



Delirium Advisory Group Identifies Challenges

The inaugural delirium advisory group meeting was held on 31 March 2015. There was consensus among attendees that while there are initial developments being completed at Health and Social Care Trust level, there is no continuity across the region.

Challenges identified included agreeing roles and responsibilities that will address the requirements for shared decision making and communication, while ensuring high quality care for patients.

The need to take into account existing service pressures when developing a bundle that could be seen as merely 'additional work' was also discussed.

The biggest challenge is thought to be raising knowledge and awareness among staff around the serious nature and impact of delirium on the patient, their family and the service as a whole.

However there was positivity that there is now a dedicated programme to provide cohesion to ongoing work and identify the best way to develop and implement the Northern Ireland-specific bundle in line with proven quality improvement methodology used by the PHA Safety Forum.

Outcomes from this meeting included:

- agreement, in principle, of regional delirium 'at risk' and screening criteria;
- agreement on which location is most appropriate to implement management of delirium in Northern Ireland;
- initiation of work on Northern Ireland-specific educational resources for all HSC staff working in the acute setting;
- nomination of pilot wards across the region.

The initial emergency departments meeting highlighted the National College of Emergency Medicine audit for assessment of older people for cognitive impairment, and potential to utilise the information to establish baseline information for regional emergency departments. We also see this as a positive driver in agreeing what is achievable in emergency departments as part of the Northern Ireland bundle development.



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Awareness Raising, Information and Support

This has been a busy few months with the completion of a scoping report around the area of information provision in Northern Ireland. This looked at the needs of those affected by a dementia, both the person with a dementia and those who support them. They were asked what information they needed and how best this information should be delivered. In general those asked thought there was a lack of information at the point of diagnosis and ongoing information support in the areas of local services, financial and legal matters. This differed from results obtained from those organisations who provide information, where these areas were not covered as regularly as others. This showed a gap in information provision in the region which Dementia Together NI can help to fill.

The scoping report also noted that the best method of information delivery was a mixed model of face-to-face and written information. This emphasised the need for the development of the Dementia Navigator post, another area being developed through meetings with key stakeholder groups. This role will complement the good work already happening in the region and fill any gaps in information delivery.

The first stakeholder meeting for the development of the public information campaign also took place. We were supported at this meeting by an expert with experience from Dementia NI. This was a great commitment from their organisation and it means that anything developed for the campaign will meet the needs of those with a dementia and take their lived experiences into account.

This has been a really exciting time for this area and as always, if you feel you have anything to contribute, please just call!



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Northern Ireland Audit of Dementia Care in Acute Hospitals

We are delighted to report that the first Northern Ireland Audit of Dementia Care in Acute Hospitals has just been completed. This was led by Dr Suzanne Timmons, Senior Lecturer at the Centre for Gerontology and Rehabilitation, University College Cork.

This first audit, which took place in all 12 acute hospitals in Northern Ireland, will obtain a baseline picture of the quality of care from admission through to discharge. This is an important area for development given the evidence to suggest that hospital admission is distressing and disorientating for a person with dementia, and is associated with a decline in their cognitive ability and functioning.

The following questions informed the audit:

- What structures and resources do hospitals have in place to enable them to identify and meet the care needs of patients with dementia?

Training and Development

Following the completion of the training needs analysis, a Knowledge and Skills Framework (KSF) working group has been established. The group includes representatives from universities and colleges, Health and Social Care Trusts, training organisations and regulators, as well as representatives from the community and voluntary sector, people with dementia and their carers.

The group had its first meeting on 4 June to look at other KSF models in England and Scotland. The plan is to have a KSF developed for Northern Ireland by January 2016.

The focus is now on plans to recruit over 300 Dementia Champions on a phased basis for health and social care staff. Their role will be to advocate for people with dementia, provide information and support and promote best practice in dementia care.

Funding has been allocated to take forward the Carers Information and Support Programme (CrISP) which is specifically aimed at supporting up to a maximum of 12 carers per programme, incorporating themed talks such as understanding dementia, legal and money matters, providing support and care and coping with everyday issues.

Should you have an interest in any of the above areas or wish to seek further information or clarification, feel free to make contact with project officer Teresa McGarvey.



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- What evidence can be assembled to demonstrate that hospitalised patients with dementia receive an acceptable level of care?

A formal feedback session on the results took place on 26 June and the recommendations from this work will support the implementation of the strategy in acute hospitals. Highlights of the findings will be shared in the next edition.

Funding for this audit of dementia care was very generously granted by Atlantic Philanthropies.

www.ucc.ie/en/inad/northernirelandauditofdementia



Newly designed Dementia Care Ward and therapeutic hub opened in Waterside Hospital

The official opening of the newly refurbished Dementia Care Ward and a state-of-the-art therapeutic hub at the Waterside Hospital in Londonderry took place on 1 October 2014.

A dementia design audit had been carried out on the dementia ward in February 2014 and a number of areas were identified as problematic for people with dementia.

