



South Eastern HSCT at Dementia Friendly Awards

The South Eastern Health and Social Care Trust (SEHSCT) Memory and Wellbeing Programme were finalists at the Alzheimer's Society Dementia Friendly Awards 2015, and runners up in the Best Dementia Friendly Involvement Initiative and the Best Dementia Friendly Organisational Initiative.

The awards showcased the innovative and

valuable work being carried out across Northern Ireland to enable people to live well in their communities. The SEHSCT Memory and Wellbeing Programme have also presented at, and won, a poster award at the recent College of Occupational Therapists Specialist Section Mental Health Conference, held in South West Area Hospital (SWAH) Enniskillen on 1 October 2015.



Pictured (L-R): Jane Mitchell Service Lead OT for Mental Health, Jane Brown Programme Participant, Sarah Travers TV Presenter, Victoria Croft and Danielle Brock Specialist OTs.

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Dementia research needs you!

What is Join Dementia Research?

Join Dementia Research www.joindementiaresearch.nihr.ac.uk is a new nationwide online and telephone service that makes it easier for people to register their interest in volunteering for dementia research studies.

Why is the service important?

Dementia affects almost 850,000 people in the UK and almost 20,000 people in Northern



Ireland, but currently only around 5% of people with dementia take part in research. There are numerous questions about the cause, diagnosis, treatments and best care for which there are no clear answers as yet. Research into dementia will help find these answers.

Who can get involved?

Anyone, with or without dementia, can register as a volunteer or sign up for someone else, providing that you have their consent. You must however be over 18 years old.

How can people get involved?

You can register for the service by:

- visiting www.joindementiaresearch.nihr.ac.uk
- contacting the helplines of Alzheimer's Research UK tel: 0300 111 5111 or the Alzheimer's Society tel: 0300 222 1122.

What is so special about the service?

The service allows you to see which studies your information matches to, and you can also express an interest in finding out more about studies. However, there is absolutely no obligation to take part in any of the studies. Current research studies range from clinical trials of new treatments to surveys identifying what works in improving the quality of life for people with dementia.

How can you help?

1. **Sign yourself up to the service** as many of the studies are looking for healthy volunteers.
2. Encourage others to sign up and **talk about the service** to anyone you know who has dementia or is caring for someone with dementia.



Dementia NI charity launches at Stormont

Dementia NI was incorporated as a company on 15 January 2015 by five people living with a diagnosis of dementia. The five wanted to ensure that the voices of people living with dementia are at the core of policy, practice and service delivery across Northern Ireland. Atlantic Philanthropies provided funding in order to set up the charity.

The charity officially launched on 25 November 2015 in the Long Gallery, Stormont. The evening was hosted by Chris Lyttle MLA, who said: "Dementia affects many people in our community and the launch of this charity will give people living with dementia in Northern Ireland further empowerment to make their voice heard and to achieve the support they need and deserve."

Dementia NI are now in the process of establishing dementia empowerment groups across Northern Ireland to provide a place where people with dementia can come and share, reflect and lobby for services and policies that better meet their individual needs and challenge the stigma of dementia. Recruitment is currently taking place for group members within the South Eastern and Belfast HSCT areas.

Dementia NI aims to:

- challenge the stigma of having a diagnosis by raising awareness about dementia;
- promote the rights of people living with dementia to influence policy, practice and service delivery across Northern Ireland;
- provide training, education and awareness to organisations and the public on how to live well with dementia;

- support people living with dementia to lobby and raise awareness of dementia in their own right.

Dementia NI Vice Chair John McErlean, who is living with dementia, said: "We have a very important job to do in challenging the stigma of dementia. I may have dementia but I can still do things for myself and make decisions; I just need society to allow me the time to do it in my way. I don't know how much time I have but I do know that we need to be challenging the stigma of dementia and that is what we plan to do through Dementia NI."

Dementia NI is a membership organisation for people living with a diagnosis of dementia. - please join and let us together challenge the stigma of dementia through lobbying and influencing policy, practice and service delivery for people living with dementia. If you are living with a diagnosis of dementia and would like to be involved please contact us by email on info@dementiani.org or telephone 079 6688 1419. Expressions of interest for volunteers are also welcome.



Dementia NI Board of Directors with Chris Lyttle MLA - John McErlean, Brian O'Hagan, Tara Collins, Thelma Abernethy, Danny McQuillan, Chris Lyttle MLA

CrISP workshops from the Alzheimer's Society

The Alzheimer's Society Carer Information and Support Programme (CrISP) is a series of workshops for carers and family members of someone with dementia. CrISP aims to improve the carers' knowledge, skills and understanding of dementia.

It allows carers to meet in a friendly and confidential environment where they can talk openly about their experiences of dementia and the impact caring has on their lives. The programme is designed to include information talks regarding a particular topic and gives carers the opportunity to get involved in discussions and ask questions.

