



Dementia Together NI project update

It's hard to believe that we have come to the end of the three year Dementia Together NI Project; this will be our last newsletter.

In our first newsletter, back in March 2015, we set out our plans to promote awareness of dementia, tackle the stigma associated with the condition, develop training initiatives and provide information, support and services to people living with dementia and their carers.

We are delighted to say that with the funding available through the Delivering Social Change programme, we have been able to realise all of our objectives and in many instances have exceeded our expectations.

The recent Celebration Event, attended by 250 delegates, provided us with a platform to showcase the many and varied areas of work that we have been engaged in. This last edition of the newsletter describes in a little more detail what has happened across the four work streams.

The end of the project does not, however, signal the end of the work to implement the regional strategy. There is much still to do, including the need to further develop dementia care in hospitals, redesign memory services and implement the new regional dementia care pathway.



Seamus McErlean, Health & Social Care Board and Eleanor Ross, Public Health Agency

We hope that you enjoy this edition of the newsletter and may we take this opportunity to thank the many people from the voluntary, independent and statutory sectors along with colleagues from academia, people with dementia and their carers who all contributed so much to the success of the entire project - we could not have done it without you.

**Eleanor Ross
PHA**

**Seamus McErlean
HSCB**

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Moving forward together: planning for the future in dementia care

Local people living with a dementia, their families and carers, voluntary organisations and health and social care professionals are committed to partnership working, moving forward together, in the future development of dementia services in Northern Ireland. This was the key message from the Dementia Together NI Celebration Event held on 30 November 2017 at the Hilton Hotel in Templepatrick.

This regional event, organised by the Dementia Together NI partnership, recognised the valuable contribution of people living with a dementia, their families and carers. Through co-production, involving people who provide services in collaboration with people with lived experience, dementia initiatives have been implemented to raise awareness and address the stigma surrounding dementia.



Martin McCrory and Nichola Cullen from the Dementia Together NI team providing information and resources about the project at the event.

The Dementia Together NI Project was funded by the Department of Health, the Executive Office and Atlantic Philanthropies, under the



Assumpta Ryan, Professor of Ageing and Health at Ulster University, delivers the opening address at the DTNI event.

auspices of Delivering Social Change. The Delivering Social Change Dementia Signature Project was launched in 2014 by the Executive Office to transform the commissioning, design and delivery of dementia services for people in Northern Ireland. The Project Board chaired by the Department of Health tasked the Health and Social Care Board and the Public Health Agency (PHA) with taking forward this work in partnership with the Alzheimer's Society and with service user support from Dementia NI.

Launching the celebration, Andrew Dougal, Chair of the Public Health Agency, said: "It is my great pleasure today to commend everyone involved in the work undertaken by the Dementia Together NI Partnership. Our achievements include the Still Me awareness raising campaign, the development of the Dementia Learning and Development Framework, the completion of Dementia Champions Training by over 260 staff and the recruitment of Dementia Navigators across all Health and Social Care Trusts. For families and carers, Dementia Training for Informal Caregivers has been provided to over 2,000 people and innovative carer support schemes, enabling them to continue to provide care for their loved ones, have been piloted."

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Launching their new dementia information guides, at the Dementia Together NI Celebration Event held on 30 November 2017, are from left to right: Geraldine Teague, Public Health Agency, Sarah Penney, Ulster University and Dr Gillian Carter, Queen's University Belfast (absent is Professor Brian Taylor who developed the *Talking About Risk and Dementia Guide*).

In her opening address, Professor Assumpta Ryan, University of Ulster, praised the partnership approach to improving services for people with dementia. Professor Ryan said: "Today's event is an opportunity to highlight the work that Dementia Together NI has completed since 2014. The focus on collaborative working with partner organisations has been key to its success. By bringing together resources and knowledge we increase the potential for improving the lives of people with dementia. Moving into the future it is important that we are able to sustain this engagement with people living with a dementia and their carers. By talking openly with them about their experience of dementia we can identify their needs and those of their carers which helps shape the dementia care services of the future."

Sean Holland, Chief Social Worker for Northern Ireland, said: "This has been a ground-breaking partnership between Executive departments

and Atlantic Philanthropies. As well as delivering real benefits on the ground, it has served as a genuinely valuable and positive experiment in government working outside its traditional boundaries. The Department of Health is hugely grateful for the opportunity to participate in this unique programme of work."

