



## Awareness raising information and support

### What are the current knowledge and attitudes of people in Northern Ireland to dementia?

This is a key question currently being asked by the Health and Social Care Board (HSCB) and Public Health Agency (PHA). A survey is currently underway to ascertain people's knowledge and attitudes to three areas of dementia:

- symptoms of dementia;
- stigma of dementia; and
- risk factors associated with dementia.

The results are expected by the end of September and it will be fascinating to have an understanding of people's perceptions. We can then see how we can change some of the negative attitudes that exist surrounding the illness and show how people can live better with dementia. Some good work has already been carried out in this area by Access, Research and Knowledge (ARK) in the Northern Ireland Life and Times survey and our work will build on this. Hopefully at the end of the planned public

information campaign and in conjunction with all the other work being done, not only in Dementia Together NI but in many other organisations, we can show how positively people with a dementia can still contribute to our life.

People affected by dementia and their families have specific informational needs. Dementia Together NI is currently developing an information stakeholder group to help create specific resources for those with a dementia and their family/carers. If you work in an area of dementia or are a person affected by dementia or their family, please make contact using the details below to find out how you can contribute. We plan to develop information for those affected by dementia to support them through the whole journey, from pre-diagnosis to end of life. Work has already begun in this area with several focus groups having met and we envisage that this will gain momentum over the coming months.



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## Short breaks pilot scheme

The scoping report on the short breaks pilot scheme has been completed. During the consultation process a number of recommendations for short break pilots were made in accordance with the needs identified by people with dementia and their informal care givers.

A draft programme specification was drawn up and once finalised a call for organisations to tender to provide the identified short break pilots will be made. It is anticipated that this will take place in October. After the successful candidates have been identified a number of project steering groups will be established. If you would like to be involved in one of these please feel free to contact me on the details below.

A short break directory of services is being developed. If you know of an organisation or you are a member of an organisation that provides short break services for people with dementia and their informal carers, please feel free to contact me.

I am also trying to identify people with a dual diagnosis of learning disability and dementia along with their informal caregivers, to be involved in a focus group, participate in one-to-one interviews or to complete a questionnaire. Their input would help to enhance the information



gathered during the consultation to provide more specific short break services for this client group.



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## Learning disability and dementia

Research shows that people with a learning disability are at an increased risk of developing dementia.

For people with Down's syndrome, the symptoms of dementia can appear as early 40 years old, and for those over 60 years, there is a 50% risk of acquiring dementia. The research shows a 13% risk of developing dementia among people with other types of learning disability. This compares with a figure of around 2% in the population of people over 60 years without a learning disability.

The individual faces the multiple jeopardy of learning disability, ageing and dementia. They may experience marginalisation, stigma and stereotyping and may not have the same knowledge of or access to, services as others. Carers of people with a learning disability are often older than carers in the general population and this places additional demands on families and service providers.

## Training and development

It is a very exciting time for the training and development work stream. The title for the framework has been agreed as the **Northern Ireland Dementia Learning and Development Framework**. Three workshops have been held to date with good attendance and contributions from all stakeholders as well as the virtual reference group. The Dementia Journey has been finalised and the focus is now on agreeing levels within the framework and the associated knowledge and skills required. The September workshop included a presentation from Joanne Agnelli, from Four Seasons Health Care, on the importance of terminology within dementia care.

A scoping exercise of the **Dementia Champions** model has been undertaken to examine the various training models used as well as identifying the core skills of dementia champions. The first meeting of the **Dementia Champions Stakeholder** group took place in August 2015.

Dementia Together NI team members along with Atlantic Philanthropies staff visited Scotland in September to learn from the Scottish experience of developing and



L-R Angela Hodkinson, Atlantic Philanthropies, Lorna Conn, Dementia Together NI, Susanne Forrest, NHS Education for Scotland (NES) Teresa McGarvey, Dementia Together NI, Patricia Howie, NHS Education for Scotland, Brendan Murtagh, Queen's University Belfast.

implementing training and development. The opportunity was also taken to improve our understanding of the Scottish model of Dementia Champions and their role in supporting those affected by a dementia. Some interesting contacts were made and innovative ideas were shared.



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The regional dementia strategy recommends the development of a regional care pathway for younger people with dementia. This includes those with a learning disability. The strategy also recommends better diagnostic and support services to enable those people with a learning disability to have access to the full range of specialist dementia services to meet individual needs.

The Regional Learning Disability and Dementia Group (RLD&D) is implementing these recommendations, maintaining close links with the progression of the wider project. The RLD&D Group has participated in the various scoping exercises to help identify gaps in provision. On 18 September 2015 a half-day workshop began mapping the Dementia Care Pathway for people with learning disabilities with each Health and Social Care Trust.



## Delirium conference held in London

The European Delirium Association and British Geriatrics Society delirium conference has taken place in King's College, London.

This three day conference allowed the multidisciplinary audience to meet people with a shared interest of improving services of care for people with delirium.

The initial training day provided attendees with information from experts in:

- making a diagnosis;
- prevention and management;
- delirium in special situations – medical, post-operative, palliative care, etc;
- challenging case studies.

The main conference was for health professionals interested in delirium research, education and policy.

Sessions included:

- biological basis of delirium;
- critical care and perioperative delirium;
- palliative care and nursing home delirium;
- innovations in delirium education;
- setting up a delirium service.

As Dementia Together NI takes its first steps towards establishing a regional 'Delirium

Bundle' the conference was a perfect forum to discuss service development with European members and indeed some from as far afield as Australia. We presented a poster to outline our proposed collaborative work and draft materials to be used in the initial pilot across the region.

