



Alzheimer's Society is calling for a new deal on dementia

Alzheimer's Society, the UK's leading dementia charity, has called for a new deal on dementia in Northern Ireland, with speakers at the annual conference urging the new Assembly to make dementia a priority.

Alzheimer's Society estimates there are over 20,000 people with dementia in Northern Ireland. They are living with the effects of a serious, complex and progressive health condition that has a profound and changing impact on their daily life. Worryingly, an estimated 7,000 do not have a diagnosis and may be coping alone without

information about their condition, or without adequate care and support.

Alzheimer's Society's **'It's all about Rights'** campaign highlights the fact that people with a dementia have rights to information, care and support and the new Northern Ireland Assembly has a duty to develop a new deal on dementia to ensure their rights are being realised.

There are three key priorities of the **It's all about Rights** campaign:

1. Dementia is a serious, complex and progressive health condition. Good quality care and support can make a huge difference to those affected by it.
2. As research shows the number of people with a dementia will continue to rise - the Executive must ensure the condition receives the Health and Social Care priority it warrants.
3. People with a dementia have rights to care and support - the government has a responsibility to respect and enable those rights.



(L-R) Commissioner for Older People in Northern Ireland Eddie Lynch, Kathy Ryan from the Irish Dementia Working Group, Operations Director for Alzheimer's Society in Northern Ireland Bernadine McCrory.

Eddie Lynch, Commissioner for Older People in Northern Ireland, the keynote speaker at the

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conference said: "I am calling on government to ensure that the needs of older people living with dementia and their carers are met. While some positive steps have already been made, I often hear from carers and older people living with dementia who feel unsupported, and speak of the many challenges that they face.

"Dementia is an area with a large amount of funding spent on a wide range of projects. As Commissioner I often see great work by groups and organisations, and often the ideas are very simple but effective. Yet these ideas and initiatives cannot reach their full potential if they are pilot projects, involving a small number of older people in one geographical area. Government must pull all of the strands together and lead on a consistent approach, integrating all areas of best practice so that everyone living with dementia can be better supported regardless of where they live."



Bernadine McCrory, Operations Director for Alzheimer's Society in Northern Ireland, said: "Too often we hear people affected by dementia telling us about the barriers they face, when they were worried they might have dementia and couldn't get their doctor to treat their concerns with urgency.

'We know that people are often left to cope after a diagnosis without the information and support they need to live well with dementia. As prevalence data shows dementia is not going away and will continue to rise, it must get the Health and Social Care priority it warrants.

'People with dementia have rights to receive adequate care and support, and the newly elected Executive has a responsibility to respect and enable those rights to ensure people with the condition are supported to live well and independently for as long as possible.'

The conference, held in Belfast Castle on Wednesday 8 March 2017, also focused on the benefits of working in partnership, and showcased examples where Alzheimer's Society successfully worked in partnership with other organisations. The conference also outlined the challenges facing people with learning disabilities who have developed dementia - and the support needed for them to live well.

An unusual guest on the podium was MARIO, a humanoid robotic device that can help people with dementia find their keys or wallet, give them reminders, play films and music on request, and even reminisce and show them family photos.

Funded by the EU, the National University of Ireland in Galway has led on the development, with input from people with dementia and is currently being piloted in Stockport, England.

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MARIO is designed to support people with a dementia as they go about their daily lives. The robot holds a touch-screen monitor for people with a dementia to use and is able to do things such as answer questions such as what the weather and the time is; find lost items for their owner such as glasses, keys, remote controls; play music and films on request; and use voice recognition to communicate with their owner. Mario is also able to reminisce with its owner by

showing them old family pictures of past holidays, Christmases or weddings. It can also provide brain games, such as testing owners on who the people in the photos are and when the pictures were taken, using programmed information about the photos. It also has an emergency call button down low in case a person has a fall and needs help.

To sign up to Alzheimer's Society It's all about Rights campaign please go to:
https://www.alzheimers.org.uk/info/20088/northern_ireland

Dementia NI work with BBC NI

Keep a watch out for Dementia NI members presenting their BBC NI charity appeal this coming May. The appeal will be broadcast as part of the new Community Life programme on BBC Northern Ireland. This programme will profile the work and support needs of the featured charity Dementia NI, and will also include news about developments within the community and voluntary sectors.

