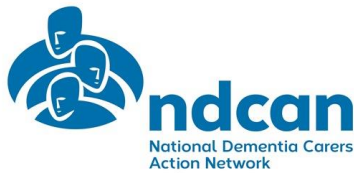


NDCAN Newsletter



Welcome to our Newsletter!

Welcome to the very first edition of our newsletter. Alzheimer Scotland's National Dementia Carers Action Network (NDCAN) is a national **activist** group, whose members all have experience of caring for someone with dementia. NDCAN provides a platform and a greater voice to empower those who care for people with dementia to influence and inform dementia policy and practice, with particular reference to the needs of people caring for someone with dementia, at a local and national level, throughout every stage and in every setting. **Irene Oldfather: Chair, NDCAN**

We would welcome contributions for future Newsletters – please contact crussell@alzscot.org with your ideas.

NDCAN and SDWG at the NHS National Conference

Members of the National Dementia Carers Action Network (NDCAN) and the Scottish Dementia Working Group (SDWG) played an important part at the recent NHS Scotland Event, held at the Scottish Exhibition and Conference Centre in Glasgow in June. NDCAN member Myra Lamont (pictured) gave a keynote address at the plenary session, sharing a platform with the Cabinet Secretary for Health, Wellbeing and Sport, Shona Robison MSP. Myra made an impassioned plea for the needs of the family carer to be taken into account when professionals are organising and delivering nursing care to their loved one.

When her husband was seriously ill, Myra was keen to keep him at home. However, she described a "tsunami" of professionals and equipment coming through her door, with over 30 different nurses over a 2 week period. One of these nurses, Gordon McGlynn, realised that he was dealing with a very complex situation. He took the time to listen to Myra, and to engage properly with how she was feeling. The organisers of the event had tracked Gordon down, and he and Myra were re-united on the stage.



Myra Lamont speaking at the NHS National Conference
Picture courtesy of YoungMedia

Myra and Gordon's story gave a powerful message to all delegates of how stressed carers can become when they feel they are losing control, and how important it is to make a human connection, simply by asking the question, "and how are you doing?" Given the theme of the conference was "leading integration for quality", it was appropriate to re-enforce the aspiration of the integration agenda to keep people well at home or in a homely setting for as long as possible. Myra demonstrated that it is possible, but only if the carer is supported. With the right community structures in place the whole episode could have been managed in a more

planned way, instead of a reactive, crisis response.

Myra and Gordon went on to chat “on the sofa” over lunchtime – and you can catch their discussion on YouTube.

<https://www.youtube.com/watch?v=yi4tVI4JDbY>

Ann in the Telegraph

Friend of NDCAN Ann Pascoe shared her experiences as a carer in a recent article in the Daily Telegraph. It has had a significant response, with many people contacting Ann to reflect that they have had similar experiences – and to thank Ann for describing her situation so eloquently. You can read the article by following the link here:

<http://www.telegraph.co.uk/news/health/11730021/Im-no-longer-a-wife-Im-a-carer-but-I-need-as-much-support-as-my-husband.html>

Open Day – Saturday 3rd October

NDCAN is holding its second Open Day at Oxford St in Glasgow from noon until 4pm on the 3rd October 2015. Alzheimer Scotland’s new Director of Operations, Marcia Ramsey, is coming along to meet NDCAN members and Friends and we look forward to welcoming her. Our guest speaker is Dr. Maggie Ellis, Fellow in Dementia Care: School of Psychology and Neuroscience, University of St. Andrews (pictured). Maggie works on projects to develop



and evaluate novel interventions to support positive communication and care relationships

between people living with dementia and those who care for them.

The session will be workshop-based: Maggie is very interested in hearing the views of carers, so there will be opportunities for participation.

Maggie says,

“My main career ambition is to improve the lives of people living with dementia, their friends, families and caregivers via translational research. I am committed to contributing to a positive change in this area and in doing so, collaborating with all concerned; from people with dementia to policy makers”.

<http://maggieellis.wp.st-andrews.ac.uk/about-me/>

We look forward to welcoming all Friends of NDCAN to this exciting event – please register your interest with crussell@alzscot.org

Emma’s Friendship Blanket

Friend of NDCAN Emma Woods asked many friends to get their knitting needles out to help make a Friendship Blanket.



There is a lovely back-story to this blanket – it was started when Emma’s late mother picked up her knitting needles and (to everyone’s surprise) started to knit. Emma describes how it

was such a pleasure for her mum, as she had been a very creative person before she developed dementia, and it was also very therapeutic.