Commenting on improvements in hospital care, Mary Hinds, Director of Nursing at the PHA, said: "Training in delirium awareness has been delivered to over 2,500 hospital staff regionally. Forty staff have been trained as Delirium Trainers to enable workplace training, complemented by an eLearning resource, to continue in other hospital environments. It is vital that we can continue to build on this innovative work and further embed these dementia initiatives. Furthermore, a new dementia care pathway will see the development of new roles for staff and offer people with a dementia a new community-based model of care."



Accolade Community Choir kick off proceedings under the direction of Musical Directors, Vessie Ivanova and Nikolay Ivanov.

Attendees were entertained by the Accolade Community Choir who sang a medley of seasonal songs, and by The Top Ten Women's Drama Group who presented a play specially written for the event to raise awareness of how to ensure that people with a dementia remain fully involved in the Christmas festivities.

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A video of the project's work was presented by Lorna Conn, Project Manager, and four new booklets were launched by Geraldine Teague (AHP Consultant, PHA); Sarah Penney (Research and Teaching Fellow, Ulster University); Brian Taylor (Professor of Social Work, Ulster University); and Dr Gillian Carter (School of Nursing and Midwifery, QUB). Dr Gail Johnston (Programme Manager, PHA) also provided an update regarding ongoing research into dementia care.

Members of Dementia NI shared their experiences of their involvement in all aspects of the project work and health and social care staff spoke of the benefits of the training provided in both delirium and through the dementia champions programme.

Delegates had the opportunity to hear about developments in dementia care supported by the Project, namely the CLEAR model, Dementia Companions, Cognitive Rehabilitation and Pain Management. The conference concluded with Seamus McErlean and Eleanor Ross (Dementia Leads, HSCB/PHA) outlining future developments



At the Dementia Together NI Celebration Event are from left to right: Angela Hodgkinson, Atlantic Philanthropies, Jerome Dawson, Department of Health Elderly & Community Care Unit and Roberta Dalton, Mark Browne and Joan Hardy, the Executive Office

in dementia care in hospitals, the progress planned for redesigning memory services and the need to implement the new regional dementia care pathway.

The conference was closed by Chris Matthews (Director of Mental Health, Disability and Older People, Department of Health) who commended the Dementia Together NI Project for the excellent work which had been achieved during the last three years.



Some of the event speakers pictured at the DTNI event. Back row (from L-R): Eleanor Ross, Public Health Agency, Seamus McErlean, Health & Social Care Board, Chris Matthews, Department of Health Elderly & Community Care Unit, Tara Collins, Dementia NI, and Professor Assumpta Ryan, Ulster University. Front row (from L-R): Jerome Dawson, Department of Health Elderly & Community Care Unit, Andrew Dougal, Public Health Agency, Lorna Conn, Health & Social Care Board, and Sarah Penney, Ulster University