Patients found it difficult to understand and navigate the ward, affecting their functioning, behaviour and independence. Ward staff reported that the physical environment was contributing to patient's confusion and agitation. Incidents of challenging behaviour were regularly recorded on DATEX. Patients also had limited access to therapeutic interventions.

This was affecting their recovery, rehabilitation and timely discharge from hospital. Length of stays were significant. With this in mind the Dementia assessment ward was refurbished and a new therapeutic hub constructed. Both are in keeping with best practice in dementia design.

The therapeutic hub has an activity and a therapy room, relaxation room, clinic room, resource library, skills kitchen and an external therapeutic garden.

An evaluation was carried out with staff and families to find out if the refurbishment of the Dementia Care Ward made a difference to patient care, families and staff experience. Staff reported that the dementia friendly environmental changes had positive effects on patients' ability to understand and navigate the ward. They reported a calmer atmosphere where patients are free to move about in a safer environment. Families reported the same. Incident reports for the three months following refurbishment showed a 50% reduction in falls when compared to the three month period the previous year.

The recorded incidents of patients being challenging with fellow patients and staff also showed a significant reduction.



Pictured at the official opening of the Dementia Care Ward and therapeutic hub in Waterside Hospital on 1 October 2014 are Pauline Casey, Head of Service, WHSCT; Brenda Stevenson, Mayor of Londonderry; Geraldine Brown, Assistant Director, WHSCT; Gerard Guckian, Chairman, WHSCT; Elaine Way, Chief Executive, WHSCT; Winifred O'Kane, Dementia Ward Manager, WHSCT; Dr Jungawala, Consultant Psychiatrist, WHSCT.

MLAs hear about the importance of improved post-diagnosis support for people with dementia and family carers

The Alzheimer's Society has called on MLAs, policy makers and health professionals to support the 'Right to Know' campaign to ensure no one in Northern Ireland is denied access to information and support following a dementia diagnosis.

There are nearly 7,000 people with dementia in Northern Ireland who don't have a diagnosis. One quarter of people diagnosed receive no support or information and 90% feel the support they do receive is inadequate. The 'Right to Know' campaign sets out to change this.

MLAs and a wide range of health and social care professionals, including members of the Dementia Together NI team, attended the 'Right to know' campaign breakfast on 15 April for the launch of a new information booklet. They heard from personal experience about the benefits of early diagnosis and immediate access to post diagnosis support from a dementia support worker.

At the event in Parliament Buildings, participants heard about the campaign's three key calls to government and health and social care professionals: an increase in diagnosis rates to reach 75% by 2017; no one must wait longer than 12 weeks between initially seeking GP help and getting a diagnosis; and everyone with a diagnosis must have access to a dementia support worker from the point of diagnosis.

Pam Traill from Bushmills is a carer for her husband Richard, who was diagnosed with dementia with Lewy bodies in 2007. Speaking at the campaign breakfast about their experience, Pam said:

"I first noticed a change in Richard when we were on holiday in Vancouver for our golden wedding anniversary in 2007. He was very forgetful and just wasn't like himself. As soon as we returned home we went to our GP. Initially we were told it was just age, however I pushed for Richard to be tested and he was diagnosed with dementia with Lewy bodies shortly after.

"We were lucky that we had a fantastic specialist that quickly referred us to the Alzheimer's Society Dementia Support Worker in our area who explained the support and information available to us. I feel lucky we got the diagnosis early, and got the right support and information given to us straight away, as I know this is not the case for many people.

"Co-ordination is key. GPs, specialists and social services need to work together to create an effective system to ensure people get a diagnosis before they start to get worried or upset."



R-L Martin McCrory (Dementia Together NI), Bernadine McCrory (Alzheimer's Society) and Lorna Conn (Dementia Together NI).

Short breaks and support to carers

Since the last newsletter a scoping template has been sent to all HSCTs in Northern Ireland and all independent short break providers to gather information on current short break provision for people with dementia and their carers.

The full report on these findings is due to be completed by the end of June. It is evident that people with dementia and their families/caregiver place a high value on short break services. Some themes which occurred within the consultation process included:

Day care

Carers and people with a dementia were generally happy with the day care service they received within centres. Comments included "It gives me a much needed break and the cared-for person a change of scenery, stimulation and company."

However all stated that there could be improvements made by making the service more flexible to meet needs.

Home support

Those carers who received domiciliary short breaks at home found them beneficial. However, as with day care they felt that improvements could be made regarding the flexibility of the service and in the provision of additional training for staff.

Residential and nursing care

Most carers who used residential or nursing care indicated that they did so as a last resort when they felt they couldn't cope any longer at home. The majority of people stated residential/nursing care was of benefit to them. However, carers also felt that improvements needed to be made concerning the accessibility and flexibility of the service.

Essentially the findings indicated that provision should be person centred, take into account personal circumstances and preferences and meet the needs of different populations such as people with a learning disability and dementia, younger people with dementia and people with different types and at different stages of dementia.

The next stage in this work stream will be to develop a number of short break pilots for people with dementia and their carers in Northern Ireland.



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