Since then, many people have been involved including a few well known faces. Phyllida Law has been very helpful and passionate about the cause, and has written to Emma a number of times. There is also a picture of actor Greg Wise knitting a square and Derek Jacobi has also contributed. Schoolchildren have also been involved in the project.

Plans are underway to auction the blanket to raise funds for Alzheimer Scotland. A huge thank you to Emma for all her efforts with this beautiful blanket.

NDCAN Summer Workshops 2015

NDCAN is holding a series of workshops for existing members and new Friends. The purpose is to bring people up to date with current issues and policies. It will also be an opportunity to share views and ideas. We would welcome members of our sister organisation, the Scottish Dementia Working Group, as well as Alzheimer Scotland colleagues.

Self-Directed Support

Thursday 13 August 1.30-4pm
81 Oxford Street, Glasgow

Overview by Laura Finnan Cowan, SDS Manager, Alzheimer Scotland (pictured).



Laura will cover definitions of SDS: values and principles: pathways to SDS and options: where to go for info and advice: and finally, some of the challenges inherent in SDS. We will discuss how we can raise awareness of SDS both locally

and nationally and hear of some examples of SDS in practice.

Contact crussell@alzscot.org to book your place – make sure to specify “SDS”.

Alzheimer Scotland’s Policy Team

Wednesday 19th August 2-4.30pm
81 Oxford Street, Glasgow
Thursday 17th September 1.30-4pm
Walker Street Meeting Room
22 Walker Street, Edinburgh, EH3 7HR

These sessions – one in Glasgow and one in Edinburgh – will provide members and Friends with an induction overview of the Policy team. It is hoped to cover the roles and responsibilities within the team, as well as the key issues currently being addressed. An important part of the team is the Dementia Helpline, and the manager will come to brief participants about her work. Both NDCAN and SDWG are part of the Policy Team, so this is a great chance to hear more about current activities.

Contact crussell@alzscot.org to book your place – make sure to specify Policy Briefing Edinburgh or Policy Briefing Glasgow

Working with the Carers Trust

Thursday 24th September
81 Oxford Street, Glasgow



Come and meet our colleagues from the Carers Trust, Heather Noller and Karen Martin. We will hear about the expertise of the Carers Trust, particularly pertaining to the health and well-being of carers. There will be opportunities to discuss a variety of issues, including the activities of the Carers Trust, particularly relating to carer’s health and well-being. We will also hear more about Carer Centres. Contact crussell@alzscot.org to book your place – make sure to specify “Carers Trust”.

Publications and Social Media

Wednesday 7th October 2-4pm
22 Drumsheugh Gardens, Edinburgh

Kirsty Yanik and colleagues from the Communications team will introduce NDCAN members and Friends to the world of media relations and effective information-sharing. There will also be an opportunity to learn more about using Facebook, Twitter and other social media. If there is enough interest, we can repeat this session in Glasgow – just let us know. Contact crussell@alzscot.org to book your place – make sure to specify Communications – Edinburgh.

Glasgow Declaration – have you signed?

Finally, have you signed the Glasgow declaration? Alzheimer Scotland is working with Alzheimer Europe to increase the number of signatures on the Glasgow Declaration, launched at the Alzheimer Europe conference in October last year.



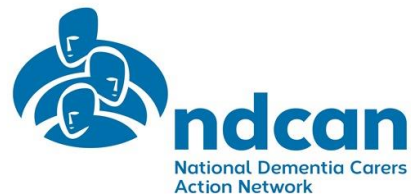
NDCAN Committee Members signing the Glasgow Declaration

The goal is 10,000 signatures. The NDCAN Committee members present at the conference signed the poster document, however as these signatures are not included in the online register we would like to ask the Committee members and all other members and Friends of NDCAN to go to the website and sign the online register – it only takes two minutes, please do add your name to this important document. You can sign and also download the declaration by following the link below

http://www.alzscot.org/campaigning/international_activity

PS: don't forget to send your ideas for our next Newsletter to crussell@alzscot.org
Look forward to hearing from you!

Contact Information



Email: ndcan@alzscot.org

Tel: 0141 410 0100

Address: Alzheimer Scotland, Hampden Park,
Glasgow, G42 9BA

www.alzscot.org/campaigning



24 HOUR
Dementia
Helpline
Freephone 0808 808 3000
Email helpline@alzscot.org

**Alzheimer
Scotland**
Action on Dementia