Awareness raising, information and support

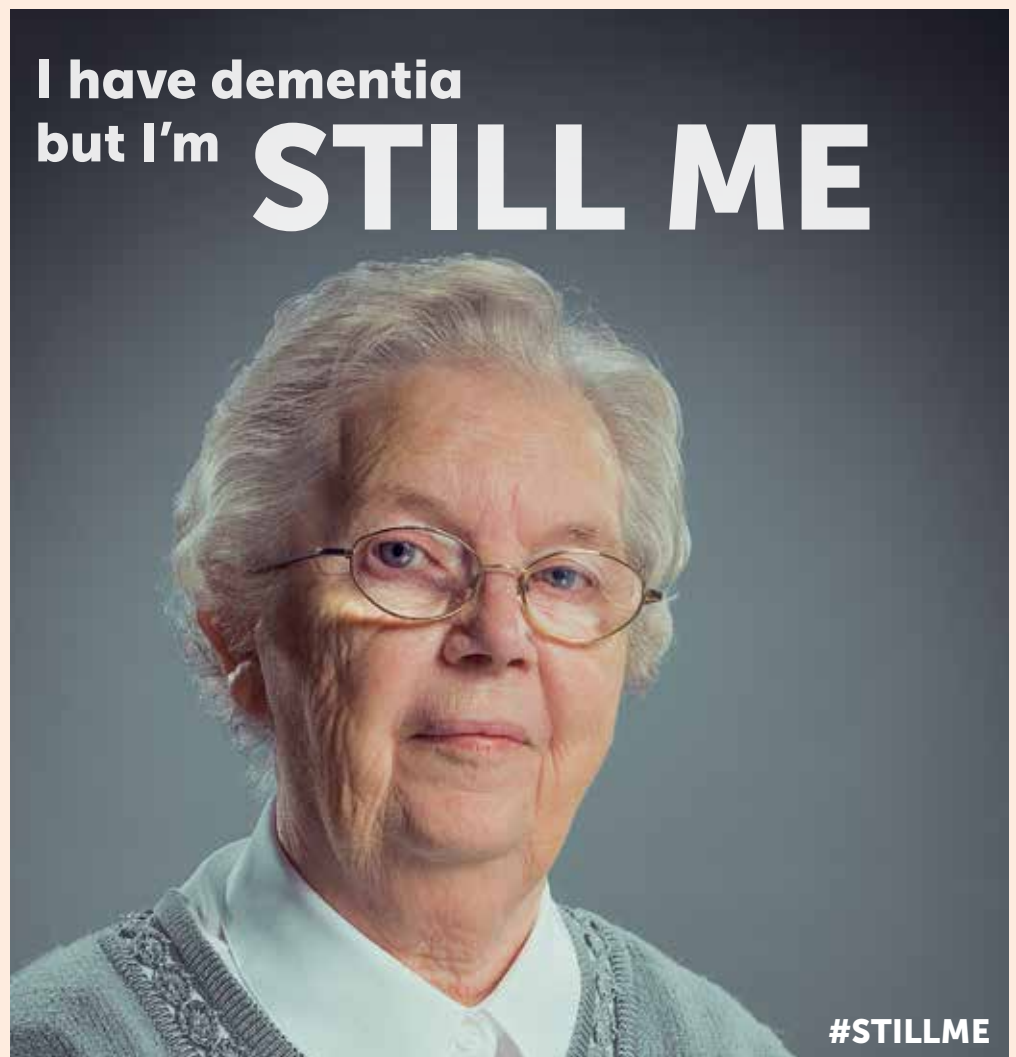
‘Still Me’

The campaign aims to raise awareness of the signs and symptoms of dementia, reduce stigma and fears about the condition, and encourage those experiencing signs or symptoms to seek help. It has been a great success in the region across two phases with a huge reach across many different target audiences with **86%** of the general public recognising one or more of the campaign adverts.

It is the first publicly funded dementia campaign in the region to star real people with a dementia and was developed with the voices of those with a dementia being central to everything we did. The stars of our TV and print advertisements, both those with a dementia and those who provide support, gave so much to the success of the campaign. We at Dementia Together NI would like to sincerely thank them for the amazing contribution they made in showing the public that those with a dementia still have so much to contribute to our society and that whilst getting a diagnosis might be a worrying time, there is help and support out there to help you live well with a dementia.

The campaign development process was supported by the Dementia Public Information Campaign Steering Group, which included representation from relevant voluntary group involved with dementia such as Age NI, Alzheimer’s Society and Dementia NI, as well as service users and representatives from the Public Health Agency and Health and Social Care Board. We would like to thank all of these organisations for the contribution to the development and implementation of the campaign.

There is still so much more to be done to reduce the stigma of dementia in society but with the great work of the community and voluntary organisations involved and with the voices of those with a dementia being heard more clearly than ever before, this will continue to help increase understanding of the condition in the region.



Awareness raising, information and support

Information provision

Dementia Together NI developed a range of online and printed information with regional involvement. This information was developed based on the needs of those with a dementia and those who provide support who helped with its production. **Eleven** booklets have been developed in total and covered information regarding the early stages of dementia right through to planning for the future as specific information regarding issues such as oral health care, communication, sight loss, risk and moving into a care home. These have been very well received across the region and we would like to acknowledge and thank all of the various experts and health care professionals who have developed and assisted with this information provision. See NIDirect or www.pha.site/dementiadocs

We have also worked closely with nidirect to create a variety of online information at www.nidirect.gov.uk/dementia. The site includes case studies showcasing people living with a dementia talking about their experiences of living with the condition. The latest figures show traffic of **13,000** visits to these resources.