Dementia NI members from throughout Northern Ireland came together to take part in the filming. All members of Dementia NI have a diagnosis of dementia and are themselves actively involved in raising awareness, by informing others how to support everyone with dementia in Northern Ireland. Co-Chair and member of Dementia NI John McErlane presented the charity appeal. John said: "It was hard work but I thoroughly enjoyed the experience."

If you would like to become involved with Dementia NI by becoming a member or volunteer, please contact Tara Collins on 028 9068 6768 or email info@dementiani.org



Dementia NI member John McErlane presents a piece to camera

Poem by Michael McMullan, student nurse

*My memory is a little hazy,
I repeat to you what I say,
I sometimes wander off,
For I cannot remember my way.*

*My words are a little muddled.
My thoughts I cannot express,
I may sometimes lose my temper,
When confused or in distress.*

*I may forget your name,
Or not even remember we've met,
But I have lived a life like you,
That, you must not forget.*

*So please don't neglect,
The person within me,
The one with wonderful memories,
Which you all struggle to see.*

*Try to understand me,
In this confused state I'm in,
Put yourself in my shoes,
And imagine where they've been.*

*For these old feet have covered many miles,
And these ears heard many a tale.
I only wish you could see me,
As more than old and frail.*

*So please try to appreciate,
The journey I'm going through,
And respect my values and wishes,
For one day this could be you.*

Northern Ireland's first Dementia Champions graduate

On 1 February 2017, Health and Social Care (HSC) staff from all care sectors celebrated their graduation from the first Dementia Champions training to take place in Northern Ireland.

Congratulating the graduates, Lorna Conn, Dementia Together NI Project Manager, HSCB, said: "This is a very special day. This graduation ceremony represents the culmination of the hard work and dedication of our graduates, their managers and our training providers Connected Health and the North West Regional College.

"All of us, at some point in our lives, need to engage with HSC staff and we expect and deserve to receive the very best possible care and treatment from trained and committed staff. Training helps to provide the knowledge and skills necessary to deliver the service that we need and expect. On a daily basis our Dementia Champions work to improve the quality of life, care and wellbeing of people with a dementia and their carers. Their commitment to this innovative course reflects their commitment to delivering that shared vision."

The Dementia Champions Training Programme was developed and provided in partnership by

the Health and Social Care Board, the Public Health Agency, Connected Health, North West Regional College, the Department of Health and Atlantic Philanthropies.

Geraldine Lavery, Head of Health at North West Regional College (NWRC), highlighted how those who took part in the Dementia Champions programme have developed not only improved dementia practice skills but also e-Learning skills which they can now apply professionally and as lifelong learners. She added: "NWRC is delighted to work in partnership with Connected Health to deliver this innovative blended learning programme which consisted of participants taking part in one day of workshops every six weeks alongside online mentoring.

"Staff from our Health and Social Care department worked with colleagues from our Technology Enhanced Learning Support team to develop a programme that marries high quality online materials, communications technologies and active learning tools to provide an engaging learning programme. Our training team's commitment to excellence in delivering

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the programme was evident throughout and we have already seen participants implementing real change across work places throughout Northern Ireland. I would like to congratulate all those who took part and we look forward to continuing with this innovative programme in 2017."

Key areas covered by the programme include receiving a dementia diagnosis, research and evidence based practice in dementia care, communication and promoting enabling environments. The course is delivered via a blended learning approach of five study days, online resources and the submission of work-based assignments. Open to HSC staff from all disciplines and work settings, it is unique in that students are required to undertake a change project within their area of work that will lead to improved practice, care, support and treatment for people with a dementia and their carers.

The Dementia Champions Programme focuses on the standards set out within the

regional Dementia Learning and Development Framework launched in September 2016.

This framework outlines the importance of a well-trained HSC workforce in providing care for people living with a dementia. The Dementia Champions training demonstrates the action being taken to build on good practice and develop dementia care which meets current and future service need.

During 2017 a further two cohorts will complete the Dementia Champions training programme which will bring the number of Dementia Champions in Northern Ireland to over 300.

Commendations also went out to representatives and staff from Dementia NI, staff from across the voluntary, statutory and independent sectors and academics and regulators for their contribution to the development of a competent and skilled workforce for the 21st Century, through their commitment to the Dementia Champions training.