There were opportunities for learning about current innovations which included one team who had developed a service providing a 'virtual ward'. This allows people with delirium to recover in their own home with 24 hour care provision for three weeks. This team demonstrated the significant benefits to patients in reducing the number of nursing home admissions and ultimately demonstrating an average saving per person of approximately £10,000 per annum.

We were also able to make contact with people with experience and information on what is effective for providing optimum care for those with delirium and their families/carers.

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## New team members for Dementia Together NI

The Dementia Together NI team continues to grow as our work gathers momentum. Since the last newsletter, we have been joined by three new staff members, Thelma Swann and Trudy Harkness, pictured on the right as well as Isobel McFarland. Thelma and Trudy are our Business Support Managers and will assist with various aspects of the work streams, whilst Isobel is our project secretary. They have already contributed in such a positive way to the team and we look forward to working together in the future.



# Northern Ireland hospitals audit on dementia

On 26 June Dr Suzanne Timmons, Consultant Geriatrician and Senior Lecturer from Cork, presented the findings of the first Northern Ireland audit into care of people with dementia in acute hospital wards.

All 12 hospitals in Northern Ireland were audited based on similar studies carried out in England, Wales and the Republic of Ireland. Data collated in the report considered a wide range of elements of dementia care including staffing levels, staff training, nutrition, ward environments, discharge and palliative care.

Key findings included:

- No hospitals reported having a dementia care pathway in place, or in development.
- 25% of hospitals could identify people with dementia when reviewing their data on delayed discharges/transfers.
- 33% of hospitals could identify people with dementia when reviewing in-patient falls.
- In 33% of hospitals the management team receives feedback on a regular basis from clinical leads for older people, including people with dementia.
- 83% of hospitals have a named officer with designated responsibility for the protection of vulnerable adults, including people with dementia.
- No wards had access to speech and language therapy, dietetics or continence services at the weekends.
- Most wards reported no access to psychology (64%) and specialist continence services (53%).

- One in five people with dementia admitted from home are discharged to a nursing home/long-term care.
- The median length of stay for those admitted from and discharged to a nursing home (9 days), was shorter than those awaiting new nursing home placement (20.5 days), and those admitted from and discharged home (10 days).
- Those admitted from a nursing home were less likely to receive a cognitive assessment (10%) or an assessment of functioning (17%), than those admitted from and discharged to their own home (41%, 37% respectively).

These findings will be important in helping professionals develop a baseline quality of care and improve our understanding of the particular needs of people with dementia who are admitted to an acute hospital ward.

The audit would not have been possible without the cooperation received from HSCT chief executives and their staff. In order to take forward the recommendations, a regional work group has been established with representation from all five HSCTs. A work plan will be developed, with agreed outcomes and timeframes and readers will be updated on developments as the work progresses.

HSCT staff will work alongside Eleanor Ross and Seamus McErlean to address these findings. We would be keen to be involved in future comparison audits with England, Wales or the Republic of Ireland to ensure that the momentum and drive to improve is maintained.

A copy of the report is available at [www.ucc.ie/en/inad/northernirelandauditofdementia](http://www.ucc.ie/en/inad/northernirelandauditofdementia)

# Recovering ordinary lives through memory

*“Having four showers a day because you can’t remember if you did. Forgetting what happened yesterday. Losing specs, keys and confidence. Shrinking your world, doing only the bare minimum, so you don’t make a slip up. Getting wrapped in cotton wool by well meaning relatives, putting your life on pause.”*

At the Occupational Therapy led Memory and Wellbeing Programme provided throughout the South Eastern Health and Social Care Trust, we get to the heart of how memory problems impact on daily life. How the rhythm of a day can become a painful cycle of searching for what you were planning to do, who you were meant to ring and where you were meant to go. The programme focuses on the need to maintain identity. This is done through developing strategies to enable people with cognitive impairment and dementia to retain participation in what is meaningful and purposeful to them.

The Memory and Wellbeing Programme is provided over seven sessions and is punctuated with hope, peer support, carer and service user education and practical memory rehabilitation and wellness tools. Families and carers are invited to attend a pre programme workshop to learn about the strategies and ethos that will be covered within the six weeks. The programme is available to service users of the mental health services for older people and the Dementia Navigators within the trust play a key role in informing service users and making referrals to the programme.

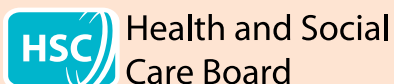
The Memory and Wellbeing Programme goes beyond the discussion, by providing anchors to

hold onto, methods to overcome and routes to go beyond surviving to thriving. These highly flexible and practical interventions include a white board in the hub of the house which becomes the command centre of what needs done and when. Roles and responsibilities continue to be fulfilled. This simple, discreet solution can immediately increase confidence and accommodate memory problems. A calendar becomes a lifeline to maintain contact for birthdays, anniversaries, holidays, and a prompt to explore hobbies.

A beautiful, highly organised journal or memory book used several times a day weaves together the threads of life detailing the poignant moments of the day. It documents in words the happenings, capturing the pop-up thoughts that make that person so uniquely them. Occupational therapists can assess the impact memory problems are having on functioning. They work with the person both through education and task analysis to increase the person’s satisfaction with their abilities.

This programme (a 2015 Safety Quality Experience (SQE) Programme finalist) is based on the work of Dr Mary McGrath, Clinical Specialist Occupational Therapist, BHSC and the Glasgow Occupation and Memory Group. It is designed and delivered by Mental Health Services for Older People Occupational Therapists Danielle Brock and Victoria Croft.

For further information please contact Mental Health Lead Occupational Therapist Jane Mitchell [Jane.Mitchell@setrust.hscni.net](mailto:Jane.Mitchell@setrust.hscni.net)



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