Awareness raising, information and support

Dementia Navigators

The Dementia Together NI project created and implemented the roll out of a new post - the **Dementia Navigator** – across the region with **10** staff located in HSC Trusts across NI. Navigators are a key source of support and sign posting to those affected by a dementia from the outset of their journey through to the later stages.

This role emanated directly from consultation with those with a dementia and their carers who advised that one key point of contact from the start would be of great benefit as well as someone who would be available at various point throughout the person's journey with dementia.

As well as working directly with those affected by a dementia, the navigators link closely with any groups/directorates/organisations across the region to better understand the great work going on and to raise awareness of the condition. Navigators quickly became a key source of support and sign posting to those affected by a dementia from the outset of their journey through to the later stages. **100%** of the people with dementia and their carers reported that this service had helped them and provided them with needs-specific information and support.

Dementia Together NI would like to thank all Dementia Navigators for their work to date and look forward to seeing this role grow and thrive in the future to provide the best possible support to all those affected by a dementia.

Training and development

Training for informal caregivers

Over **180** individual training courses and support were delivered right across Northern Ireland leading to **2,463** informal caregivers receiving training. The training was modular in delivery over a six week period and both



providers also used very innovative methods of delivery including focused training to family group members as well as providing DVDs of training sessions for those carers who were not always available to attend the face to face training. This training was positively rated by carers with **100%** of carers rating it as relevant and having helped them and **99%** stating it had improved their care/life balance.



Training and development

Dementia Champions

Regional training for HSC staff across statutory and independent sectors working with people with a dementia culminated in a total of **260 staff** being trained as **Dementia Champions** with a view to improving the lived experience of people with a dementia.

All **260** Dementia Champions undertook a change project and these are currently being implemented within their work settings in order to embed the learning and contribute to service improvements for people with a dementia wherever they encounter health and social care services.

The course was very favourably reviewed with 100% of staff trained reporting that the training had positively impacted on their practice and 100% of managers considering that it had had a positive impact on the care provided to people with dementia within their work setting.

Staff comments included:

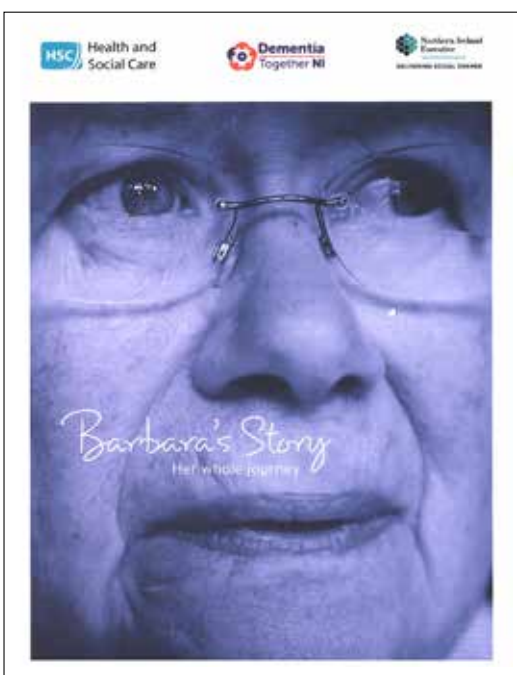
“I feel this training is excellent as it relates to so many different staff on so many different levels and can have an impact for service users in the community, acute, residential and nursing care settings.”

“I can now communicate effectively with a person with a dementia and try to make their stay in our ward a more positive and person centred experience.”

“I have learnt so much and am much more confident in my knowledge and skills. This is impacting my work on a daily basis and I am making positive changes.”



Training and development



Training resources

A number of stand-alone **training resources** have been developed. Dementia Together NI worked very closely with Northern Ireland Social Care Council (NISCC) in the development of a training app for domiciliary care staff and plans are at a very advanced stage in relation to the development of further online training resource for adult residential/nursing and day care staff.

1,000 copies of a training pack entitled Barbara's Story were issued to health and social care facilities, GPs, pharmacists, opticians, dentists, prison staff, PSNI and the NI Ambulance Service.

