medical students from the University of Dundee.

The primary goal of the meeting was to introduce the students to our Active Voice initiative, and to provide them with a better understanding of dementia through personal narratives. Maureen from NDCAN and Kenny from SDWG shared their personal journeys, offering invaluable insights into living with dementia and caring for those affected by the condition.

Their stories shed light on the real life challenges faced by individuals and emphasised the importance of empathy, patience, and understanding in healthcare. Additionally, Maureen and Kenny provided practical tips on how students can effectively engage with people living with dementia. This inspiring session not only broadened students' knowledge but also encouraged a more person-centred approach to their future careers in healthcare.

And finally... looking ahead

As we wrap up this summer edition, we're proud to reflect on the energy and commitment shown by members of SDWG and NDCAN. It really has been a busy and inspiring summer, with national awareness campaigns such as Dementia Awareness Week, Volunteering Week, and Carers Week providing powerful platforms for people with lived experience to lead the conversation.

From local engagement to national engagement, and the continued campaigning work of our Active Voice groups, each story in this newsletter highlights the power of lived experience in shaping a more compassionate and inclusive future. Thank you to everyone who contributed, participated, and supported these initiatives. We look forward to building on this momentum in the months ahead and continuing to share the voices and actions that drive positive change.

Want to know more about the Active Voice at Alzheimer Scotland?

The Active Voice of people living with dementia and their carers is about upholding rights and driving change. We support people with lived experience to help influence and shape policy practice – Your Voice Matters! You don't have to be politically minded or need any qualifications to get involved. The only important thing is you know what issues affect you as a person whose life has been affected by dementia. If you would like further information or an informal chat with a member of the Active Team, please email us at: activevoice@alzscot.org

Active Voice

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