Young at Heart Retirement Living Exhibition

On Wednesday 29 March 2017, the Young at Heart Retirement Living Exhibition celebrated its 20th anniversary in the Clayton Hotel, Ormeau Avenue, Belfast. Established in 1997, the free admission event is aimed at anyone retired in the community with useful information and advice on travel, health, finance and ideas for the home. The event also featured the popular Antique Roadshow where visitors were able to bring along antiques and heirlooms for free valuation. Exhibitors included Specsavers, the Consumer Council, Translink, Northern Ireland Housing Executive, Dementia Together NI as well as a large number of charities, voluntary organisations, energy companies, housing providers and representatives from the travel and leisure sector. The event

attracted hundreds of visitors from across Belfast and North Down who enjoyed perusing the stands, gathering useful information and advice on all aspects of retirement living.



Launch of regional delirium awareness and promotion materials

Frontline HSC staff have been made aware, through regional delirium training sessions, of the cause of associated distresses and behavioural changes, which they have to treat in addition to the clinical cause of delirium. They told us that they felt more empowered to provide assistance and support, and that they realise that it is not 'rocket science' to prevent or manage delirium.

Although they acknowledge it can put additional stress on their care provision, they realise that a period of time to engage with the person, their family or carer can make a big impact on the experience of all involved.

Providing reassurance, comfort and information to those in distress is ultimately what can help staff to engage and provide best care to the person. We agreed that #smartsandhearts would reflect our regional learning for the launch and it was very apt that Valentine's Day was the agreed date to launch the regional awareness and promotional materials!

We engaged with our regional collaborative teams, internal and external co-producers, who helped us to achieve the outcomes outlined in the Regional Dementia Strategy 2011 for improving outcomes for people with a dementia who are at an increased risk of developing delirium. The

Think Delirium

Make a Delirium Difference

Is your family member more confused than normal?

Have there been sudden changes in their behaviour?

Have they become more agitated/restless?

Have they become more withdrawn?

Are they seeing or hearing things that aren't there?

Have they become more fearful or anxious?

Act now!

If you see any of these changes please tell a member of staff

Dementia Together NI

HSC Health and Social Care

Northern Ireland Executive
www.northernireland.gov.uk
DELIVERING SOCIAL CHANGE

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

Graphic created by GoAnimate

programme enabled staff to hear from Dementia NI members, Anne Scott and Seamus Mullen, about real life experiences of living with a dementia and how this impacts on their engagement with HSC staff. Christine Armstrong outlined how the regional 'Ten thousand voices' initiative will demonstrate experiences of delirium care across HSC, and Gary Loughran advised how the regional development of the Electronic Healthcare Record (EHCR) can be utilised to improve communication and reduce risks associated with delirium.

Frontline staff shared local improvement experiences reflective of measurement of screening, prevention and management of delirium in at risk patients. All HSCTs indicated improvement in additional areas such as reduction of falls, prescribing of antipsychotic medications and incidents of aggression towards staff.

Fourth annual social work and social care research conference

The fourth annual social work and social care research conference was held in Belfast Castle on Wednesday 1 March 2017. The conference was designed to promote opportunities for research partnerships and showcase research activity in Northern Ireland. It supports the social work profession and social care as it continues to build a research and evidence-informed organisational culture. The recently launched Social Work Research and Continuous Improvement Strategy (2015) aims to build the capacity, capability and confidence of social work staff to engage in research and evidence related activities and continuous professional development.



The conference provided an opportunity to connect with social work colleagues and with other

professions, service users and carers. It allowed us to showcase the work of the whole project and how it has been underpinned by research methodology and PPI.

The project presented a poster presentation entitled Intervening to strengthen carers, families and communities to develop training, information and services for better outcomes in dementia. It focused on the short breaks pilots and how the robust process followed should lead to service improvement and better outcomes in short break provision. The team also hosted a raising awareness stand at the event.



World Delirium Day Wednesday 15 March 2017 #WDD2017

The international European, American and Australian delirium associations held a social media day on Wednesday 15 March 2017.

The aim was to improve engagement and awareness about 'All things delirium'. We welcomed the chance to share the learning of the regional delirium improvement project with our peers across the globe. We were lucky to have excellent working relationships with our pilot wards and beyond who ensured that each of the six HSC Trusts engaged in promotion locally. We also had support and engagement beyond HSC with our community and voluntary co-producers from the Alzheimer's Society and the Northern Ireland

Hospice. Most importantly, Dementia NI have given 'real life' experience, throughout our project to date and were delighted to lend their support to the day. We had an excellent social media campaign of engagement helped by PHA and HSC Board, which ensured that we topped the poll for most number of tweets for #WDD2017, a great achievement and acknowledgement of the work of the regional group in producing tangible improvement for those who are often most vulnerable in our hospitals.



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