Delirium assessment and management tool

Think Delirium



Delirium is a medical emergency • It can be prevented and is treatable

Is your patient more confused than normal?

Early intervention is key to prevention

At risk patients include those:

- who are over 65;
- with existing cognitive decline;
- who are acutely ill;
- with a fractured neck of femur.

Single Question to identify Delirium (SQiD):

Are they more confused than normal?

Screen for increased risk factors

- D** Dehydration
- E** Eyes and ears
- L** Limited mobility
- I** Infection
- R** Reduce pain
- I** Impaired cognition
- U** Up at night
- M** Medication



Prevention and management

1. Treat the cause of delirium.
2. Avoid transfers.
3. Reorientate to current place and time.
4. Pain management.
5. Adequate fluids.
6. Use of eyeglasses and hearing aids, if applicable.
7. Familiar objects and stimulating activities.
8. Reduce noise and avoid sleep interruptions when possible.
9. Address mobility.
10. Engage with family and carers

Assessment and review

- Review level of confusion on admission
- Daily observation for at risk patients
- Use 4AT rapid assessment test for delirium to diagnose delirium in more confused patients
- Clinical assessments to identify source of delirium



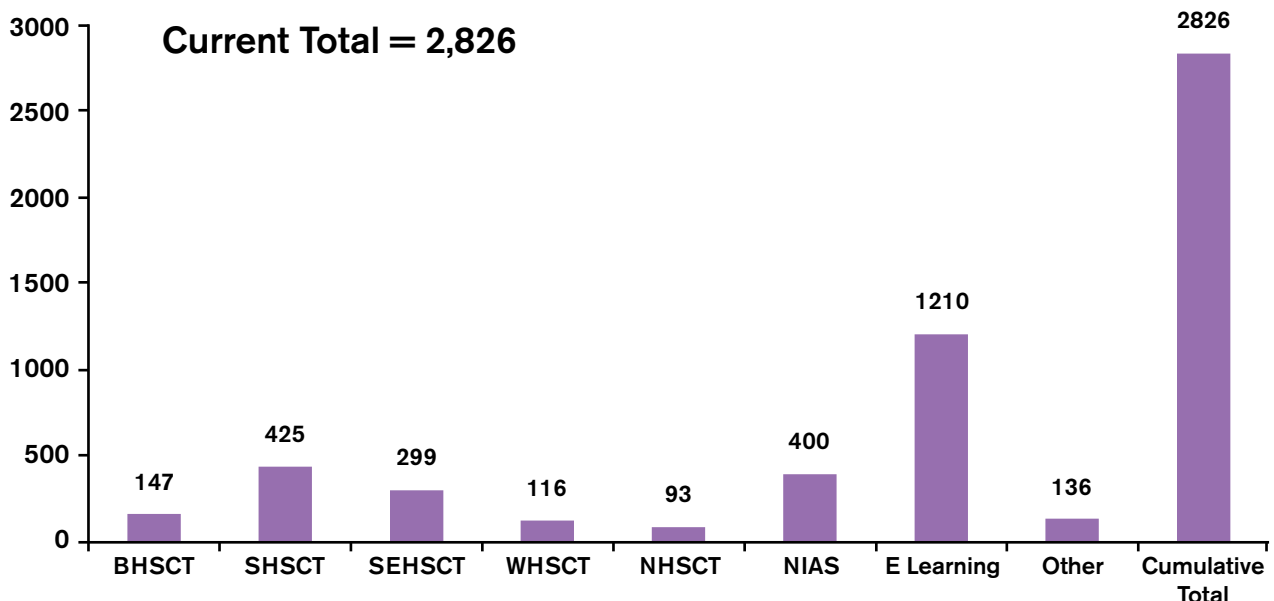
Public Health Agency, 12-22 Linenhall Street, Belfast BT2 8BS. Tel: 0300 555 0114 (local rate). www.publichealth.hscni.net

Graphic created by GoAnimate

A delirium assessment and management tool was developed with regional input and was piloted across the region to assist in the early identification and prevention/treatment of delirium.

This tool was complemented by extensive training with a total **2,826** HSC staff receiving training across the region.

This work was also supported by **'train the trainer'** sessions and the provision of a teaching pack, a module which has been located on the HSC Learning Platform and an animation which is accessible on YouTube.