It also gives carers the opportunity to get support from others who are in the same position and to share ideas and advice.

Topics covered include:

- what is dementia?
- Legal and financial matters;
- practical advice on providing support and care;
- carers looking after themselves;
- support services available.

Carers who have attended the workshop have found it very beneficial. Feedback shows that they know more about dementia and have practical strategies to help them care for the person with dementia. They are more confident in their caring role and know that there is help and support available to them. One carer said:

"The course has provided me with an opportunity to share ideas, tips and perhaps most importantly, some of my biggest fears."

For more information about upcoming programmes in your area please contact:

- Northern area – Aoife McMaster on 078 6025 8728 or aoife.mcmaster@alzheimers.org.uk
- South Eastern area – Zelig Clark on 078 6025 8814 or zelie.clark@alzheimers.org.uk
- Belfast area – Danny Wilson on 078 8964 8793 or danny.wilson@alzheimers.org.uk
- Southern area – Heather Von Loggerenberg on 077 1832 2722 or h.vonloggerenberg@alzheimers.org.uk
- Western area – Paula Canney on 077 1832 2726 or paula.canney@alzheimers.org.uk

Introducing 'John's Campaign'

On 24 November 2015, members of the Dementia Together NI team met with Julia Jones, one of the founders of John's Campaign www.johnscampaign.org.uk to help launch the campaign here in Northern Ireland. John's Campaign emphasises the right of a carer to stay with people with a dementia in hospital and the right of the person with a dementia to have their carer stay with them.

Julia Jones said: "John's Campaign is a request for both access and recognition. Carers should not just be allowed on the ward, but welcomed."

John's story

John Gerrard was 86. He had been diagnosed with Alzheimer's disease in his mid-seventies but had been living well with it until he was admitted to hospital for leg ulcer treatment. Family visiting was severely restricted during his five week stay and during this time he lost his

ability to function independently and required 24 hour care for the rest of his life.

The Dementia Together NI project team are aware of many facilities in Northern Ireland that are already working closely with carers. In fact, just this past month, the Downe Dementia Unit in the South Eastern Trust has become the first ward in Northern Ireland to sign up to John's Campaign. It is quick and easy to do. All a hospital needs to do to be part of John's Campaign is to welcome carers whenever the patient needs them – 24/7 if necessary.



It's that simple. If you welcome carers 24/7 please email julia-jones@talk21.com and say so in 50 words. By endorsing the campaign and lending our support, we hope to raise its profile in Northern Ireland and indeed promote the existing good practice in the region.

Innovative support from the Alzheimer's Society

The Alzheimer's Society have some very useful initiatives for those needing to access support if they are feeling isolated or cannot gain support through other means. These include a National Dementia Helpline and an online community for those affected by a dementia.



National Dementia Helpline

The National Dementia Helpline provides information, advice and support through listening, guidance and appropriate signposting to anyone affected by a dementia. The helpline is open seven days a week and the service is delivered by trained helpline advisers. You can contact the Helpline on 0300 222 11 22 or email helpline@alzheimers.org.uk. For more information about the National Dementia Helpline please visit www.alzheimers.org.uk/helpline

Talking Point

Talking Point is a helpful online community where anyone who is affected by a dementia can receive valuable support. It is free, open day and night and to access it you just need an internet connection. For more information about Talking Point please visit www.alzheimers.org.uk/talkingpoint

"Talking Point has helped me no end. Finding someone else who has the same difficulty but is at a different stage in the journey is very reassuring." (Person living with a dementia)

"When facing a difficult illness, peer support is considered to be essential. Talking Point provides peer support and so much more. Becoming a member allows you to help others and to receive help in a non-judgmental environment." (Carer of person living with a dementia)

Delirium group makes progress

The Regional General Ward Collaborative, which aims to address the required improvements in care for people with delirium, held its inaugural meeting on 25 November 2015. The group will also highlight how communication is imperative to optimise care in acute wards.

Ten pilot wards have been nominated across five HSC Trusts to take part in the regional work, and staff of all grades attended from these wards. The group revised Draft V4 of the regional delirium tool, which is reflective of the National Institute for Health and Care Excellence *Clinical Guideline 103 - Delirium: prevention, diagnosis and management*, to screen, assess, prevent and manage delirium.

Amendments have been made according to feedback and V5 has been issued as the 'test tool' for use in the pilot wards. We were very fortunate to have a user's experience of delirium in a cardiac intensive care unit shared with the group. Mrs Willey explained how her delirium manifested in the hospital setting and the impact of this, even after she was discharged. She has been very pro-active in assisting in service improvement and support for people who have experienced delirium. This was very informative and enlightening for staff to be able to see the 'other side' of delirium, compared to identifying and dealing only with its symptoms.

HSCT leads and actions have been agreed and the next meeting will be held 26 February 2016.



Health and
Social Care

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Find us on:



Dementia
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www.northernireland.gov.uk

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