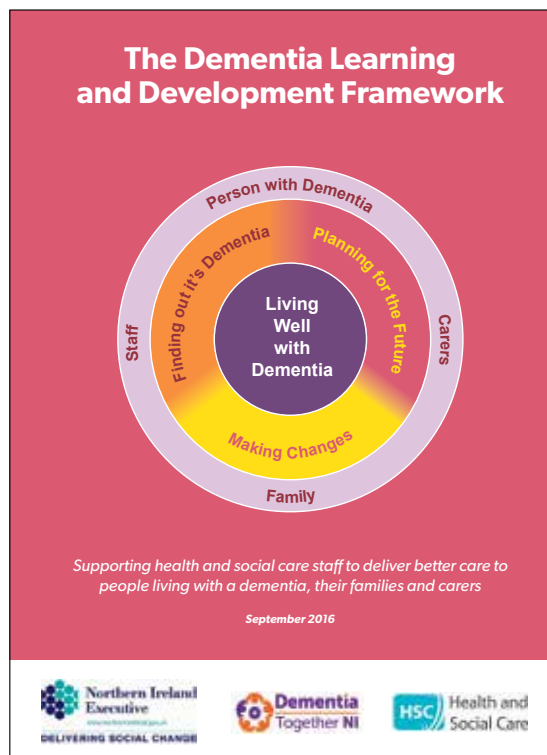
Training and development

Dementia Learning and Development Framework

A New NI Dementia Learning and Development Framework was produced and subsequently launched by the Health Minister Michelle O'Neill in September 2016. This framework was developed during a series of seven regional collaborative workshops held in 2015 and involved contributions from over **200** stakeholders from the statutory and independent sectors as well as universities, colleges, professional groups and people with dementia and their carers.

The Learning and Development Framework incorporates **13** thematic subject areas and details the knowledge and skills required by HSC staff to support them to deliver improved care and develop their expertise in working with people with a dementia and their carers.

The Learning and Development Framework is now being widely implemented into professional courses in both of the universities, into training provided by private care providers and training organisations such as the Social Services Training Units and the Clinical Education Centres. It has also been endorsed by NISCC and RQIA and is being used in appraisal and professional development processes within several HSC trusts.



Short breaks and support to carers

The project set out to develop and pilot new, innovative models of short breaks to support those with a dementia and those who provide support to them.

These pilots were based on an extensive scoping exercise designed to understand existing service provision and to ascertain what those affected by a dementia and their carers felt was needed to better support them to continue to provide care.

These pilots were in operation from May 2016–September 2017 and provided support to **229** people affected by a dementia and their families.

100% of people with a dementia and their carers reported that the new models of short breaks helped them.

Comments included:

“This short break has transformed my life”.

“It was worth a billion pounds for me as I got to go away for my birthday. It gave me my life back as I hadn’t been anywhere for ten years.”

“It is excellent as I had nothing before this”.

Learning and Development Framework prompts UU to launch new suite of dementia training



Dr Liz Laird, lecturer in nursing and lead for Dementia Training at Ulster University, is pleased to announce a suite of Dementia Update Training, commencing in January 2018.

Dementia Update Training Part 1 and Part 2

This training package is suitable for anyone caring for (or working with) a person living with dementia and their families, including support workers, care assistants, registered nurses, allied health professionals, social workers and physicians.

Dementia Update Training Part 1 will be delivered 16 January in the Jordanstown Campus, and 19 January in the Magee Campus, from 9.00am–4.15pm. The Update Training Part 1 addresses Themes 1-7 of Northern Ireland Dementia Learning and Development

Framework, and is full of interesting learning and skills development workshops pitched up to and including Tier 3.

Dementia Update Training Part 2 will be delivered in June 2018, and will address Themes 8-13 of the Dementia Learning and Development Framework, again pitched up to and including Tier 3.

International Dementia Summer School

A 4-day International Dementia Summer School is planned for September 2018, and will be pitched to meet Tier 4 requirements of specialists, managers, leaders and service planners across all themes of the Learning and Development Framework.

For further details on dementia training delivered by Ulster University, please contact Liz Laird. Email: ea.laird@ulster.ac.uk



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